Appendix B – Evidence tables

Critical appraisal and findings tables

Contents

Critical appraisal tables

Review question 1: Which aspects of the experience of using adult social care services are positive or valued by people who use services?

Review question 2: For people who use adult social care services, what are the barriers related to improving their experience of care?

Review question 3: For people who use adult social care services, what would help improve their experience of care?

Review question 4: What methods and approaches for gathering, monitoring and evaluating the experiences of people using adult social care services are effective and cost-effective?

1. Abbott D, Ottaway H, Gosling J et al. (2017) Lesbian, gay, bisexual, transgender, queer and intersex (LGBTQI+) disabled people and self-directed social care support. Bristol: University of Bristol

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Is the mixed-methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed-methods question? Yes The mixed methods research design is appropriate to address the qualitative and quantitative research questions. In particular, the survey data provides very useful context and lends weight to the findings from the qualitative interviews. However, there is no information about the different elements of the research design. **Is the integration of qualitative and quantitative data (or results) relevant to address the research question?** Yes Integrating the quantitative survey data with the qualitative data from the interviews and focus groups	**Qualitative comp 1** **Which component?** Survey of 56 LGBTQI+ disabled adults **Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?** Yes The research protocol stipulates the intention to survey the membership of REGARD who live in England, both those who are formal members (n=58) and those who are connected to REGARD via Facebook (n= unknown in terms of how many are in England)'. In the actual research itself, 56 individuals were included in the survey. **Is the process for analysing qualitative data relevant to address the research question?** Unclear	**Does the study's research question match the review question?** Yes Research Questions in study protocol are: 1. What are the circumstances in which LGBTQI+ disabled men and women feel empowered by social care staff and the circumstances in which they feel disempowered/discriminated against? 2. What kind of social care needs do LGBTQI+ disabled women and men have that could be said to be more closely related to their sexual identity? In what ways do they want social care staff do support these? 3. How are sexuality-related needs and/or sexual identity issues dealt with in e.g. support planning, hiring and employing support workers, support worker training, support reviews? 4. What are support worker/PAs experiences of negotiating the sexuality related needs of the people they work for?	**Overall assessment of internal validity** **+** Lack of information about research methodology. **Overall assessment of external validity** **++** **Overall validity score** **+** Lack of information about research methodology.

provides a detailed and explicit account of the key issues relevant to this topic. **Is appropriate consideration given to the limitations associated with this integration, such as the divergence of qualitative and quantitative data (or results)?** No This aspect has not been reported on.	No information provided on how survey data was analysed **Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data were collected?** No No information provided on how survey findings relate to context. **Is appropriate consideration given to how findings relate to researchers' influence; for example, though their interactions with participants?** No No information provided on how survey findings relate to researchers' influence. **Qualitative comp 2** **Which component?** Qualitative interviews with 20 LGBTQI+ disabled people. **Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research**	5. What are the implications for the delivery and organisation of high quality social care for LGBTQI+ disabled people? **Has the study dealt appropriately with any ethical concerns?** Yes The University of Bristol is the study Sponsor. The Social Care Research Ethics Committee (SCREC) are responsible for reviewing the study. The protocol makes reference to information about individuals being stored in accordance with Data Protection Act principles and guidance…. The protocol also stipulates that the role of the Chief Investigator is to be responsible for ensuring that the team are compliant with the Data Protection Act'.(Page 3). **Were service users involved in the study?** Yes **Is there a clear focus on the guideline topic?** Yes Concerns service user experience of self-directed social care support.	

	question? Yes The protocol stipulated the intention to carry out 30 interviews, which was thought to be feasible within time and budget. Researchers also stated that this 'is the right saturation point for qualitative interviews given a quite specific group on a quite specific topic. '(Page 5). However, the final study was made up of 20 interviews. **Is the process for analysing qualitative data relevant to address the research question?** Unclear No detail provided on how interview data was analysed. **Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data were collected?** No No information provided on how interview findings relate to context.	**Is the study population the same as at least one of the groups covered by the guideline?** Yes Lesbian, Gay, Bisexual and Transgender, Queer and Intersex (LGBTQI+) disabled men & women. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes Study context is people's homes and locations where social care is provided as suggested by the research findings. **Does the study relate to at least one of the activities covered by the guideline?** Yes Study relates to activities covered by the scope e.g. Access to services; Assessment; Choosing and managing care. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes	

	Is appropriate consideration given to how findings relate to researchers' influence; for example, though their interactions with participants? No No information provided on how findings from interviews relate to researchers' influence. **Qualitative comp 3** **Which component?** A focus group of PAs **Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?** Yes The protocol stipulated the intention to organise two focus groups of between 6-8 PAs in each group who currently support LGBTQI+ disabled people as this '... might provide a useful counterpoint to hear how some PAs, from their perspective, go about doing this work – as well as thinking about what kind of training and support would help them to do the job well'. (Page 6). The final study however, refers to one focus group of PAs.	**Does the study have a UK perspective?** Yes Based in England and findings are transferable within UK context.	

	Is the process for analysing qualitative data relevant to address the research question? Unclear No detail provided on how the focus group data was analysed. **Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data were collected?** No No information provided on how focus group findings relate to context **Is appropriate consideration given to how findings relate to researchers' influence; for example, though their interactions with participants?** No No info provided on how findings from focus groups relate to researchers' influence. **Quantitative comp** **Descriptive A** Survey **Is the sampling strategy relevant to address the quantitative research question?**		

	Unclear Sample drawn from the membership of REGARD who live in England, both those who are formal members (n=58) and those who are connected to REGARD via Facebook (n= unknown in terms of how many are in England). No detail provided on sampling strategy in the published research. **Is the sample representative of the population under study?** Unclear The research provides no information on how survey sample was selected. **Are measurements appropriate?** Unclear **Is there an acceptable response rate (60% or above)?** Unclear.		

2. Abbott S, Fisk M and Forward L (2000) Social and democratic participation in residential settings for older people: realities and aspirations. Ageing and Society 20, 327–340

Internal validity – approach and sample.	**Internal validity – performance and analysis.**	**External validity.**	**Overall validity rating.**
Methodology Qualitative study	**How well was the data collection carried out?**	**Does the study's research question match the review**	**As far as can be ascertained from the paper, how well was**

Internal validity – approach and sample.	**Internal validity – performance and analysis.**	**External validity.**	**Overall validity rating.**
Qualitative interviews – quota samples. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology?** Somewhat defensible Clear from the methodology how the study was carried out BUT the sample ended up being 'opportunistic' even though the researchers aim for quota sampling. **Is the context clearly described?** Unclear. Possible biases are not discussed but authors do state the study did not set out to be representative. **Was the sampling carried out in an appropriate way?** Somewhat appropriate	Appropriately. **Are the data 'rich'?** Mixed. While the study aimed to include a diversity of views, and the sampling included participants from sheltered housing and residential care settings, the results do not record which quotes or themes arose from which type of setting. Also because sampling did not take detailed histories, associations between gender, health, lifestyle etc. and views are not reliable. **Is the analysis reliable?** Reliable. **Are the findings convincing?** Somewhat convincing The analysis involved thematic content analysis, which is appropriate for this study design, but it is difficult to conclude much about the diversity of views since little analysis was done drawing out differences and similarities by settings. **Are the conclusions adequate?** Somewhat adequate	**question?** Partly. None of the study questions ask about service use but they do ask for participant views. **Has the study dealt appropriately with any ethical concerns?** No. **Were service users involved in the study?** Yes. All 122 participants were using either sheltered housing or residential care services. **Is there a clear focus on the guideline topic?** Partly. The study is seeking views and experiences of living in sheltered and/or residential care so on scope in terms of the settings but not directly about service use per se – the service use element comes out of themes developed from discussions with participants. **Is the study population the same as at least one of the**	**the study conducted?** + **Overall assessment of external validity** + **Overall score** +

Internal validity – approach and sample.	**Internal validity – performance and analysis.**	**External validity.**	**Overall validity rating.**
It could be that those who completed it were more positive because the sample ended up being opportunistic. Although the researchers did go to much effort to secure participation from 'those less likely to volunteer' to participate (p329). **Were the methods reliable?** Reliable. Apart from the caveats mentioned already about how the sample was derived. Field notes were used to supplement the interviews.	Given the paper's focus was on diversity, it is surprising there is not much discussion about the extent of diverse views in the conclusions. Mostly the conclusions summarise the overall thematic points from the findings section.	**groups covered by the guideline?** Yes. Older people in receipt of social services. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Residential care. **Does the study relate to at least one of the activities covered by the guideline?** Yes, experiences of using residential care services. **(For views questions) Are the views and experiences reported relevant to the guideline?** Partly. Some are and some not. The relevant aspects are those to do with levels of participation residents have in their own lives including what happens to them in the settings. **Does the study have a UK perspective?** Yes.	

3. Barnes C and Mercer G (2006) Creating user-led disability services in a disabling society. Bristol: Policy Press

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
Methodology Qualitative study Interviews in nine case study sites. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear. The project was initiated by the BCODP Research Committee in 1998 and developed with the National Centre for Independent Living (NCIL). Its main aim was to assess the development of Centres for Independent/Integrated/Inclusive Living (CILs) and similar user-directed organisations (Authors, p63). **How defensible/rigorous is the research design/methodology?** Defensible. The project comprised four	**How well was the data collection carried out?** Appropriately. Data collection from the nine case study sites included collection of documentary evidence (for example, mission statements and minutes of AGMs); semi-structured interviews with staff and users. Data from users was collected as part of stage 3 of the project. Interviewees chose their preferred method of interview, whether individually, in pairs or as part of a focus group. Sign language, interpreters and personal assistance was offered if needed. Researchers attempted to match the interview style to the needs of interviewees. Interviews were tape-recorded and transcripts checked with interviewees (p67). **Are the data 'rich'?** Rich. User views presented in chapter	**Does the study's research question match the review question?** Yes. User views of user-led disability services. **Has the study dealt appropriately with any ethical concerns?** Yes. **Were service users involved in the study?** Yes. User views described on a range of services. **Is there a clear focus on the guideline topic?** Yes. About user views in social care. **Is the study population the same as at least one of the groups covered by the guideline?**	**As far as can be ascertained from the paper, how well was the study conducted?** ++ **Overall assessment of external validity** ++ **Overall score** ++

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
stages: 1. Establishing research themes and postal survey of user-led organisations 2. Visits to nine case study sites including interviews with staff 3. In-depth interviews with users from nine case study sites 4. Return visits to sites to present and explore findings (p63). **Is the context clearly described?** Clear Observations made in a variety of settings. Chapter four briefly describes the characteristics of the participants and the nine case study organisations. **Was the sampling carried out in an appropriate way?** Somewhat appropriate. Authors point out that the sample from the nine case study sites was not representative. As membership and user lists are confidential, researchers resorted to using a range of methods to recruit participants, including sending invitations to potential participants in local newsletters, letters sent di-	seven are rich in their descriptions. **Is the analysis reliable?** Reliable. Qualitative data was analysed using 'constant comparison' approach. (Glaser and Strauss, 1967). Categories were identified and two researchers examined the data to identify the existence and consistency of key themes across participants and research sites (p66). **Are the findings convincing?** Convincing. **Are the conclusions adequate?** Adequate.	Yes. Disabled adults. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes Range of settings – including community, care home, day centres in the statutory, voluntary and private sector. **Does the study relate to at least one of the activities covered by the guideline?** Yes. Describes views of disabled people in nine case study organisations providing services for disabled people. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?**	

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
rectly to individuals in organisations, or approaching potential interviewees for names of individuals who might be interested (p66). **Were the methods reliable?** Reliable. The researchers aimed to ensure that the research should be accountable to disabled people, so it was managed by a small advisory group including disabled people and members of organisations controlled by disabled people (who were in the majority), which met every two months to review progress. The initial five months were focused on discussing aims and objectives of the research with key figures in Britain's Disabled People's Movement. Data analysis and drafts were shared with reps of disabled people's organisations and the advisory group for their comment (p56).		Yes. Nine organisations included: 1. Cardiff and Vale Coalition of Disabled People (CVCDP) 2. CIL de Gwynedd (CILdG) 3. Centre for Independent (now changed to 'Inclusive') Living in Glasgow 4. Derbyshire Coalition for Independent Living (DCIL) 5. Disability Action North East (DANE) 6. Greenwich Association of Disabled People's Centres for Independent Living (GAD) 7. Lothian Centre for Independent (now changed to 'Integrated') Living (LCIL) 8. Surrey Users' Network (SUN) 9. West of England Centre for Independent Living (WECIL) (p65).	

4. Beech R, Henderson C, Ashby S et al. (2013) Does integrated governance lead to integrated patient care? Findings from the innovation forum. Health & Social Care in the Community 21, 598–605

Internal validity – approach and sample.	**Internal validity – performance and analysis.**	**External validity.**	**Overall validity rating.**
Methodology Qualitative study. Qualitative methods within a case study design. **Is a qualitative approach appropriate?** Appropriate. Qualitative research methods as part of a case study to map individual patient journeys. This design (see McLeod et al. 2011, Toscan et al. 2011) is recommended as a method for capturing patients' experiences about services (NHS Institute for Innovation & Improvement 2009). **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology?** Defensible. 'Case study design (see McLeod et al. 2011, Toscan et al. 2011) is recommended as an approach for capturing patients' experiences about services (NHS Institute for Innovation & Improvement 2009).	**How well was the data collection carried out?** Appropriately. Data collection took place between February and July 2008. 'Researchers conducted up to three semi-structured interviews with each patient using a topic guide to elicit patient experiences of care. The guide was informed by consultation with a public involvement advisory group convened by one of the participating research organisations. The first interview, at a time close to the participant's health crisis, covered the events leading up to it. The second covered clinical interventions received (generally in an acute hospital) and the third, ongoing care following discharge from an acute hospital or care closer to home service'. (Page 589). **Are the data 'rich'?** Rich. **Is the analysis reliable?** Reliable. Tape-recorded interviews were transcribed and anonymised.	**Does the study's research question match the review question?** Yes. Patient interviews (46) covered care received before, at the time of and following a health crisis. **Has the study dealt appropriately with any ethical concerns?** Yes Ethics approval for the study was granted by the Eastern MREC. Research governance approval was obtained from the relevant Primary Care Trust and Local Authority committees. **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least one of the groups covered by the guideline?** Yes.	**As far as can be ascertained from the paper, how well was the study conducted?** ++ **Overall assessment of external validity** ++ **Overall score** ++

Internal validity – approach and sample.	**Internal validity – performance and analysis.**	**External validity.**	**Overall validity rating.**
Up to three interviews per patient undertaken. The study was designed to follow patients within/across both service boundaries and across time to capture their experiences as they were referred to and discharged from services. Patients were recruited with assistance from hospital and/or community-based staff and use of the modified Appropriateness Evaluation Protocol criteria [an audit tool for identifying avoidable acute hospital bed use (Beech 2005)]' (p599). **Is the context clearly described?** Clear **Was the sampling carried out in an appropriate way?** Appropriate 'The identification of the patient sample was purposive. Patients were recruited with assistance from hospital and/or community-based staff and use of the modified Appropriateness Evaluation Protocol criteria [an audit tool for identifying avoidable acute hospital bed use (Beech 2005)]. If patients met the inclusion criteria, they were approached initially by	Themes were identified, and categories developed and refined inductively, employing the constant comparative method of grounded theory (Glaser and Strauss 1967). The researcher responsible for each site (SA, AD, CH) independently coded the data for their site line by line. During a series of face-to-face and teleconference meetings to enable sharing of data and ideas, the joint coding-framework was agreed. Themes common to all sites as well as differences were discussed, compared and developed as analysis progressed. Emergent findings were also informed by other data such as interviews with senior managers and documentary analysis. Themes that were substantially present in the data from all three sites remained in the final analytical framework. **Are the findings convincing?** Convincing. **Are the conclusions adequate?** Adequate.	Older people. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Across and within organisational boundaries. **Does the study relate to at least one of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. Views focus on the care delivery experiences of patients during three key phases of their journeys: pre-crisis, crisis and rehabilitation (including discharge from acute care). **Does the study have a UK perspective?** Yes.	

Internal validity – approach and sample.	**Internal validity – performance and analysis.**	**External validity.**	**Overall validity rating.**
a member of staff involved in their care to assess potential interest in participation and were given an information sheet giving details of the study. A researcher then contacted the patient, answered any questions and arranged a suitable time and venue for the initial interview. Patients were given at least 24 hours to consider their participation before the researcher sought written consent' (p599). **Were the methods reliable?** Reliable. Where possible, if the patient agreed, an additional interview was undertaken with an identified carer. Also, researchers carried out semi-structured interviews with a range of key staff involved in the patient's care, e.g. hospital nursing staff, allied health or medical team and, in community settings, intermediate care or rehabilitation team members. Interviews were conducted face-to-face or by telephone, and were tape-recorded with the participant's consent (p600).			

5. Blake M, Bowes A, Valdeep G et al. (2016) A collaborative exploration of the reasons for lower satisfaction with services among Bangladeshi and Pakistani social care users. Health & Social Care in the Community. Advance online publication. doi: 10.1111/hsc.12411

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
Methodology In-depth interviews with social care users. **Is a qualitative approach appropriate?** Appropriate. The aim of the study was to understand the views and experiences of a group of BME adult social care service users, in order to understand why they have lower levels of satisfaction with these services than white UK service users. **Is the study clear in what it seeks to do?** Clear. The purpose of the study, to understand the reasons for BME service users' lower level of satisfaction, and then work collaboratively to consider solutions, was clear. **How defensible/rigorous is the research design/methodology?** Defensible. Since the aim of the study was to explore the different satisfaction levels of BME and	**How well was the data collection carried out?** Appropriately. 'Interview topic guides for service users and social care providers were developed using themes identified from the research literature. Interviews with service users and their families lasted around 60 minutes and were conducted by trained qualitative research specialists. Researchers attended fieldwork briefings where the study context, the methods and topic coverage were discussed. These covered daily routines, formal care and informal care. An exploration of cultural and personal expectations, and experiences of accessing and receiving social care sought to identify drivers of satisfaction and dissatisfaction. Focus groups were conducted with social workers and home care workers and in-depth interviews with social care managers. Topics mirrored those used for the service users,	**Does the study's research question match the review question?** Yes. The study does not specifically provide a research question, but it does state in the abstract that it 'explored underlying reasons for the expression of dissatisfaction with services among Bangladeshi and Pakistani social care users in England and investigated, using a collaborative approach, how these could be addressed'. (Page1). The study makes clear that the reference is specifically to adult social care. **Has the study dealt appropriately with any ethical concerns?** Yes. 'Ethics approval was obtained from the Social Care Research Ethics Committee supported by the Social Care Institute for Excellence (scie.org.uk). Information about the research was available in accessible formats and translated into the relevant written languages (Urdu and Ben-	**As far as can be ascertained from the paper, how well was the study conducted?** ++ **Overall assessment of external validity** ++ **Overall score** ++

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
white UK service users, it was appropriate to carry out interviews with both groups. Bangladeshi and Pakistani interviewees were selected because they are groups that have consistently shown low satisfaction levels with care services, and again this was appropriate as the aim was to explore the reasons for dissatisfaction, not to quantify it. The use of practitioner interviewees allowed for explanations to be provided for some of the causes of dissatisfaction, e.g. inadequate resources, lack of training. It also allowed for collaborative working between service users and practitioners in developing solutions. **Is the context clearly described?** Unclear. The wider context for the study, BME adult social care service user dissatisfaction, is clearly explained. However the settings where the interviews informing this study took place are not described. This is worth noting, since it is part of the context for the interviews and could influence how	and perspectives on, and experiences of, providing care were explored'. (Page 4). **Are the data 'rich'?** Rich. There is rich and detailed data about the reasons for interviewee dissatisfaction with adult social care services. **Is the analysis reliable?** Reliable. The study report states that a thematic analysis was carried out, and this is reflected in the thematic structure of the report. The analysis is detailed and consistent, and appears to be an impartial presentation of the data derived from the interviewees. **Are the findings convincing?** Yes. The study presents a consistent and detailed picture. **Are the conclusions adequate?** Yes.	gali). The research was also explained verbally and participant consent was sought at the start of each data encounter. The interviews were offered in the main languages spoken by study participants (Urdu, Punjabi, Bengali and Sylheti). Service users were offered £20 to thank them for their participation'. (Page 5). **Were service users involved in the study?** Yes. Although service users were not involved in designing the study or carrying out the research, they were involved in the collaborative workshops which helped produce recommendations for improving services to BME communities. **Is there a clear focus on the guideline topic?** Yes. The study explores the experiences of Bangladeshi and Pakistani social care service users, in order to find out why BME communities show lower levels of satisfaction than white British user of	

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
participants feel about being interviewed and what they are willing to state in the interview. **Was the sampling carried out in an appropriate way?** Appropriate. As a qualitative study, what was important was not to get a representative sample of BME carers who were dissatisfied with the adult social care provided to them so much as to interview service users who could express what their dissatisfactions were. It was therefore appropriate to pick members of groups who had consistently expressed dissatisfaction with the service. Although the interviewees were all from urban areas, and not rural areas, this allowed the researchers to focus on areas with a higher BME population, and there was a geographic spread in the locations chosen – north, south and Midlands. There may be specific dimensions to the experience of rural BME service users, who may, for example, be more isolated, but it was understandable and acceptable to use the sample which could be the	The conclusions not only provide an adequate explanation for the user dissatisfaction of the interviewees, they also include suggestions with which the interviewees collaborated in order to address the dissatisfactions.	Adult Social Care services. The study identifies some barriers and facilitators to service provision, and makes some proposals for how services could be improved. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. The study population consisted of 2 groups: adult social care service users of Bangladeshi and Pakistani background; and practitioners responsible for providing adult social care services. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. All the service user participants in the study were being provided with care in their home, and not in a residential setting. **Does the study relate to at least one of the activities covered by the guideline?** Yes.	

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
most easily contacted and identified. It was also appropriate to select groups of white British service users and social care practitioners for comparison with the views of the BME interviewees. **Were the methods reliable?** Reliable. There is no reason to doubt the reliability of the research design, the data collection or the analysis.		The study related to the following activities: access to services; choosing and managing care; involving people using services in policy and strategies for local service improvement; views of people who use services, including carers' or family members' perceptions of how well services support them to be actively involved in their care planning and delivery; and working with the people who use services to ensure the right care is delivered at the right time. **Are the views and experiences reported relevant to the guideline?** Yes. The views and experiences sought are all from people who either use or provide adult social care services, with the aim of improving service provision for BME communities. **Does the study have a UK perspective?** Yes. Participants in the study were drawn from 4 local authorities in 3 English cities: Birmingham, Leeds,	

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
		and predominantly Redbridge and Newham in London.	

6. Cameron A, Abrahams H, Morgan K et al. (2016) From pillar to post: homeless women's experiences of social care. Health & Social Care in the Community 24(3), 345–352

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
Methodology Qualitative study **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology?** Defensible. **Is the context clearly described?** Clear. **Was the sampling carried out in an appropriate way?** Appropriate	**How well was the data collection carried out?** Appropriately. The first interview focused on women's views of their living arrangements, past and present. It also explored factors thought to have an impact on homelessness, e.g. experiences of domestic violence, time spent in 'care' as a child and involvement with the criminal justice system. At the end of the interview, women were offered a cash payment of £20 and invited to follow-up interviews, with permission for the researchers to contact any of the services that they were currently using – in order to trace them if necessary. Confidentiality was assured and that their consent or dissent (to contact services) would not affect the services they received. Between interviews, researchers	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** Yes. Ethical review for the project was provided by (School for Policy Studies) Research Ethics Committee. After gaining women's agreement to take part, informed consent was gained before each interview. Confidentiality and anonymity have been secured by using pseudonyms. The authors acknowledge that a longitudinal study of this nature raises many ethical issues, 'not least the sensitivity of discussing homelessness; discussions of these are published	**As far as can be ascertained from the paper, how well was the study conducted?** ++ **Overall assessment of external validity** ++ **Overall score** ++

Internal validity – approach and sample.	**Internal validity – performance and analysis.**	**External validity.**	**Overall validity rating.**
Women were recruited through hostels (nine), the night shelter and specialist services that supported homeless women and those at risk of homelessness (two). **Were the methods reliable?** Reliable.	maintained contact with women by text or email. At the second stage, 6 months later, 28 women were re-interviewed. Again, the interviews covered their current living arrangements. In addition, questions were asked about their experiences of services (including social care) and their relationships with family and friends. At the final stage, 6 months later, 22 women were interviewed. The interviews covered similar areas in stages one and two, but also asked women to reflect on their experiences of taking part in the study. **Are the data 'rich'?** Yes Rich quotes from a variety of contexts. **Is the analysis reliable?** Reliable. 'Interviews were digitally recorded and transcribed in full. Transcripts were analysed thematically using a priori codes derived from the existing research literature and supplemented with additional codes as the analysis proceeded (Flick	elsewhere (Williamson et al. 2014)'. (Authors, page 347). **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least one of the groups covered by the guideline?** Yes Homeless women receiving statutory and non-statutory social care. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Non-statutory and statutory social care for homeless women provided in a variety of settings. **Does the study relate to at least one of the activities covered by**	

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
	2009). Occasionally, codes overlapped (Gilbert 2008), reflecting the interconnectedness of events and feelings reported by participants. Coded transcripts were cross-checked by members of the team to ensure consistency. Data were managed using computer-assisted analysis software (NVivo9)' (Authors, p347). **Are the findings convincing?** Convincing Findings clearly presented and address the study question. **Are the conclusions adequate?** Adequate Clear links between data, interpretation and conclusions and enhances understanding of the research topic. Implications of the research clearly defined as well as discussion of limitations. Authors said: 'Despite repeated visits to hostels and support services, we recruited 38 women, instead of the 40 we had hoped. Additionally, 16 women dropped out of the study. Some women only revealed detail about their needs as they grew to	**the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. Detailed experiences described of the use of social care services. **Does the study have a UK perspective?** Yes	

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
	trust the researchers. Consequently, although we are able to offer an account of the social care support they received, as well as their experiences of this, we are unable to provide much detail about how their needs changed over time' (p350).		

7. Clark J (2009) Providing intimate continence care for people with learning disabilities. Nursing times 105, 26–8

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
Methodology Qualitative study Participant observation in residential care homes, staff interviews and analysis of documents (including support guidelines and oganisational policies) were used to ascertain the personal care experiences of six people with learning disabilities. **Is a qualitative approach appropriate?** Appropriate. Observations were necessary because residents could not communicate on their own.	**How well was the data collection carried out?** Somewhat appropriately It is not clear how recruitment of residents was made or how access to the care homes was gained and there is no discussion of study limitations. It is unclear how consent was gained and how the observations were carried out. No discussion of how the observations may have impacted on the participants. **Are the data 'rich'?** Rich. Lots of useful narratives reported on barriers and service use.	**Does the study's research question match the review question?** Yes. The study asks about the experience of intimate and personal care for adults with severe and profound learning disabilities. **Has the study dealt appropriately with any ethical concerns?** No. The study does not make explicit how consent was gained and how the observations were carried out. No discussion of how the observations may have impacted on the participants.	**As far as can be ascertained from the paper, how well was the study conducted?** + **Overall assessment of external validity** + **Overall score** +

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
Is the study clear in what it seeks to do? Clear. The study aimed to address a gap in knowledge by answering this research question: 'How do adults with severe and profound learning disabilities experience intimate and personal care?’ **How defensible/rigorous is the research design/methodology?** Somewhat defensible. Clear what methodology was used but not clear how recruitment of residents was made or of how access to the care homes was gained and no discussion of study limitations. **Is the context clearly described?** Unclear. Background context provided but not clear how residential care homes selected. Nothing is reported about the context of the residential care home such as size, age and gender profile of the residents.	**Is the analysis reliable?** Unreliable because unclear which methodology elicited which of the data findings. **Are the findings convincing?** Somewhat convincing. The findings link well to the study aims, and are very useful for answering the research question. However, it is difficult to distinguish which methods elicited which results. **Are the conclusions adequate?** Adequate. The summarising of the results is good and links well to the findings reported in the paper.	**Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes. Study includes the views and experiences of people in residential care. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. Adults with severe and profound learning disabilities. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Care homes. **Does the study relate to at least one of the activities covered by the guideline?** Yes	

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
Was the sampling carried out in an appropriate way? Not sure Details of the sampling of participants or the care homes is not reported. **Were the methods reliable?** Unreliable. Insufficient detail is provided.		**(For views questions) Are the views and experiences reported relevant to the guideline?** Yes.	

8. Colston G (2013) Perspectives on personal outcomes of early stage support for people with dementia and their carers. Edinburgh: Centre for Research on Families and Relationships

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
Methodology Qualitative study Semi-structured interviews with people recently diagnosed with dementia. The researcher was also a practitioner or manager of the service. Questionnaires conducted online with staff and volunteers, and interviews with carers not reported here. **Is a qualitative approach appropriate?** Appropriate.	**How well was the data collection carried out?** Inappropriately. Researcher was known to respondents. **Are the data 'rich'?** Poor. Diversity of perspective and content has not been explored. Also lack of detail and depth in participant responses. Apart from the odd reference, it is not explicit which aspects of the service individuals are referring to.	**Does the study's research question match the review question?** Yes. Study aims to get a sense of the experience of using the early stage support service and what it means to the individuals in the early stage of dementia and their family. **Has the study dealt appropriately with any ethical concerns?**	**As far as can be ascertained from the paper, how well was the study conducted?** Relationship of researcher/practitioner to respondents through the Resource Centre has potentially biased the responses favourably. The researcher stated that this relationship, as well as an understanding of dementia, helped to ensure that participants could contribute to their full potential. She was mindful of not influenc-

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
Is the study clear in what it seeks to do? Mixed. **How defensible/rigorous is the research design/methodology?** Indefensible. Methodology not made explicit. **Is the context clearly described?** Unclear. **Was the sampling carried out in an appropriate way?** Not sure Detail not provided on how participants were selected. **Were the methods reliable?** Unreliable	**Is the analysis reliable?** Unreliable. The narrative was analysed using the Talking Points Personal Outcomes Approach, categorising responses that are valued by users (Cook and Miller Joint Improvement Team 2012) (p4). The researcher (practitioner) knew the majority of the participants through their use of the Resource Centre. This relationship, as well as an understanding of dementia, helped to ensure that participants could contribute to their full potential. The researcher was mindful of not putting the participants under duress or encourage them to only highlight positive aspects, but admitted that her presence may have influenced participant responses. There was no evidence that responses/transcripts were checked with another researcher. **Are the findings convincing?** Not convincing **Are the conclusions adequate?** Inadequate.	Partly. All the participants have early stage dementia and capacity and therefore able to consent to take part in the research. Consent to conduct the research was sought and agreed by Alzheimer Scotland to approach participants, in accordance with organisational policy and procedures. Gaining consent involved contacting the Policy and Research Officer at Alzheimer's Scotland and completing a Research Access questionnaire providing an outline of the research, who the participants will be, how they will be recruited, what information they will receive and asking to highlight any potential ethical concerns. Data collection and confidentiality was analysed. Ultimately, consent was granted by the Chief Executive of Alzheimer Scotland. In order that participants could decide whether to consent or not, they were given an information sheet outlining the research, clarifying that participation was entirely optional, and that the answers would be anonymous and subject to confidentiality in accordance with Alzheimer's Scotland. In terms of supporting the person with dementia in the	ing participant responses, but admitted that this might not have been avoidable. The researcher does not detail how the sample was recruited and there was no evidence that responses/transcripts were checked with another researcher. There is a noticeable lack of detail and depth in participant responses and it is not explicit which aspects of the service individuals are referring to. **Overall assessment of external validity** + **Overall score** -

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
		research, the majority of people who access the service were known to the researcher through their contact with the Resource Centre. This relationship, as well as an understanding of dementia, helped to ensure that participants could contribute to their full potential. The researcher stressed that individuals did not feel obliged to participate or obliged to highlight only the positive aspects, but this might have influenced responses in favour of the service. **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. Older people recently diagnosed with dementia.	

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
		Is the study setting the same as at least one of the settings covered by the guideline? Yes. Community setting. **Does the study relate to at least one of the activities covered by the guideline?** Yes. Use of post-diagnostic support in the community. **(For views questions) Are the views and experiences reported relevant to the guideline?** Partly. Mixture of views about the service and perceptions about individual feelings, fears, anxieties, etc. **Does the study have a UK perspective?** No	

9. Cook G, Brown-Wilson C and Forte D (2006) The impact of sensory impairment on social interaction between residents in care homes. International Journal of Older People Nursing 1, 216–224.

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
Methodology **Qualitative study** The paper draws on two research studies, The first study, 'a hermeneutic inquiry examining the meaning ascribed to living in a care home' and the second study, 'a constructivist study, exploring relationships between residents, families and staff'. 'Both studies drew on older people's narrative accounts to explore their experiences of living in a care home. On independently interpreting the narratives a similar theme emerged around the challenges to social interactions experienced by residents with sight and/or hearing impairment. This resulted in a cross-study analysis to further illuminate this theme' (p216). The first study involved 53 interviews with people aged between 52 and 95 years who had lived in four different care homes between 1.5 and 6 years. The second study involved 18 residents (aged 70–100 years) who lived in one of the care homes within this study. Data in this home was collected through six semi-structured interviews with residents, 100 hours of participant observation and two resident focus group interviews.	**How well was the data collection carried out?** Appropriately Defensible details are given of how the participants of each study were recruited and of ethical considerations. **Are the data 'rich'?** Mixed Study findings are rich for meeting the study aims but thin in terms of providing evidence for barriers to adults using social care. **Is the analysis reliable?** Reliable. A clear analytical framework is reported on page 218: 'Both studies utilized an interpretative framework for the analysis of the participants' stories of life as a resident.' **Are the findings convincing?** Convincing for meeting the study aims. **Are the conclusions adequate?** Somewhat adequate Key analytical themes are explored and reported which are	**Does the study's research question match the review question?** Partly. Not directly about service use but relevant information is given through the narratives discussing life in residential care settings. **Has the study dealt appropriately with any ethical concerns?** Yes. Local Research Ethics Committee approval was sought. The participants were fully informed of the nature of the study and what would be required of them. In addition, informed consent was revisited at the beginning of each interview. Some details about how the researcher collected data but not how they were introduced to the participants or how they gained access to the settings. **Were service users involved in the study?** Yes. Residential care home residents.	**As far as can be ascertained from the paper, how well was the study conducted?** + Not much information about barriers. **Overall assessment of external validity** + **Overall score** +

Internal validity – approach and sample.	**Internal validity – performance and analysis.**	**External validity.**	**Overall validity rating.**
Is a qualitative approach appropriate? Appropriate. **Is the study clear in what it seeks to do?** Clear. The aim was to draw on older people's narratives to illuminate the experience of living in a care home and the impact that vision and hearing impairments have on the individual's ability to engage in social interactions with other residents. **How defensible/rigorous is the research design/methodology?** Somewhat defensible Some details are given about how each of the two studies were carried out but as the paper reports on the two studies, it not clear what contribution each study made to the findings – they are merged in the presentation of the results.	drawn together for the conclusions. However, the conclusions are sparse and the authors could have said more about in what ways practice could be improved. The main conclusion seems to be for more empirical work.	**Is there a clear focus on the guideline topic?** Partly. Not much information about barriers and facilitators. **Is the study population the same as at least one of the groups covered by the guideline?** Yes **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. **Does the study relate to at least one of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
Is the context clearly described? Unclear. Care homes involved were anonymised. How the care homes were selected is unclear. **Was the sampling carried out in an appropriate way?** Appropriate. Page 218: In study 1, 8 older people, aged between 52 and 95 years, who had lived in four different care homes between 1.5 and 6 years, were invited to participate in the study during a 6-month period. In study 2, Data in this home was collected through six semi-structured interviews with residents, 100 hours of participant observation and two resident focus group interviews. The researcher attended the home on different days at different times over a 9-month period. These days and times were mutually negotiated with all participants, following a process of informed consent, as identified in Local Research Ethics approval. Opportunities to speak with residents were negotiated on the day the visit took place to enable all participants to be involved			

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
or not depending on their health and wellbeing. **Were the methods reliable?** Somewhat reliable. Enough detail is given to support replicating the type of study but the types of questions asked are not given and it is not clear how the care homes were selected or how access to the care homes was obtained.			

10. Cook G, Thompson J and Reed J (2015) Re-conceptualising the status of residents in a care home: older people wanting to 'live with care'. Ageing & Society 35, 1587–1613

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
Methodology Qualitative study 'This study was a biographical investigation that sought to explore the meaning and meaningfulness that older people attribute to their experiences of living in a care home. The research design followed Gadamer's (1975, 1976, 1989) hermeneutic dialogical process, in which a dialogue is created between the researcher's and the participant's understandings of particular phenomena, with	**How well was the data collection carried out?** Appropriately. Interviews started with invitations to participants to narrate their life histories. At follow-up interviews, participants were asked to give accounts of their lives since the previous interviews. In addition, specific issues about communal living and the meaning of 'home' were introduced by generative questions such as: 'Could you tell me about living with others in this	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** Yes. The interviewees were properly informed about the study and had agreed to be interviewed. Informed consent was confirmed at the beginning of each interview to	**As far as can be ascertained from the paper, how well was the study conducted?** ++ **Overall assessment of external validity** ++ **Overall score** ++

Internal validity – approach and sample.	**Internal validity – performance and analysis.**	**External validity.**	**Overall validity rating.**
a view to attaining a greater appreciation of the participant's stance' (p1591). Multiple interview approach to explore the narratives in depth. **Is a qualitative approach appropriate?** Appropriate. 'This study was a biographical investigation that sought to explore the meaning and meaningfulness that older people attribute to their experiences of living in a care home. The research design followed Gadamer's (1975, 1976, 1989) hermeneutic dialogical process, in which a dialogue is created between the researcher's and the participant's understandings of particular phenomena, with a view to attaining a greater appreciation of the participant's stance. This research design supported the study's aim to facilitate older people to tell their stories of life in a care home. A multiple interview approach was adopted to explore the narratives in depth' (p1591).	care home?' The benefit of this approach to data collection was the addition of new topics to the interview schedule based upon previous stories that participants told, and having the opportunity for clarification of inconsistencies in individual interviewees' responses through revisiting topics (Cohen, Khan and Steeves 2000; Dumay 2010). The interviews were held fortnightly, but were flexible to allow for residents' own convenience and health situations. Trust between researcher and resident was nurtured and enabled examination of quite sensitive topics. **Are the data 'rich'?** Rich. **Is the analysis reliable?** Reliable. 'Narrative analysis was used to interpret how participants viewed their experiences and environment. Following each interview, audio recordings were transcribed verbatim, and open coding undertaken to identify what stories were told, and the topics/issues raised	ensure on-going consent. The study was compliant with the directives of University and NHS Local Research Ethics Committees which ensured interviewees' rights to confidentiality were upheld via anonymisation of data and use of pseudonyms. **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes. The study explores the views and experiences of care home residents in care homes. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Care homes.	

Internal validity – approach and sample.	**Internal validity – performance and analysis.**	**External validity.**	**Overall validity rating.**
Is the study clear in what it seeks to do? Clear. **How defensible/rigorous is the research design/methodology?** Defensible A multiple interview approach was used to explore the narratives in depth. Episodic interviewing was adopted as the data collection method (Flick 1998, 2000) and this technique combines narrative interviewing and more direct forms of questioning to allow the researcher to access both episodic (knowledge of direct experiences) and semantic knowledge (knowledge of concepts and assumptions). According to Flick, this method of data collection is appropriate when the aim of the research is to explore routines and normal everyday phenomena. **Is the context clearly described?** Clear. **Was the sampling carried out in an appropriate way?** Appropriate.	by the respondent. This method facilitated interaction with individual resident's stories. Consequently, a dialectic movement between the whole and the parts of interviews and interview sequences was initiated, allowing for shifts between description and interpretation. The initial interpretation began with developing a surface understanding of the data that aimed to acquire a sense of the whole. This was followed by a structural analysis in which the dialogue was examined to explain 'what it says' and 'how it was said'. The third phase consisted of a critical in-depth interpretation using the FHN framework in order to analyse narratives in terms of what they said about participants' experiences and aspirations regarding the physical, social and self-actualisation needs that 'home' should fulfil. This provided a broader frame of reference than the ADL framework that dominates practice in the care home sector' (p1593). **Are the findings convincing?** Convincing.	**Does the study relate to at least one of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
In the first instance, care home managers were approached to recruit the sample and get consent for participation in the study. The sampling strategy aimed to recruit a broad range of care home types in terms of registration category, number of residents, proprietor arrangements, philosophy and organisation of care, the social activities programme and type of living areas in the home. Eight older people volunteered to take part in the study and, after having the study explained to them, agreed to be interviewed. Informed consent was checked at the start of each interview to ensure continued consent. **Were the methods reliable?** Reliable. Rigorous data collection, methods, sampling and analysis	The authors suggest that being reliant on a small sample who lived in four different care home environments where not much was known about the culture and surroundings may mean that generalising from data is an issue. This has been compensated for by in-depth and continued contact with interviewees over a long period, which provided new insights into their lives including the challenges. It was only during the later interviews that participants discussed very sensitive issues such as their anticipated death. These frank discussions depended on the development of trust between the researcher and the participant, which is not attainable in the context of a single interview. **Are the conclusions adequate?** Adequate.		

11. Cooper C, Dow B, Hay S et al. (2013) Care workers' abusive behavior to residents in care homes: a qualitative study of types of abuse, barriers, and facilitators to good care and development of an instrument for reporting of abuse anonymously. International psychogeriatrics / IPA 25, 733–41

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
Methodology Qualitative study Qualitative focus groups with 36 care workers from four London care homes, asking about abuse they had witnessed or perpetrated. **Is a qualitative approach appropriate?** Appropriate. The aim was to find out and describe what triggered abuse of older people by care home staff. Use of focus groups was appropriate for this aim. **Is the study clear in what it seeks to do?** Mixed Clear but lacks an actual stated aim. Also, part of the study seems to be testing or validating a questionnaire of items assessing abuse of elderly people but this is not stated as an explicit aim. **How defensible/rigorous is the research design/methodology?** Somewhat defensible	**How well was the data collection carried out?** Appropriately. Purposive sampling was carried out to include care workers from a range of care settings (private, voluntary, or local authority; nursing or residential; dementia specialist or not) and with different levels of experience. Care home managers from organisations agreed to participate in the research. Care workers employed to give direct (hands-on) care to people with dementia were invited to participate. This included care assistants and nursing staff. **Are the data 'rich'?** Rich. Lots of discussion and examples included about barriers to social care from the viewpoint of carers. **Is the analysis reliable?** Reliable but as these are reports from the participants who were carers, they may or may not reflect what users think about abuse and the reasons for abuse.	**Does the study's research question match the review question?** Yes. This paper examines the types of abuse, barriers, and facilitators to good care. **Has the study dealt appropriately with any ethical concerns?** Yes. Page 734: 'Participants gave informed consent after receiving an information sheet and an opportunity to ask questions. This explained the study was to find out what helps professionals to provide high quality-care to people with dementia and what makes it harder for them to do so, and to ask their views about a new questionnaire to ask carers anonymously about potentially harmful behaviour towards people with dementia. They were asked not to disclose identifying information about staff or residents. They were advised that if researchers believed that a person was at significant risk of harm from the information disclosed, then the appropriate manager would be informed. The information sheet	**As far as can be ascertained from the paper, how well was the study conducted?** ++ **Overall assessment of external validity** ++ **Overall score** ++

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
It is clear how the study was carried out, including how care homes were selected and participants recruited so the study can be replicated. Not clear what results came out of each focus group (there were 4) or how responses may have varied by gender or other participant characteristics. Only summarised points are provided for all the focus groups. **Is the context clearly described?** Clear. Yes: older people's nursing and residential homes in inner and outer London. **Was the sampling carried out in an appropriate way?** Appropriate. Purposive sampling was carried out to include care workers from a range of care settings (private, voluntary, or local authority; nursing or residential; dementia specialist or not) and with different levels of experience. **Were the methods reliable?** Reliable.	**Are the findings convincing?** Somewhat convincing Yes but as they are only from the carer's perspective they could be biased and/or not be a good representation of what users think. **Are the conclusions adequate?** Somewhat adequate. Good discussion of what results mean but not much about what needs to happen to take good practice forward. Main point is the need for further research and testing of the data collection questionnaire items on detecting abuse.	specified that "we respect confidentiality but cannot keep it a secret if anyone is being seriously harmed or is at high risk of serious harm".' **Were service users involved in the study?** No. Views expressed are primarily those of care workers. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. About experiences of residents in care homes. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Care home. **Does the study relate to at least one of the activities covered by**	

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
Qualitative focus groups with 36 care workers from four London care homes, asking about abuse they had witnessed or perpetrated.		**the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes. Older people's care homes in inner and outer London from a range of care settings (private, voluntary, or local authority; nursing or residential; dementia specialist or not).	

12. Fleming J, Brayne C and Cambridge City (2008) Inability to Get Up after Falling, Subsequent Time on Floor, and Summoning Help: Prospective Cohort Study in People over 90. BMJ (British Medical Journal) 337, 1279–1282

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
Methodology Mixed methods. Follow-up of participants in a prospective cohort study of ageing, using fall calendars, phone calls, and visits. Data were collected on the immediate consequence of	**Qualitative comp 1** **Which component?** Narrative data from surveys with older people and any proxy informant if available.	**Does the study's research question match the review question?** Yes. This paper describes the incidence and extent of lying on the floor after falling and not being	**Overall assessment of internal validity** ++ **Overall assessment of external validity** ++

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
falls among participants of a population-based study— the Cambridge City over-75s Cohort (CC75C). The methods have been described in detail elsewhere for the cohort overall (www.cc75c.group.cam.ac.uk), a longitudinal cohort study of older old people. This cohort initially recruited participants through general practices in the 1980s, when they were all aged 75 or over. Repeated surveys since baseline have gathered data on a range of variables including socio-demographics, physical and mental health, function, and detailed cognitive assessment that included the mini-mental state examination. All those who took part in the 2002–3 survey (90 women and 20 men) were followed up in a prospective study of falls for one year or until death if sooner. Data recorded after each fall included whether the individual who fell had been able to get up without help, how long they were on the floor, any injuries, and whether they called for assistance.	**Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?** Yes. **Is the process for analysing qualitative data relevant to address the research question?** Yes. 'We recorded subjective comments of participants and relatives and coded the qualitative data from these verbatim transcripts using framework analysis methods to identify emergent themes concerning the use of call alarms and summoning help' (Authors, p4). **Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data were collected?** Yes, findings are discussed separately in the text according to the different settings in which the data were collected. **Is appropriate consideration given to how findings relate to**	able to stand up and includes narrative about the experiences of falling, including the reported barriers to using call alarm systems. **Has the study dealt appropriately with any ethical concerns?** Yes. 'For each participant written informed consent was obtained either in person or from the proxy informant, as approved by Cambridge research ethics committee' (Authors, p8). **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes. Views and experiences, especially in terms of barriers to use of call alarms. **Is the study population the same as at least one of the groups covered by the guideline?** Yes.	**Overall validity score** ++

Internal validity – approach and sample.	**Internal validity – performance and analysis.**	**External validity.**	**Overall validity rating.**
Is the mixed-methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed-methods question? Yes. **Is the integration of qualitative and quantitative data (or results) relevant to address the research question?** Yes. **Is appropriate consideration given to the limitations associated with this integration, such as the divergence of qualitative and quantitative data (or results)?** Unclear.	**researchers' influence, for example, through their interactions with participants?** Unclear. Not stated what role the researcher played. **Quantitative component (descriptive)** **Which component?** Falls data describing incidence and extent of lying on the floor for a long time after falling. **Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed-methods question)?** Details of the recruitment and sampling of the longitudinal cohort are reported elsewhere not in this paper – a link is provided. It is reported here as a 'population sample'. **Is the sample representative of the population under study?** It is reported as a 'sample population' but details are not provided in this paper.	Older people. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Own homes or care homes. **Does the study relate to at least one of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
	Are measurements appropriate (clear origin, or validity known, or standard instrument)? Main outcome measures are reported as: 1. Inability to get up without help 2. Lying on floor for a long time after falling, associated factors; availability and use of call alarm systems 3. Participants' views on using call alarms to summon help if needed after falling. **Is there an acceptable response rate (60% or above)?** Not reported in this paper.		

13 Fleming J, Glynn M, Griffin R et al. (2011) Person-centred support: choices for end of life care. London: Shaping Our Lives

Internal validity – approach and sample.	Internal validity performance and analysis.	External validity.	Overall validity rating.
Methodology Qualitative study stages involved: • Collecting statistics about the number of people who are admitted to hospital and what the outcome is. • Reviewing existing research on end of life	**How well was the data collection carried out?** Somewhat appropriately Interviews and focus groups. But the nature of the interview process, specific research questions, etc. was not detailed. With the	**Does the study's research question match the review question?** Yes. Study explores the views of residents, their carers or relatives of older people living in independent	**As far as can be ascertained from the paper, how well was the study conducted?** + The role of the researcher is not clearly described. Description of

Internal validity – approach and sample.	**Internal validity performance and analysis.**	**External validity.**	**Overall validity rating.**
care to identify key messages to inform research questions. • Collecting views of older people living in independent care homes, their relatives and carers and also staff on end of life care, barriers to person centred care. • Preparation of a report of the findings. • A seminar for all stakeholders to review the information and develop a plan of action involving carers and service users. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology?** Defensible Four nursing homes and one residential care home participated in the study. The research used a mixture of individual interviews and focus groups. 8 service users interviewed individually. 7 relatives interviewed individually; and 7 in a focus group =14. 18 individual	practitioner focus groups, the researchers found it difficult to make contact with managers and from 5 who eventually indicated that they could attend, only one manager attended. **Are the data 'rich'?** Rich. Research has plenty of examples of rich data – quotes from residents, relatives and practitioners. **Is the analysis reliable?** Not sure/not reported The study does not explain how the material was analysed except to say that there a report of the findings was published and a seminar held for all stakeholders to review the information. **Are the findings convincing?** Convincing. **Are the conclusions adequate?** Adequate.	care homes and staff in care homes on the barriers to person centred support at the end of life and how these barriers might be overcome. **Has the study dealt appropriately with any ethical concerns?** Yes. The research had ethical approval from the Ethics Committee of the Faculty of Health and Life Sciences at De Montfort University and Research Governance Approval from Camchester Health and Social Research Consortium. With participants' consent, interviews were tape-recorded and consent for this is included in the consent form. The voluntary nature of this research was made clear at all stages, and the right not to answer particular questions or to withdraw altogether was made clear, and such decisions had no consequences for their care etc. It was recognised that taking part in this research project could cause people distress and a comprehensive range of support options was offered to people if they needed them.	how data was collected, including interview questions, topic schedule in focus group not detailed. No description of how data was analysed. With the practitioner focus groups, the researchers found it difficult to make contact with managers and from five who eventually said that they could attend, only one manager attended. **Overall assessment of external validity** + **Overall score** +

Internal validity – approach and sample.	**Internal validity performance and analysis.**	**External validity.**	**Overall validity rating.**
practitioners and managers interviewed – focus group not possible due to staff schedules. **Is the context clearly described?** Clear. **Was the sampling carried out in an appropriate way?** Not sure. Not clear how sample was drawn and if respondents were likely to have a particular perspective. **Were the methods reliable?** Reliable. The research used a mixture of individual interviews and focus groups.		**Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. Care home residents, including family, relatives and staff. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Care homes. **Does the study relate to at least one of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported**	

Internal validity – approach and sample.	Internal validity performance and analysis.	External validity.	Overall validity rating.
		relevant to the guideline? Yes. **Does the study have a UK perspective?** Yes.	

14. French S and Swain John (2006) Disabled people's experiences of housing adaptations. In: Clutton S, and Grisbrooke J, editors. An Introduction to Occupational Therapy in Housing. London: Whurr Publishers Ltd

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
Methodology Qualitative study Seven targeted interviews with disabled people – four focus specifically on housing issues and three explore the relationship between occupational therapists and service users more generally. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear. The purpose of the chapter is	**How well was the data collection carried out?** Not sure/inadequately reported. **Are the data 'rich'?** Rich. Thick descriptive content, contexts of the data are clearly described, the diversity of perspective and content was explored. **Is the analysis reliable?** Not sure/not reported. **Are the findings convincing?** Somewhat convincing.	**Does the study's research question match the review question?** Yes. The authors explore some 'real world' experiences to illustrate some of the qualities that users value in therapists and some of the difficulties that may arise in therapy from the user's viewpoint. **Has the study dealt appropriately with any ethical concerns?** No reference is made to this. **Were service users involved in the study?**	**As far as can be ascertained from the paper, how well was the study conducted?** + **Overall assessment of external validity** + **Overall score** +

Internal validity – approach and sample.	**Internal validity – performance and analysis.**	**External validity.**	**Overall validity rating.**
clear with examination of underpinning values and appropriate reference to the literature. **How defensible/rigorous is the research design/methodology?** Not sure. The authors state that they did not intend to provide a representative sample of service users; their aim was to draw on the experiences of a small number of disabled people with considerable experiences with housing issues and contact with occupational therapists. Data collection and data analysis techniques have not been discussed by authors either. **Is the context clearly described?** Clear. Characteristics of the interviewees and settings are gleaned from interviewee responses. Authors have interviewed individuals with a variety of user circumstances. **Was the sampling carried out in an appropriate way?** Somewhat appropriate.	**Are the conclusions adequate?** Somewhat adequate.	Yes. Seven people were interviewed. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. Disabled people. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Study context is people's own homes and contact with occupational therapists. **Does the study relate to at least one of the activities covered by the guideline?** Yes. Use of occupational therapy. **(For views questions) Are the views and experiences reported**	

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
This was a purposive sample of seven participants. **Were the methods reliable?** Somewhat reliable. Data collected by only one method. However, the chapter is based on rich interviewee quotes.		**relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

15. Gajewska U and Trigg R (2016) Centres for people with intellectual disabilities: Attendees' perceptions of benefit. Journal of Applied Research in Intellectual Disabilities 29, 587–591

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
Methodology Qualitative study – unstructured individual interviews. **Is a qualitative approach appropriate?** Appropriate. The study seeks to investigate the views and experiences of service users. Using unstructured interviews that were up to an hour long would have allowed the researcher scope to explore participants' responses.	**How well was the data collection carried out?** Not sure/inadequately reported. Although the use of unstructured interviews could allow for full and open exploration of participants' views, details of the actual processes that occurred in the interviews is not provided. **Are the data 'rich'?** Mixed. Details with examples of the data are provided for only 4 out of the 11 subthemes identified in thematic analysis. The data examples	**Does the study's research question match the review question?** Yes. The guideline concerns improving the experience of care for people using adult social care services. The study enquires into whether a day and community learning centre meets its goals of providing social support, life skills and greater control over their lives to people with intellectual disabilities. **Has the study dealt appropriately with any ethical concerns?**	**As far as can be ascertained from the paper, how well was the study conducted?** Concerns about the researcher carrying out the interviews also being a volunteer at the day centre which is the subject of the interviews; implications that the researcher's neutrality could be compromised, and that interviewees could be guarded in what they say. **Overall assessment of external validity**

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
Is the study clear in what it seeks to do? Clear. The study was clear in its aim of exploring the views of people with intellectual disabilities about the benefits of attending a day and community learning centre. **How defensible/rigorous is the research design/methodology?** Indefensible. The researcher carrying out the interviewees was a volunteer worker at the centre where the research was carried out. Although the researcher states that this allowed the participants to be 'more comfortable and open during the interviews' (page 588), the researcher not deal with other possible impacts of being already known to participants as a volunteer at the centre, e.g. they may have been keen to please the researcher by speaking well of the centre, and the participants could have been concerned about possible consequences if they complained about the centre. The study also does not deal with the researcher's own position as a volunteer at the day	provided do provide evidence to support the findings. **Is the analysis reliable?** Somewhat reliable. Although the process of coding the themes is described in the study, there is no report of the allocation of codes being checked, nor of the neutrality of the researcher being considered as a possible factor in the positive perception of the day centre that emerges from the study. **Are the findings convincing?** Somewhat convincing. The findings presented are consistent and coherent. However, the questions about whether the participants would have felt free to speak critically about the day centre to a researcher who was also a volunteer there, and about the researcher's own neutrality for the same reason, are not answered in the study. The findings of the study about the day centre are only positive, and there must be questions about whether these are	Yes. 'Ethical approval for the study was granted by Nottingham Trent University Research Ethics Committee. Informed consent was obtained from the facility and each individual participant before the interviews began'. (Page 588). Different names and ages were used to protect participants' anonymity. **Were service users involved in the study?** No. Only as interviewees, not in terms of designing, carrying out or analysing the research. **Is there a clear focus on the guideline topic?** Yes. The focus of the study is the experience of individuals using an adult social care service for people with intellectual disabilities. **Is the study population the same as at least one of the**	+ The study is very relevant to the guideline topic. However, the smallness of the sample and the use of only a single location means that it is hard to say how widely applicable the findings are. **Overall score** +

Internal validity – approach and sample.	**Internal validity – performance and analysis.**	**External validity.**	**Overall validity rating.**
centre, i.e. having a connection with the place, the impact of whose activities is being researched, does not place the researcher in a neutral position. Additionally, although the use of unstructured interviews could allow for full and open exploration of participants' views, details of the actual processes that occurred in the interviews is not provided. **Is the context clearly described?** Clear. The context of the interviews, a day centre described as a 'Mencap facility', is provided. **Was the sampling carried out in an appropriate way?** Not sure. The study states that the participants were a 'purposive sample' (p588), but does not describe how they were selected.	the reasons. Because of this, the findings are partially convincing. **Are the conclusions adequate?** Somewhat adequate. The findings are very relevant to the aims of the study, and are presented coherently. However, because the neutrality of the researcher is compromised, and presentation of the data is quite selective, the findings can only be categorised as somewhat adequate.	**groups covered by the guideline?** Yes. All of the interviewees were people aged 18 or over who use adult social care services (a day centre). **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. The study setting is a day centre where adult social care services are provided for adults with intellectual disabilities. **Does the study relate to at least one of the activities covered by the guideline?** Yes. The study presents the views of people using an adult social care service about how the service meets their needs and promotes their wellbeing. **Are the views and experiences reported relevant to the guideline?**	

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
Were the methods reliable? Not sure. Too little detail is provided about the methods for their reliability to be judged.		Yes. A study that presents the views of adult social care service users about the service being provided to them is highly relevant to the guideline. **Does the study have a UK perspective?** Yes. The location of the study is an 'East Midlands Mencap facility'.	

16. Glendinning C, Clarke S, Hare P et al. (2008) Progress and problems in developing outcomes-focused social care services for older people in England. Health & Social Care in the Community 16, 54–63

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
Methodology Mixed methods A postal survey (using quantitative and qualitative measures) and case studies in six localities. **Is the mixed-methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed-methods question?** Yes. **Is the integration of qualitative and quantitative data (or results) relevant to address the research question?** Yes. **Is appropriate consideration given to the limitations associated with this integration, such as the divergence of qualitative and quantitative data (or results)?** N/A	**Qualitative comp 1** **Which component?** Qualitative data obtained from both the postal survey and the case studies. **Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?** Yes. POSTAL SURVEY – Aimed at adult social care managers and practitioners in England and Wales known to be interested in developing outcomes-focused services. CASE STUDIES – Interviews undertaken with managers and front-line practitioners; interviews and focus group discussions were also held with service users. Interviewees were initially identified by senior managers; front-line staff contacted service users and obtained consent for their details to be passed to the research team.	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** Yes. 'Ethical approval for the study was obtained from the Research Committee of the Association of Directors of Social Services and, where necessary, local research governance approval was also obtained. The study was guided by an advisory group of older service users and carers that met three times during the study' (Authors: page 57). **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes.	**Overall assessment of internal validity** ++ **Overall assessment of external validity** ++ **Overall validity score** ++

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
	Is the process for analysing qualitative data relevant to address the research question? Yes. POSTAL SURVEY – Qualitative data were entered into a Microsoft Access database and analysed thematically. CASE STUDIES – Across the six sites, 82 staff and 71 service users took part in interviews or discussions. Interviews conducted with managers and front-line practitioners; interviews and focus group discussions held with service users. Two semi-structured topic guides were developed for managers, one covering individual-level assessment, care planning, care management and review, the other covering broader service planning, commissioning and development activities. Both topic guides asked about factors that had helped and hindered progress. These were tape-recorded or field notes taken. **Is appropriate consideration given to how findings relate to the context, such as the setting,**	**Is the study population the same as at least one of the groups covered by the guideline?** Yes. Older people. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. **Does the study relate to at least one of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
	in which the data were collected? Yes. Good discussion of policy and context on developing outcomes-focused services. Research based on sound knowledge base and previous research (e.g. Qureshi et al. 1998) on outcomes-focused services. **Is appropriate consideration given to how findings relate to researchers' influence, for example, through their interactions with participants?** Unclear. **Quantitative component (descriptive)** **Which component?** Postal survey – quantitative data element. **Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed-methods research question)?** Yes.		

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
	'The postal survey was targeted at adult social care managers and practitioners in England and Wales known to be interested in developing outcomes-focused services. An earlier research and development programme (Qureshi et al. 1998, Nicholas et al. 2003) had established a network of practitioners and managers interested in developing outcomes-focused services. However, many contacts were out of date and some worked with other user groups. An updating and screening procedure was therefore conducted to identify the target sample – 222 in all across England and Wales – thought to be involved in developing outcomes-focused social care services for older people' (Authors, p56). **Is the sample representative of the population under study?** Yes. The postal survey was targeted at adult social care managers and practitioners in England and Wales known to be interested in developing outcomes-focused services.		

Internal validity – approach and sample.	Internal validity – performance and analysis.	External validity.	Overall validity rating.
	Are measurements appropriate (clear origin, or validity known, or standard instrument)? Yes. The postal questionnaire contained closed and open-ended questions on progress in developing outcomes-focused services; any stakeholder organisations involved; the types of activities, types of services and older people aimed at; achievements to date; and factors helping and hindering progress. Quantitative data were entered into a Microsoft Access database and transferred to SPSS for analysis. **Is there an acceptable response rate (60% or above)?** No. Fifty-four respondents from a possible 222.		

17. Goodman C, Amador S, Elmore N et al. (2013) Preferences and priorities for ongoing and end-of-life care: a qualitative study of older people with dementia resident in care homes. International journal of nursing studies 50, 1639–47

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Methodology Qualitative study	**How well was the data collection carried out?**	**Does the study's research question match the review**	**As far as can be ascertained from the paper, how well was**

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
An exploratory, qualitative study that used guided conversations with 18 people with dementia, living in six care homes. **Is a qualitative approach appropriate?** Appropriate. Exploratory, qualitative study that used guided conversations was appropriate for this group of participants. **Is the study clear in what it seeks to do?** Clear. This paper draws on findings from 18 interviews conducted as part of a four-year longitudinal mixed method study. This paper focuses on the aspects of ongoing and EOLC. **How defensible/rigorous is the research design/methodology?** Somewhat defensible. Clear accounts of the rationale/justification for the sampling, data collection and data analysis techniques were provided, but given that the target group was people with dementia,	Somewhat appropriately. Interviews were exploratory. The authors state that while there were recurring themes, data saturation may not have been reached. As some interviews were short or covered diverse topics and were not focused enough, and researchers were not acquainted enough with participants, interpretation of views was difficult. Furthermore, some interviewees found difficulty in expressing their views and this was one reason for answers that lacked detail. Other methods of communicating ideas and views about end of life were not explored through observation, visual aids or biography and stories. Despite these limitations, the authors state that careful attention was paid to what older people thought was significant about ongoing and EOLC. (Authors: page 1645). **Are the data 'rich'?** Rich. **Is the analysis reliable?** Reliable. Data were systematically grouped	**question?** Yes. **Has the study dealt appropriately with any ethical concerns?** Yes. This study (REC reference: 08/H0502/74) received a favourable ethical opinion from the Southampton & South West Hampshire Research Ethics Committee (A) on 14 July 2008. **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. Older people with dementia.	**the study conducted?** + **Overall assessment of external validity** ++ **Overall score** +

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
other methods of data collection could have been employed to allow for fuller responses. **Is the context clearly described?** Clear. Despite contextual information provided on types of care home and level of need of participants, analysis does not break down findings according to these criteria. **Was the sampling carried out in an appropriate way?** Appropriate. Older people who were either formally diagnosed with dementia or considered by the care home manager/staff as having symptoms indicating that dementia might be present were approached and invited to take part in the study and agreed to be interviewed. The sample was purposive in that residents from each of the six care homes and with different care trajectories were recruited, but the key criterion for inclusion was the ability to engage	into categories that initially kept as close as possible to the older persons' descriptions of events and experiences (Tesch, 1990). Categories were reviewed and combined or linked together where there was overlap or similarities. Within and between categories, links were made, negative cases noted and key themes identified (Coffey and Atkinson, 1996). Two researchers reviewed and refined the themes, which were checked with the wider research team and two members of the PIR group who had experience of family members living and dying in care homes. **Are the findings convincing?** Somewhat convincing. Conclusions are plausible and coherent, but the fact that some individuals had difficulty expressing their points of view and researchers did not know enough about individuals' life stories, meant that interview data may not have been interpreted precisely by researchers.	**Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Care homes. **Does the study relate to at least one of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. Participants were asked about their life in the care home, their health, thoughts for the future, and wishes surrounding end of life. **Does the study have a UK perspective?** Yes.	

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
in a conversation. This latter criterion meant that a section of residents were automatically excluded. **Were the methods reliable?** Somewhat reliable. Interviews aimed to promote meaningful participation. They were held in a location that was suitable for the resident with time built in to feel at ease with the researcher. 'The interviews were semi-structured, conversational and flexible, so that the participant was able to focus on issues that were important to them. They took the form of a 'guided conversation' (Gott et al. 2004). Specific prompts about end of life asked, ''How would you like to be looked after when you are near the end of your life?'' or, ''How would you like to be looked after if you became ill/very poorly?'' All interviews were recorded with the person's consent and were transcribed and anonymised' (Authors, p1641). However, this was the only method of data collection used and the authors acknowledge that	**Are the conclusions adequate?** Adequate.		

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
other methods such as observation, videos and diaries would have enriched the data.			

18. Hamilton S, Tew J, Szymczynska P et al. (2016) Power, Choice and Control: How Do Personal Budgets Affect the Experiences of People with Mental Health Problems and Their Relationships with Social Workers and Other Practitioners?. British Journal of Social Work, 719–736

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Methodology Qualitative study This paper draws on in-depth qualitative interviews with 52 service users with mental health problems and 28 mental health practitioners that were conducted in 2012–13 as part of a national study exploring the implementation of personal budgets (see Larsen et al. 2013). **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear.	**How well was the data collection carried out?** Appropriately. **Are the data 'rich'?** Rich. Contexts of the data are clearly described; the diversity of perspective and content was explored. **Is the analysis reliable?** Reliable. Analysis was undertaken using an Interpretive Framework Approach (Ritchie and Spencer 1994), which employs a matrix-based analytic method to classify and organise data into themes and provides a systematic and transparent overview of data at different levels of	**Does the study's research question match the review question?** Yes. Views of users in three English local authorities were sought about personal budgets in mental health social care. **Has the study dealt appropriately with any ethical concerns?** Yes. National research ethics and local governance approvals were obtained (Camberwell St Giles National Research Ethics Committee ref.11/LO/0620). Study sites were guaranteed anonymity and are described in the paper accordingly as Sites A, B and C.	**As far as can be ascertained from the paper, how well was the study conducted?** ++ **Overall assessment of external validity** ++ **Overall score** ++

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
How defensible/rigorous is the research design/methodology? Defensible. The study is based on in-depth qualitative interviews in three purposively selected local authority areas of diverse geographies (urban/rural) and at different stages of implementing personal budgets. Sampling of interviewees was done through a careful and sensitive process using a mental health professional as a conduit and allowing for potential participants to decline the invitation to participate. **Is the context clearly described?** Clear. **Was the sampling carried out in an appropriate way?** Appropriate. Interviews were conducted in three local authority areas that were selected purposively to reflect a diverse geographic spread in terms of urban–rural and diverse levels of uptake of personal budgets. Service user sample was selected from those who had accessed, or were in the process of	coding. Together with ten service user researchers who formed a research advisory group, an initial framework was designed around research questions and themes coming out of the data. A subgroup systematically coded the transcripts using the framework. Both the coding and framework were reviewed again as part of the larger advisory group to ensure consistency and see if themes had changed or new themes emerged. After consensus was established on a final framework, transcripts were coded, collated and summarised using the software NVivo9. A matrix containing summaries of each coded quote ensured there was transparency in the portrayal of agreements and differences within data. **Are the findings convincing?** Convincing. **Are the conclusions adequate?** Adequate Findings provide evidence of how personal budgets may deliver opportunities for people to take more power and control and some of	**Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes. This is about service user views of social care. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. People with various mental health conditions and in receipt of social care. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Mental health-related social care services. **Does the study relate to at least one of the activities covered by**	

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
accessing, personal budgets or Direct Payments, and had a mental health problem which made them eligible for social care services after having had a local authority assessment of need. Individuals were identified through mental health practitioners in local authorities, the voluntary sector or peer support organisations. Initial approach was through the practitioner and potential interviewees could choose whether or not they wished to be involved. **Were the methods reliable?** Somewhat reliable.	the barriers and challenges in this process. The findings may not be generalisable for two reasons: the three local authority sites may not be representative of other areas in the UK. Secondly, with local authorities experiencing rapid cuts in funding, policies and procedures concerning implementation of PBs are constantly changing; therefore approaches to practice have had little chance to become established. The findings presented are therefore only a snapshot of experiences at a particular point in time (Authors, p732).	**the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes. Based in three English local authorities. Potentially some findings may not be relevant to other parts of England or the UK.	

19. Handley M, Goodman C, Froggatt K et al. (2014) Living and dying: Responsibility for end-of-life care in care homes without on-site nursing provision — A prospective study. Health & Social Care in the Community 22, 22–29

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Methodology Mixed methods A mixed-method design was used. Interviews with care home staff and healthcare professionals alongside a review of care home notes. Limitations are noted on page 28: This study is limited in	**Qualitative comp 1** **Which component?** The findings summarised from narrative accounts of staff and other professionals and reviews of care notes.	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?**	**Overall assessment of internal validity** + **Overall assessment of external validity** ++

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
studying six care homes and associated primary care services in areas that may not be representative. To be able to address such a sensitive topic, our sample of homes was selected from care homes regarded as providing good care with good working relationships with primary healthcare professionals. It did not engage with practice in homes where there were recognised problems with quality of care. **Is the mixed-methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed-methods question?** Yes. **Is the integration of qualitative and quantitative data (or results) relevant to address the research question?** Yes.	**Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?** Yes. The findings summarised from narrative accounts of staff and other professionals (and reviews of care notes) describe the experiences of end-of-life care of older people resident in care homes, and how care home staff and the healthcare practitioners who visited the care home interpreted their role. **Is the process for analysing qualitative data relevant to address the research question?** Yes. Interviews were transcribed and entered onto NVivo qualitative data analysis software (QSR International Pty Ltd., Version 7, 2006) for organisation prior to analysis. Analysis involved three stages: (i) familiarisation, decontextualisation and segmenting the data into categories, (ii) comparing categories (both within and between) for common and divergent themes, and (iii) looking at relationships in	Yes. 'Ethics review was provided by the Southampton and South West Hampshire Research Ethics Committee (REC ref. 08/H0502/38) and local government and NHS organisations (Authors, p23). **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. Older people. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Care homes.	**Overall validity score** +

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
Is appropriate consideration given to the limitations associated with this integration, such as the divergence of qualitative and quantitative data (or results)? Unclear.	the themes identified and the practices observed. **Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data were collected?** Yes. Findings are discussed in relation to the setting in which the data were collected. Later on in the paper reflection is made about the limitations of the research including the small number of cases, which means the study is not representative of the population as a whole. **Is appropriate consideration given to how findings relate to researchers' influence, for example, through their interactions with participants?** No. Not adequately discussed in this paper. **Qualitative component 2** **Which component?**	**Does the study relate to at least one of the activities covered by the guideline?** Yes **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. Experiences of end-of-life care. **Does the study have a UK perspective?** Yes.	

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
	Review of care home notes. **Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?** Yes. Residents' care notes and medical records held within the care homes were reviewed at four time points over a 12-month period. **Is the process for analysing qualitative data relevant to address the research question?** Unclear. **Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data was collected?** Unclear. **Is appropriate consideration given to how findings relate to researchers' influence, for example, through their interactions with participants?** Unclear.		

20. Hart E, Lymbery M, Gladman JR (2005) Away from Home: An Ethnographic Study of a Transitional Rehabilitation Scheme for Older People in the UK. Social Science & Medicine 60, 1241–1250

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Methodology Qualitative study Ethnographic study. The 'core characteristics' of ethnography were: it was small in scale, focussing on TR as a social process in the settings in which the scheme was organised and delivered. The study was designed to trace the development of the scheme over 2 years, with fieldwork concentrated in two phases, 12 months apart. **Is a qualitative approach appropriate?** Appropriate. The study highlighted the need to understand intermediate care from the different perspectives of older people, providers and managers, and to recognise the possible consequences, positive and negative, of providing rehabilitation away from home. This was only possible	**How well was the data collection carried out?** Appropriately **Are the data 'rich'?** Mixed. The data are rich about the scheme and provide many examples of what older people said about their experiences. However, these views are confined to the TR scheme, which is a specific form of adult social care so it therefore is less informative about wider adult social care services. Also, while some information and examples are provided about barriers, not all of the paper is about this. **Is the analysis reliable?** Reliable. It is reported on page 1243 that all taped interviews were transcribed and entered onto NVivo 2.0 for analysis. The researchers also worked directly with hard copies of	**Does the study's research question match the review question?** Yes. Views of older people and care home managers about a transitional rehabilitation (TR) scheme. **Has the study dealt appropriately with any ethical concerns?** Yes The study was approved by the local research ethics committee. Details of ethical considerations are given in the paper. **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes.	**As far as can be ascertained from the paper, how well was the study conducted?** ++ **Overall assessment of external validity** ++ **Overall score** ++

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
to do by taking an in-depth ethnographic approach. 'The theoretical purpose behind our sampling strategy was to understand how each of three key groups experienced the scheme— managers, care staff and older people—and explore similarities and differences within and between groups' (Authors, p1243). **Is the study clear in what it seeks to do?** Clear. The study sets out clear objectives that the paper follows through from the introduction, methods, findings and conclusions. **How defensible/rigorous is the research design/methodology?** Defensible. 'We used purposive sampling (Silverman, 2001) to select participants on the basis of their experience and in-depth knowledge of the scheme rather than, as in a survey, because they were representative of a larger 'population' (Davies, 1999).' (Authors, p1243).	the transcripts and field-notes, reading and re-reading them to retain an oversight of the overall context of the study. **Are the findings convincing?** Convincing. Yes they provide a good reflection of what different stakeholders said about the experiences of using the TR scheme. The triangulation approach of asking elderly people and different groups of professionals meant the conclusions drawn were not biased. Page 1248: The authors argue that 'the ethnographic approach confirmed the advantages of this research method in generating data of considerable richness, depth and breadth (Hammersley, 1990; Savage, 2000), particularly when applied to various forms of institutional care for older people (Stafford, 2003). It enabled a focus on the perspectives of older people, and also on the views of staff (in this case, rehabilitation assistants), who have been absent from much intermediate care research.'	**Is the study population the same as at least one of the groups covered by the guideline?** Yes. Older people. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Intermediate care scheme in six care homes. **Does the study relate to at least one of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Is the context clearly described? Clear. The authors provide a clear description of the TR scheme and how the settings that took place were sampled. **Was the sampling carried out in an appropriate way?** Appropriate. 'We used purposive sampling (Silverman, 2001) to select participants on the basis of their experience and in-depth knowledge of the scheme rather than, as in a survey, because they were representative of a larger 'population' (Davies, 1999). The theoretical purpose behind our sampling strategy was to understand how each of three key groups experienced the scheme— managers, care staff and older people—and explore similarities and differences within and between groups' (Authors, p1243). **Were the methods reliable?** Reliable. The authors claim that the 'ethnographic approach confirmed the advantages of this research	**Are the conclusions adequate?** Adequate. The conclusions are well considered and link back well to the study objectives. Key to the barriers question is that: 'It is possible, even within an institutional setting, to provide specialist rehabilitation services for those older people who want them which transform their lives for the better. However, we conclude that policy makers need to be cautious in the development of residential forms of intermediate care, for two linked reasons. First, it should not always be assumed that home is best for all older people. Secondly, it is by no means straightforward to simulate the conditions of home in an institutional environment—especially one that is purpose-built' (p1249).		

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
method in generating data of considerable richness, depth and breadth (Hammersley, 1990; Savage, 2000), particularly when applied to various forms of institutional care for older people (Stafford, 2003).' They also argue that this approach was beneficial because it 'enabled a focus on the perspectives of older people, and also on the views of staff (in this case, rehabilitation assistants), who have been absent from much intermediate care research' (Authors, p1248).			

21. Hatton C and Waters J (2011) The National Personal Budget Survey: June 2011. London: Think Local Act Personal

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
Methodology Survey BUT direct user views included - 417/1,114 personal budget holders who completed the POET survey wrote in a comment about their experience of personal budgets. **Objectives of the study clearly stated?** Partly.	**Data suitable for analysis?** Yes. **Clear description of data collection methods and analysis?** Partly. Some parts more clearly described than others. Not entirely clear how participants were re-	**Is the setting similar to the UK?** Yes. **Is there a clear focus on [population]?** Yes. **Is there a clear focus on [intervention]?**	**Internal validity** + **External validity** - **Overall score** -

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
The study describes the background of the POET surveys but no objectives stated. Rationale for the survey given on page 6. **Design** *Measures for contacting non-responders?* Not described. *Response rate?* Not reported. **Describes what was measured, how it was measured and the outcomes?** Yes. **Measurements valid?** Partly. Some views and experiences of users of personal budgets are captured but the main focus is on reporting survey data. **Measurements reliable?** Partly. Captures some views and experiences of users but most of the data are survey responses.	cruited other than from local authorities. Response rates not supplied. **Methods appropriate for the data?** Yes. **Statistics correctly performed and interpreted?** Yes. **Response rate calculation provided?** No. **Methods for handling missing data described?** No. **Difference between non-respondents and respondents described?** No. **Results discussed in relation to existing knowledge on subject**	Mixed. Not clear what the 'setting is'. Implied home care. **Are the questions relevant?** Unclear Research questions not stated. No questionnaire supplied with report. **Overall assessment of external validity** -	

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Measurements reproducible? Partly. No questionnaire reported or included and not entirely clear how study participants recruited - except through local authorities. **Basic data adequately described?** Yes. Good description of respondents given. **Results presented clearly, objectively and in enough detail for readers to make personal judgements?** Partly. Clear presentation of survey data. However, views data reported only for some participants and no details given about age, gender etc. of participant. **Results internally consistent?** Yes.	**and study objectives?** No. **Limitations of the study stated?** No. **Results can be generalised?** Unclear. Not clear what the total number being sampled from is so cannot comment on this. **Appropriate attempts made to establish 'reliability' and 'validity' of analysis?** No. Not reported.		

22. Hearle D, Rees V, Prince J (2012) Balance of occupation in older adults: experiences in a residential care home. Quality in Ageing & Older Adults 13, 125–134

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
Methodology Mixed methods Single case study design using multiple data collection methods - included systematic observation, field notes and interval time sampling, both qualitative and quantitative. **Is the mixed-methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed-methods question?** Yes **Is the integration of qualitative and quantitative data (or results) relevant to address the research question?** Yes. Multiple data collection methods within a case study approach allowed for themes to be explored from various angles and included	**Qualitative comp 1** Which component? Observation schedule. **Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?** Yes. An observation schedule was developed based on an interval time sampling model (Fulton et al., 2006), which covered types of activities engaged in by residents identified in a preliminary visit in areas frequented by residents. This schedule had a qualitative and quantitative element. "Field notes regarding the environment and nature of interactions between care staff and residents were compiled at the time of observation in order to increase the meaningfulness of the observed data. These field notes also included some unsolicited comments made by the residents. A running record was made in the public places of the care home of the activities of the	**Does the study's research question match the review question?** Yes. Includes resident views about occupation in a care home. **Has the study dealt appropriately with any ethical concerns?** Yes. 'Following ethical approval by Cardiff University, informed written consent was obtained from the manager of the care home. The manager assured capacity of the residents who were given a full explanation of the nature of the study. Permission to record activities was received' (Authors: page 127). **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes.	**Overall assessment of internal validity** + **Overall assessment of external validity** - **Overall validity score** -

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
field notes and interval time sampling, both qualitative and quantitative. This made for a more robust study, reducing bias and enhancing the reliability of the findings. **Is appropriate consideration given to the limitations associated with this integration, such as the divergence of qualitative and quantitative data (or results)?** Yes. A single case study may not be representative of the experiences of residents in other care homes. Time limited observation over different locations may miss activities. Methodological limitations in that observation only provided discrete snapshots, albeit over 12 hours, of the activities of residents in one care home. Triangulation was applied by combining quantitative and qualitative approaches. The engagement of residents may have been missed in the use of interval time sampling and comments may represent the views of an articulate few. Small sample drawn from one home.	care staff, visitors, available resources, noise and seating" (Authors, p128). **Is the process for analysing qualitative data relevant to address the research question?** Yes. 'The care home was visited for periods of four hours on three occasions and the observation schedule was used to record residents' activities. This was achieved by moving through all the public places to log activities on a continuous basis. On each of the three days, records of activity were completed on four separate occasions each of 60-min duration throughout the day. This allowed each area to be visited five times in a 40-min period and 20 min allocated to the transition between areas and recording of field notes' (Authors, p127). Participants became familiar with the researcher and hence more at ease. Just one of the researchers was eventually involved in making observations as this allowed for consistency in adhering to the observation schedule. The data were analysed using the Statistical Package for	**Is the study population the same as at least one of the groups covered by the guideline?** Yes. Older adults. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Care home setting. **Does the study relate to at least one of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Partly. The engagement of residents may have been missed in the use of interval time sampling and comments from residents may represent only the views of an articulate few.	

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
	the Social Sciences version 12 (Brace et al. 2006). Descriptive statistics were used to analyse the frequencies of activities of the residents and any differences in occupation over the three days. Field notes including residents' views are included. **Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data were collected?** Partly. **Is appropriate consideration given to how findings relate to researchers' influence, for example, through their interactions with participants?** Unclear. **Quantitative component *(including non-RCT; cohort study; case-control study)*** **Which quantitative component?** Observation schedule.	**Does the study have a UK perspective?** No. As this study is only based in one care home, the findings cannot be generalised more widely.	

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
	Are participants (organisations) recruited in a way that minimises selection bias? Unclear. **Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?** "An observation schedule was drawn up, the schedule being based on an interval time sampling model (Fulton et al., 2006). This included the types of activities engaged in by residents identified in a preliminary visit in areas frequented by residents. The care home was visited for periods of four hour on three occasions and the observation schedule was used to record residents' activities. This was achieved by moving through all the public places to log activities on a continuous basis. On each of the three days, records of activity were completed on four separate occasions each of 60-min duration throughout the day. This allowed each area to be visited five times in a 40-min period and 20 min allocated to the		

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
	transition between areas and recording of field notes". (Authors: page 127). **In the groups being compared (exposed versus non-exposed; with intervention versus without; cases versus controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?** N/A **Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?** Observation design, so outcome data not applicable.		

23. Hebblethwaite A, Hames A, Donkin M et al. (2007) Investigating the experiences of people who have been homeless and are in contact with learning disability services. Learning Disability Review 12, 25–34

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
Methodology Qualitative study. Semi-structured qualitative interviews were conducted with fourteen people with learning disabilities who had experienced homelessness. **Is a qualitative approach appropriate?** Appropriate. Aim is to gather views and experiences of those homeless with learning disability needs. **Is the study clear in what it seeks to do?** Clear. Well founded in other studies, highlighting the rationale for investigating homelessness and people with learning disabilities: "Although a limited number of reports have indicated that people with learning disabilities or difficulties may be at increased risk of becoming homeless (Leedham, 2002; ODPM, 2002; Warnes et al., 2003; Crisis, 2005), very little research has been done in the UK with this group of people" (p26).	**How well was the data collection carried out?** Not sure/inadequately reported. **Are the data 'rich'?** Mixed. Clear description of quantifying numbers of participants that agree and disagree; however it is unclear if these participants are homeless or accommodated. Additionally, there is little information about their characteristics. **Is the analysis reliable?** Somewhat reliable. Qualitative data from the interviews was analysed using content analysis. As stated by the authors "Content analysis was used to identify emerging themes from the data, using two raters to ensure reliability. Unique individual experiences were also taken into account in the analysis". (Authors: page 28). The analysis questions the reliability of the data due to the brief explanation or consideration of bias, especially as it is not reported whether participants did	**Does the study's research question match the review question?** Partly. The relevant findings are about outcomes such as: wellbeing and quality of life, engagement with services and care, and support from agencies. However, the findings are generally brief and little commentary is about services delivering adult social care, but temporary accommodation for homelessness. **Has the study dealt appropriately with any ethical concerns?** Yes. The research project gained ethical approval from a local research ethics committee. Consent was given by participants. **Were service users involved in the study?** No. Not co-produced.	**As far as can be ascertained from the paper, how well was the study conducted?** The authors point out that the sample from the fourteen interviews is not representative, especially due to the focus of North East of England. This was due partly to difficulties in recruiting interviewees because of the crisis situation of homelessness. Little information is reported on their abilities and lack of personal history, i.e. previous contact with services. As reported, the study did not include representations from ethnic minorities, and is limited due to the recruitment of only two females. Compounding these limitations is a lack of information of characteristics of those participants that were interviewed, making the data difficult to contextualise and thus interpret. Please consider that findings are nine years old and provisions may have changed to assist people with greater support needs.

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
The aim is to report the experiences of those with learning disabilities that have been homeless, and ascertain their viewpoints of learning disability services in one region, North East of England. **How defensible/rigorous is the research design/methodology?** Defensible - Clear approach to gathering data, i.e. the participants were contacted due to being known to local social or health LD services. The professionals were asked whether it was appropriate for the participants to be contacted, which reduced the contact details initially provided from 38 to 14. In the limitations the authors describe how the study experienced difficulty in recruitment. **Is the context clearly described?** Not sure. Unclear. **Was the sampling carried out in an appropriate way?** Appropriate.	feedback on the findings. **Are the findings convincing?** Convincing. Report is clear and coherent, with findings supported by direct quotes from participants. **Are the conclusions adequate?** Adequate. Thorough findings and good, comprehensive discussion and conclusion supported by other studies. This report excels in exploring the limitations.	**Is there a clear focus on the guideline topic?** Yes. Adults with learning disabilities and service user experience. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. Adults with learning disabilities. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Temporary accommodation for homelessness, not specifically adults with learning disabilities, though relevant in part due to discussion of service provision. **Does the study relate to at least one of the activities covered by the guideline?** Yes. Adults social care.	**Overall assessment of external validity** Unsure if wholly relevant to research question 1 because the study explores the support within temporary accommodation, and little mention of adult social care. The study concludes that there needs to be provision designed to help greater support needs (including learning disabilities). + **Overall score** -

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Research team went through the service users professional to ensure it was an appropriate time. **Were the methods reliable?** Somewhat reliable. Collected via one method – qualitative interviews.		**(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. The aim is to report the experiences of those with learning disabilities that have been homeless, and ascertain their viewpoints of learning disability services in one region, North East of England. **Does the study have a UK perspective?** Yes – North East of England, UK.	

24. Hillcoat-Nallétamby S (2014) The meaning of "independence" for older people in different residential settings. The Journals of Gerontology: Series B: Psychological Sciences and Social Sciences 69B, 419–430

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Methodology Qualitative study The article draws on qualitative data collected from in-depth interviews conducted as part of a larger study completed in Wales (Burholt et al., 2010) designed to address knowledge gaps about meeting the needs of frail, older people residing in supported living	**How well was the data collection carried out?** Appropriately. 'The research team were trained on recruitment and interviewing techniques and the challenges of interviewing couples. Voice-recorded interviews were carried out in people's homes or in private	**Does the study's research question match the review question?** Partly. The focus of this study was the meaning of independence for older people in different settings, so this does not entirely match the review question.	**As far as can be ascertained from the paper, how well was the study conducted?** + **Overall assessment of external validity** +

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
environments. Qualitative interviews planned to gather subjective experiences of ageing and care received in community, care home and extra care settings by exploring core topics about healthcare provisions, support networks, social activities, frailty and disability, with specific extra questions on reasons and choices for moving for participants in extra-care and residential settings. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear. This research presents qualitative data from in-depth interviews conducted as part of a larger study completed in Wales (Burholt et al. 2010) designed to address knowledge gaps about meeting the needs of frail, older people residing in supported living environments.	rooms in the other settings. Respondents were reassured that interviews could be terminated at any point. If participants were living with a spouse or partner, interviewers asked for time alone with the participant to complete the interview, and this was usually not a problem. The quality of data collection was checked at regular team meetings, and interview content was compared for accuracy with some data from the quantitative survey, e.g. marital status and age. (Authors, page 3). **Are the data 'rich'?** Rich. **Is the analysis reliable?** Reliable. An analytical framework was created to guide exploration of interview transcripts. The framework was based on a review of research covering studies about older people's understandings of independence in different residential settings.	**Has the study dealt appropriately with any ethical concerns?** No reference made in the study to ethical issues. **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least one of the groups covered by the guideline?** Yes **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Community and residential settings. **Does the study relate to at least one of the activities covered by the guideline?** Yes.	**Overall score** +

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
How defensible/rigorous is the research design/methodology? Defensible. **Is the context clearly described?** Clear. The interview transcripts clearly differentiate the findings between the different kinds of residential settings. **Was the sampling carried out in an appropriate way?** Appropriate. 'The study population of older people living in extra care or residential settings was drawn from locations in Wales, identified from a specialist database including all registered schemes in the country. As Wales is a very small country, it was important to preserve the anonymity of study sites, so extra care and residential settings were not selected based on characteristics such as number of beds or type of facility. Instead, two Welsh counties were purposively sampled based on rural–urban context, as well as linguistic variations (Office of National Statistics,	**Are the findings convincing?** Convincing. **Are the conclusions adequate?** Somewhat adequate. The authors conclude that the results need to be interpreted in light of some limitations: 'The study is based on a relatively small convenience sample from Wales, and for financial reasons, qualitative data collection was only completed for half of the original total sample, thus compromising the ability to generalize from the findings; some findings are likely to be context specific, for example, physical adaptations would normally only be introduced to the private dwelling as both extra-care and residential settings are likely to incorporate these design features' (Authors, p10).	**(For views questions) Are the views and experiences reported relevant to the guideline?** Partly. Views in relation to the use of social care are relevant. **Does the study have a UK perspective?** Yes. Based in Wales.	

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
2004). All residential schemes in these counties were contacted to participate in the study, and individuals living in the community in their own homes were reached through local authority services. Team managers and community-based staff in each setting agreed to approach their clients and distribute information and participant consent forms for the project' (Authors, p2). **Were the methods reliable?** Somewhat reliable. Only one method of data collection, i.e. interviews, was used. This method itself was reliable in that it involved the development of a prior coding framework using words or phrases identified from the literature such as "independent/ence/ently," "home," "myself," "family," and "my own home,". (Authors: page 4). The framework was tested and amended over a series of peer debriefing meetings with researchers. Two researchers and the author then used the framework to manually code a random sample of 20% of transcripts and compare them for internal consistency, adjusting the			

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
coding framework based on peer consensus. Coded interview extracts were then analysed thematically by type of residential setting to explore patterns in meanings of independence across settings.			

25. Hoole L and Morgan S (2011) 'It's only right that we get involved': service-user perspectives on involvement in learning disability services. British Journal of Learning Disabilities 39, 5–10

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
Methodology Qualitative study. Focus group held with seven people with learning disabilities recruited from a self-advocacy group and day centre for people with learning disabilities. **Is a qualitative approach appropriate?** Appropriate. Focus group conducted with 7 participants to meet aim of study, which is about gathering people's experience of learning disabilities services.	**How well was the data collection carried out?** Appropriately. Excellent ethical consent when considering the recruitment of people with learning disabilities. The researchers considered how to facilitate, which included the authors, two trainee clinical psychologists and a familiar staff-member. Additionally, they were governed by previous guidance Gates and Waight (2007), which proposes the role of facilitation is to guide participants' attention and to create a flowing discussion. The	**Does the study's research question match the review question?** Yes. Service user experience incorporating participants with learning disabilities explore their experience of services. **Has the study dealt appropriately with any ethical concerns?** Yes. Excellent research governance establishing the participants are able to give consent under relevant legislation - Mental Capacity	**As far as can be ascertained from the paper, how well was the study conducted?** + Very thorough methodology and preparation. Note: the sample is one focus group consisting of seven participants where there is a brief description of the characteristics. However, the user views presented do not distinguish between the individuals, and direct quotes are not contextualised. The discussions highlight the limitations of the study in which, when conducting a focus group, some

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
Is the study clear in what it seeks to do? Clear aim with objectives and methods that seek to gain service user experiences. **How defensible/rigorous is the research design/methodology?** Defensible. The authors note the effectiveness of focus groups and how the use of this method of data collection with people with learning disabilities is a valuable approach: "health understanding and promotion (Bollard 2003; Fraser and Fraser 2001; Martin et al. 1997), accommodation (Barr et al. 2003) and understanding of 'Best Value' quality mechanisms (Cambridge and McCarthy 2001)" (p6). It is important to note that due to the nature of the research – a local audit – the aim was to inform local providers of service-user experiences, so is an efficient way to ascertain data promptly.	focus group was hosted in a familiar environment, which again was founded in research to promote participation (Gates and Waight 2007, page 7). Through a semi-structured focus group, the research team were satisfied with the format, noted here: 'We found discussion gathered its own momentum and participants had strong views that they wished to share.' (Page 7). The research team are also aware of the impact of video recording; however, consent was gained. **Are the data 'rich'?** Yes. **Is the analysis reliable?** Reliable – Comprehensive analysis where data has been recorded, then analysed using thematic analysis (Braun and Clarke 2006). The authors note that non-verbal cues were not analysed, as they were interested in the narrative. It is significant that analysis was fed back to each participant in an accessible summary of the findings.	Act. Permission was sought to video record discussion and participants were able to opt in using appropriate accessible consent forms. Ethical approval was not reported from a research committee but it is unclear if this is appropriate given the ethical considerations. **Were service users involved in the study?** No. Study not co-produced. **Is there a clear focus on the guideline topic?** Yes. Service user experience. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. Adults with learning disabilities.	participants were more domineering. **Overall assessment of external validity** ++ Relevant to review question one, with clear link to guideline topic. The participants are recruited by the individual organisations, following thorough ethical consideration. **Overall score** +

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
Is the context clearly described? Not sure. Not adequately reported. **Was the sampling carried out in an appropriate way?** Appropriate 'Participants were recruited from an established self-advocacy group and from a day centre for people with learning disabilities, both situated in a borough of South West London' (p6). The research team went through the manager and staff of each entity to ensure that the participants felt like they had a choice if they were a part of the focus group or not. The inclusion criteria were similar to other studies conducted with people with learning disabilities (Barr et al. 2003; Cambridge and McCarthy 2001). **Were the methods reliable?** Somewhat reliable - Only one method of data collection, which was a small-scale focus group.	**Are the findings convincing?** Convincing. Services assessed by people with learning disabilities (n=7), considered their insights into the varying experiences, which have been analysed in three key themes: (1) Feelings of unfairness and inequality; (2) Experiences of inclusion and power; and (3) Future visions. The only criticism would be that the quotes and experiences are not contextualised. **Are the conclusions adequate?** Adequate – The discussion highlights the limitations of the study in which, when conducting a focus group, some participants were more domineering. The conclusion states that services have made people with disabilities experience problems in the current and past of inclusion and exclusion of power, and their hopes for future outcomes.	**Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Day centre for people with learning disabilities. **Does the study relate to at least one of the activities covered by the guideline?** Yes – Adult social care. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes – The aim was to conduct a focus group with service users with learning disabilities in order to ascertain 'their experiences of services, what was helpful and unhelpful, whether they felt involved and listened to, and suggestions for improving involvement' (p6). **Does the study have a UK perspective?** Yes – London	

26. IFF Research (2008) Employment aspects and workforce implications of direct payments: research report. London: IFF Research

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
Methodology Qualitative study. This is a three-phase, large-scale quantitative research project encompassing the following: 1. Main employer survey – 526 face-to-face interviews with Direct Payment employers in sixteen Local Authority areas. 2. Self-completion survey of Personal Assistants 3. Telephone survey of Personal Assistants - 100 individuals who had completed the self-completion survey. The SUE review is based on the first phase focusing on qualitative data from the main employer survey, carried out between February and November 2007. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear.	**How well was the data collection carried out?** Appropriately. Interviews were conducted, either in the person's home or a convenient location, and with the employer alone, or where requested by the employer, with a representative or support person present. It was stressed that the survey questions would focus largely on the person or persons employed through Direct Payments, and that therefore, these individuals should not be present during the interview. Where the Personal Assistant and the person in receipt of or responsible for administering the Direct Payments and arranging care was one and the same person (i.e. a carer or a parent of a child recipient) representatives could be present or complete the survey on the employer’s behalf. (Page 14). **Are the data ‘rich’?** Rich.	**Does the study’s research question match the review question?** Yes. Interviews focused on the following: 1. employer's history of involvement with DP 2. employer satisfaction with the current Personal Assistant(s) employed through Direct Payments 3. problems experienced under Direct Payments, general concerns and additional support requirements 4. employer attitudes to being an independent employer, including formal contracts and training for Personal Assistants 5. attitudes towards the registration of Personal Assistants 6. some details on the job role and work / training history of current Personal Assistants. Interviews also asked about any experience of abuse when employing a PA or using Local Authority-arranged support services.	**As far as can be ascertained from the paper, how well was the study conducted?** + **Overall assessment of external validity** ++ **Overall score** +

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
How defensible/rigorous is the research design/methodology? Defensible. The main employer questionnaire was based on the findings of the Sheffield/New Types of Worker research and other key published research, and developed in consultation with the project steering group. This group consisted of representatives of Skills for Care, the General Social Care Council (GSCC), a representative of Skills for Care's People who Use Services and Carers Task and Finish Group, the Sheffield researcher and the Social Care Institute for Excellence (SCIE). The survey was piloted in two phases, initially with five Direct Payment employers, and revisions made on their feedback, and then a full version of it was piloted with 11 DP employers within one Local Authority region to develop a final questionnaire in conjunction with Skills for Care (p15). **Is the context clearly described?** Clear	Contexts of the data are clearly described and varied rich quotes. **Is the analysis reliable?** Not sure/not reported **Are the findings convincing?** Convincing **Are the conclusions adequate?** Adequate	**Has the study dealt appropriately with any ethical concerns?** No. **Were service users involved in the study?** Yes **Is there a clear focus on the guideline topic?** Yes. Views of direct payment users. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. People receiving direct payments. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Services accessed through direct payments in people's own homes and other settings.	

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
Was the sampling carried out in an appropriate way? Appropriate. Letters were sent to Direct Payment employers covered by the participating Local Authorities, asking them to contact IFF Research if they did not want to be contacted in relation to the survey. Those individuals not opting out of the survey were invited to participate in a face-to-face interview (p13). 'It should also be noted that whilst steps were taken to ensure that the proportion of interviews conducted with employers of different genders and disability types matched those found in the sample obtained, there were no such quotas set according to age or ethnicity... the weighting of the survey data by administrative category has not led to any particular skew in the weighted profile of gender, ethnicity and age' (p 20). A relatively equal balance of male and female employers were interviewed (58% female, 42% male). Reflecting the characteristics of the samples of Direct Payment employers provided, the vast majority of employers participating		**Does the study relate to at least one of the activities covered by the guideline?** Yes. **Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
(88%) were white. Note that because of the relatively low numbers of Asian, Black and Mixed ethnicity employers that were interviewed, it has been difficult to make meaningful comparisons between employers of different ethnicities. Only statistically significant differences between employers of different ethnicities are presented in the report. A relatively even spread of employers of different ages were interviewed. The male employers surveyed were generally younger than the female participants; 31% of males were under the age of 24, compared to 16% of female employers (unweighted figures) (p21). **Were the methods reliable?** Reliable. Questionnaire was piloted extensively involving two phases. Data collected for the whole research itself involved more than one method.			

27. Institute of Public Care. Oxford Brookes University (2010) Oxfordshire County Council: support to the early intervention and prevention services for older people and vulnerable adults programme: report on study of care pathways. Bath: Oxford Brookes University

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Methodology Mixed methods The project combined a quantitative and qualitative approach. 1. Secondary analysis of admissions records. The aim was to obtain data on a quarter of all admissions across the county over the year prior to the study. 2. Interviews with a sample of the 115 older people admitted to a care home in 2008–2009, their informal main carers where available, and care managers. A total of 21 interviews, including seven older people, eight carers and eight care managers, were carried out. There were three cases where the carers of older people with dementia were interviewed. The completed interviews were transcribed and an analysis of the transcripts carried out using qualitative data analysis software. This was triangulated with the data from the file audit. Older people and their carers were asked about circumstances and experiences prior to entering a care home, including: the previous living arrangements of the older person; their health	**Qualitative comp 1** **Which component?** Interviews with care home residents, their informal main carers where available, and care managers. **Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?** Partly. The qualitative part of the study included sections about social services used and support relevant to this review but other sections of the research report are not relevant (e.g. views about primary care). **Is the process for analysing qualitative data relevant to address the research question?** Yes. No research questions stated but views are clearly an important means of eliciting information about critical 'circumstances and events' prior to admission.	**Does the study's research question match the review question?** Yes. This aim of this paper was to identify the critical characteristics, circumstances and events that lead to a care home admission in order to provide appropriate services to prevent or delay such an admission. **Has the study dealt appropriately with any ethical concerns?** Yes. Ethical and practical reasons are referred to by the authors in their decision not to interview people with dementia. (Page 6). **Were service users involved in the study?** Yes. Service users were interviewed for this study. **Is there a clear focus on the guideline topic?** Yes.	**Overall assessment of internal validity** + **Overall assessment of external validity** + **Overall validity score** +

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
and need for care in the four to five years leading up to admission; the circumstances around the decision to go into care; and whether there were any services or support that they felt could have enabled them to continue living in their own home for longer. This phase of the project also included mapping timelines for the older people who were interviewed to visually demonstrate their pathway into care. **Is the mixed-methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed-methods question?** Yes. Secondary analyses of records provide important contextual information for the interviews that followed. **Is the integration of qualitative and quantitative data (or results) relevant to address the research question?** Yes.	**Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data were collected?** Yes. Analysis was conducted about circumstances prior to admission and this information was used to understand differences between the samples. **Is appropriate consideration given to how findings relate to researchers' influence, for example, through their interactions with participants?** Unclear. Nothing is stated about this in the report. **Quantitative component (descriptive)** **Which component?** Secondary analysis of admission records.	The qualitative part of the study included sections about social services used and support relevant to this review. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. Older people. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Care homes. **Does the study relate to at least one of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** No.	

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
Interview data was triangulated with the data from secondary analysis of records. **Is appropriate consideration given to the limitations associated with this integration, such as the divergence of qualitative and quantitative data (or results)?** N/A	**Is the sampling strategy relevant to address the quantitative research question?** Unclear. It was unclear how the secondary analysis was carried out and what elements of the admissions data was analysed. **Is the sample representative of the population under study?** Not stated – although the admissions data looks like it's about the same cases sampled from the qualitative component, which is broadly representative of the population in terms of its demographics. **Are measurements appropriate (clear origin, or validity known, or standard instrument)?** Unclear. **Is there an acceptable response rate (60% or above)?** Not stated – not a survey with response rates. A comment is made on page 1 that: 'It should be noted that the quality of file data depends on the approach of individual staff to recording the data and	Details of the type of care home not provided so it is hard to gauge if settings characteristics have a UK-wide perspective.	

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
	this obviously creates varying degrees of bias. For example, information prior to admission to a care home may emphasise the severity of an older person's situation in order to ensure that they are considered eligible for admission' (Authors, p1).		

28. Irvine F, Yeung EYW, and Partridge M et al. (2016) The impact of personalisation on people from Chinese backgrounds: qualitative accounts of social care experience. Health Soc Care Community, Advance online publication. doi: 10.1111/hsc.12374

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Methodology Qualitative study In-depth semi-structured interviews - in the language of choice of the participants (English, Cantonese or Mandarin) between July 2012 and February 2013. **Is a qualitative approach appropriate?** Appropriate. In-depth interviews – appropriate for obtaining views of social services.	**How well was the data collection carried out?** Somewhat appropriately. Purposive sampling to recruit people from a Chinese background with a physical impairment who had received social care from adult services in the previous 6 months. Snowballing techniques were used with individuals who agreed to take part in the study, who were asked to pass on recruitment flyers to potential participants. The research team invited all who took part in an interview to	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** Yes. Written consent was obtained from each participant to take part in interviews and focus groups, and for these to be audio-recorded. Confidentiality was assured and all data were anonymised. The study gained ethics approval	**As far as can be ascertained from the paper, how well was the study conducted?** + **Overall assessment of external validity** ++ **Overall score** +

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Is the study clear in what it seeks to do? Clear. **How defensible/rigorous is the research design/methodology?** Somewhat defensible There are a number of notable limitations reported by the authors on page 8: 1. 24/26 respondents resided in major English cities and were mainly recruited through Chinese welfare organisations. This may have influenced their experiences and their levels of satisfaction such that they would not be transferable to people living in suburban or rural locations. While the authors say they attempted to portray a balanced report of participants' experiences, they agree it is possible that their accounts were coloured by their perceptions of the interviewing researchers and the perceived balance of power between researcher and researched; 2. The authors say that the professional social worker status of the 'insider' may have influenced or inhibited participants' disclosure of their experiences.	attend the focus groups. No second stage sampling or filtering was conducted. **Are the data 'rich'?** Rich. **Is the analysis reliable?** Reliable. Page 4. The authors report that: The interviews and focus groups were audio recorded, fully transcribed and anonymised. Transcripts were analysed in the original language of the interview, and bilingual labelling was used through the analysis to accurately describe participants' experiences and in order to retain any linguistic nuances. The research team read the interview transcripts to examine patterns in the data, coded them and identified initial subthemes before agreeing on a preliminary thematic framework. Decision processes were traced and themes were scrutinised by an independent researcher by cross-checking case charts with data reconstruction sheets to ensure correspondence, and systematically tracing interview quotations	from the Social Care Research Ethics Committee. **Were service users involved in the study?** Yes. Participants were those with Chinese background with a physical impairment who had received social care from adult services in the previous 6 months. **Is there a clear focus on the guideline topic?** Yes. Views and experiences of social services. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Home Care.	

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Is the context clearly described? Unclear. Although it is clear the respondents were those with a physical impairment who had used social services recently, it is not clear where the participants were receiving the care. It seems likely all were home care based but this is not confirmed in the paper. **Was the sampling carried out in an appropriate way?** Somewhat appropriate. Purposive sampling was used; all participants were accepted into the focus groups. **Were the methods reliable?** Reliable.	through all stages of analysis to ensure dependability. **Are the findings convincing?** Convincing. Findings are summarised well and quotes link well to the summative points being made by the authors. **Are the conclusions adequate?** Adequate.	**Does the study relate to at least one of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. Views of service users – directly reported. **Does the study have a UK perspective?** Yes. England.	

29. Jones K, Netten A, Francis J et al. (2007) Using older home care user experiences in performance monitoring. Health and Social Care in the Community 15, 322–332

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Methodology Cross-sectional study	**Measurements and outcomes clear?** Yes. Appropriate techniques used	**Is the setting similar to the UK?** Yes.	**Internal validity** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
To avoid response bias that the majority of the questionnaires be self-completed although alternative methods, such as face-to-face interviews or telephone interviews, would be acceptable where necessary. Councils were advised to plan to send out a maximum of two reminder letters to these service users. A pairwise correlation matrix was analysed to overcome the problem of missing data. Reliability analysis using Cronbach's alpha was performed to measure the internal consistency of the factors. **Objectives of study clearly stated?** Yes, the study aims to examine whether best value performance indicators reflect quality of home care as experienced by people who use the services. **Clearly specified and appropriate research design?** Partly. Some councils were permitted to add and remove questions. Two councils removed a question on	when exploring the association between a continuous variable and a dichotomous variable. Because of the tendency of older service users to over-rate the performance of services, raw scores for the quality items were transformed into dichotomous (binary) scores with the extreme or top level scoring 1 and all other responses 0. **Measurements valid?** Yes. **Setting for data collection justified?** Partly Respondents were advised to avoid response bias by ensuring most questionnaires were self-completed; however, overall 43% of people who completed the questionnaire needed help to do so. **All important outcomes and results considered?** Yes. The study looks at whether the experiences of home care reflect the performance indicators of quality. It also finds that other factors may	**Is there a clear focus on [population]?** Yes. **Is the intervention clearly [intervention]?** Yes. **Are the outcomes relevant?** Yes. Measurement of the perceptions and experience of service users, and how this can be translated into best value performance indicators, towards improving home care services is highly relevant to this review question.	**External validity** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
the skills and attitudes to carers due to concerns of the length of the questionnaire. There was no sensitivity analysis to see if this was an important question to omit or had an effect on the underlying construct of home care quality. **Subjects recruited in acceptable way?** Partly. All councils were requested to select a random sample of eligible home care service users aged 65 and over from their records in 2003. It is not stated how this was done in practice, although guidance was given to councils on the required sample size. **Sample representative of defined population?** Unclear. There were no baseline statistics of national characteristics of service users to compare with. Authors state that London boroughs were underrepresented in the sample population due to another study being carried out in London at the same time.	be important in determining service quality than these two indicators alone. **Tables/graphs adequately labelled and understandable?** Yes. **Appropriate choice and use of statistical methods?** Yes. Identifies whether the performance indicators reflect aspects of quality. Factor extraction was performed using principal component analysis with an orthogonal rotation using the varimax method for interpretation. **Are sufficient data presented to support the findings?** Yes. **Results discussed in relation to existing knowledge on the subject and study objectives?** Yes. **Results can be generalised?** Partly.		

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Overall validity rating**
	The study compares existing measures of quality and finds that the two factors are associated with quality of care as perceived by the respondents. However, the study also finds other indicators of quality than the two in the performance indicators. It is less clear how this can be tested and generalised. **Do conclusions match findings?** Yes.		

30. Katz J, Holland C, Peace S et al. (2011) A Better Life: What older people with high support needs value. York: Joseph Rowntree Foundation

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
Methodology Qualitative study Framework developed through a two-phase approach: 1. Evidence review of people's (with high support needs) views about what they value and aspire to, in order to identify the headings for an evidence framework. 2. Conversations with people with high support needs about what they want and value in order to	**How well was the data collection carried out?** Appropriately. The conversations were recorded with permission of interviewees, then transcribed and analysed against the categories in the evidence framework. New categories were added as necessary and this process was cross-checked by team members.	**Does the study's research question match the review question?** Partly. Research question was what older people with high support needs want and value in their lives, so not explicitly social care. **Has the study dealt appropriately with any ethical concerns?** Yes.	**As far as can be ascertained from the paper, how well was the study conducted?** + **Overall assessment of external validity** + **Overall score** +

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
validate the framework. The researchers also spoke to volunteers and professionals working with people with high support needs in a range of organisations. Most of these conversations were held on the phone. **Is a qualitative approach appropriate?** Appropriate. The study aimed to improve understanding of what older people with high support needs want and value by proposing a model based on a research review and discussions with study participants and therefore a qualitative approach is appropriate. **Is the study clear in what it seeks to do?** Clear. Research with service users involving younger adults with high support needs and, to a lesser extent, older people in general, is fairly well established. Research with older people with high support needs is a more recent phenomena and this paper builds on that.	**Are the data 'rich'?** Mixed. **Is the analysis reliable?** Reliable. 'The transcribed conversations were analysed against the categories in the evidence framework, with new categories added as necessary, then cross-checked by team members.' (Authors, page 19). In their analysis, the researchers grouped themes or subthemes according to how often they were mentioned and the importance given to them by participants. (Page 20). Analysis also involved comparing the evidence framework with frameworks produced in other comparable studies. **Are the findings convincing?** Convincing Authors state that the findings were based on a small sample of people and therefore may not be representative. However, the 'conversations provided some verification by older people with high support needs of the recurring themes from other studies.' (Page 19).	Researchers ensured that all participants were able to fully engage with the research process, and where this was not possible, carers accompanied older people and acted as proxy. The use of an adapted existing interview tool called the 'facets of life wheel' using the concepts identified through the literature review, enabled people to lead on topics as much as possible. **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. Older (and some younger) people with high support needs.	

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
How defensible/rigorous is the research design/methodology? Defensible. Researchers adapted an existing interview tool called the 'facets of life wheel', using the concepts identified through an earlier literature review and included in the interim framework. The wheel supports user-led and semi-structured discussions (Peace et al. 2006) enabling people to lead on topics as much as possible and talk about different aspects of their lives including their wishes (Authors, p19). **Is the context clearly described?** Clear. Characteristics of the participants and settings not always clearly defined. **Was the sampling carried out in an appropriate way?** Somewhat appropriate. A purposive sample was recruited through contacts of the Open University's (researchers') network across the UK, instead of through	**Are the conclusions adequate?** Adequate. This study enhances our understanding of the topic. Researchers acknowledged the limitations of gathering certain types of factual information from people with cognitive impairments, but felt confident that the information collected was reliable (Authors, p19).	**Is the study setting the same as at least one of the settings covered by the guideline?** Yes own home and institutional settings. **Does the study relate to at least one of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
national organisations. The researchers said that this helped them to identify a mix of people (in terms of age, disability, geographical location, living circumstances, etc.) who are not usually consulted. **Were the methods reliable?** Somewhat reliable. Conversations lasted from 45 and 90 minutes. Some of the participants with dementia were unable to give reliable information and proxy carer views were used where possible. However, the visual nature of the 'wheel' meant that it was a good tool to prompt conversations with these participants in particular. The simplicity of the tool also meant that it worked well with people with sensory impairment, as it was easy to explain. While researchers were aware of the limitations of gathering certain types of factual information from people with cognitive impairments, they felt confident with the information collected (Authors, p19).			

31. Komaromy C, Sidell M, Katz J (2000) The quality of terminal care in residential and nursing homes. International journal of palliative nursing 6, 192–200

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Methodology Mixed methods The study involved three stages — a postal questionnaire (Stage 1), interviews with heads of 100 homes (Stage 2) and 12 case studies (Stage 3). **Is the mixed-methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed-methods question?** Yes. **Is the integration of qualitative and quantitative data (or results) relevant to address the research question?** Unclear. This study suits a multi-method approach (3 types of study design). But there is no description of how these methods complement each other, or how each	**Qualitative comp 1** **Which component?** Stages 2 and 3 included 100 interviews with heads of homes and 12 case studies. **Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?** Yes. Interviews with the heads of homes and 12 case studies complement the quantitative element, i.e. postal questionnaire. **Is the process for analysing qualitative data relevant to address the research question?** No. There is no discussion of analysis of the interviews or data from the case study sites. The only reference to interviews in the Methods section refers to the use of structured and semi-structured questions and what they included, e.g. resources available for terminal	**Does the study's research question match the review question?** Yes. Resident views about social care.	**Overall assessment of internal validity** - **Overall assessment of external validity** + Despite adequate and appropriate references to previous literature to provide context, the study does not appear to be clear in its aims. The authors state their focus is to report on the postal survey aspect of the research but much of the reporting is mixed with the Stage 2 aspect, i.e. the interviews with heads of homes. **Overall validity score** -

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
method informs or shapes the other. **Is appropriate consideration given to the limitations associated with this integration, such as the divergence of qualitative and quantitative data (or results)?** No. The data from the questionnaires (Stage 1) and the structured elements of the interviews (Stage 2) were analysed using the Statistical Package for the Social Sciences (SPSS). There is no detail about the differences between care homes. Responses not compared and contrasted across groups/sites.	care, reasons for transfer of residents, and knowledge and training in palliative care. **Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data were collected?** No. **Is appropriate consideration given to how findings relate to researchers' influence, for example, through their interactions with participants?** No **Quantitative component (descriptive)** **Which component?** Postal survey of 1000 homes. **Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed-methods question)?** Unclear		

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
	No sampling information. Only reporting in methods section is “This article focuses on the quantitative data collected from the postal survey of 1000 homes which yielded a response rate of 41% (n = 412)....' (Authors, p193). **Is the sample representative of the population under study?** Unclear. **Are measurements appropriate (clear origin, or validity known, or standard instrument)?** No. Data collected from the postal survey of 1000 homes yielded a response rate of 41% (n = 412). **Is there an acceptable response rate (60% or above)?** No.		

32. Mair M and McLeod B (2008) An evaluation and assessment of deferred payment agreements. Edinburgh: Scottish Government Social Research

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
Methodology Qualitative study The research was based on 14 local authorities, and used qualitative methods to gather information from residents and their relatives, older people in the community and local authority officials. Fieldwork was carried out as follows: • One–to-one interviews with 4 individuals who have gone through the process of setting up a DPA, gathering views and experiences of the process • One-to-one interviews with 6 individuals who have no DPA in place, including a mix of individuals who have sold their property prior to moving into care, or who have had a Charging Order placed on their property as an alternative to a DPA, gathering views and experiences of the processes they had been through • Focus groups with 2 community-based groups of older people gathering information relating to knowledge of DPAs and attitudes towards relevant issues relating to payment of care home fees • One-to-one interviews with 10 local authority representatives from social	**How well was the data collection carried out?** Somewhat appropriately Fieldwork was carried out as follows: • One–to-one interviews with 4 individuals who have gone through the process of setting up a DPA, gathering views and experiences of the process • One-to-one interviews with 6 individuals who have no DPA in place, including a mix of individuals who have sold their property prior to moving into care, or who have had a Charging Order placed on their property as an alternative to a DPA, gathering views and experiences of the processes they had been through • Focus groups with 2 community-based groups of older people gathering information relating to knowledge of DPAs and attitudes towards relevant issues relating to payment of care home fees • One-to-one interviews with 10 local authority representatives from social work finance. • 2 one-to-one interviews with front-line social work staff responsible for advising residents about funding	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** No. Not stated. **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. Care home residents. **Is the study setting the same as at least one of the settings covered by the guideline?**	**15. As far as can be ascertained from the paper, how well was the study conducted?** + **Overall score** +

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
work finance. • 2 one-to-one interviews with front-line social work staff responsible for advising residents about funding options and arrangements, to gather information on practices and views in relation to DPAs and Charging Orders • Additional one-to-one interviews with a further four local authority representatives, which included staff from social work finance and legal services. **Is a qualitative approach appropriate?** Appropriate. Interviews and focus groups were used to elicit the views of older people and their relatives about DPAs. **Is the study clear in what it seeks to do?** Clear. Yes the aims are well stated. **How defensible/rigorous is the research design/methodology?** Somewhat defensible.	options and arrangements, to gather information on practices and views in relation to DPAs and Charging Orders • Additional one-to-one interviews with a further four local authority representatives, which included staff from social work finance and legal services. (Authors, page 8) Although it had been hoped to gather the views of stakeholder organisations, it is reported that neither Help the Aged nor Age Concern felt that they had sufficient knowledge and experience to contribute to the project. **Are the data 'rich'?** Rich. Yes the perspectives of various stakeholders are clearly represented and then each section has a summary bringing together the key points from these perspectives. **Is the analysis reliable?** Somewhat reliable. Not clear how the analysis was conducted.	Yes. Care homes. **Does the study relate to at least one of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. Includes care home residents' knowledge of, attitudes towards, and experiences of Deferred Payment Agreements. **Does the study have a UK perspective?** Yes.	

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
Although some information on sampling is given - in terms of size - it is not clear on what criteria the participants within the LAs were chosen. It seems (but is not very explicit) that the participants were a mixture of those with and without experience of DPAs. **Is the context clearly described?** Clear. Yes the background of DPAs is very clearly described. **Was the sampling carried out in an appropriate way?** Somewhat appropriate. On page 9, it is reported that the original sample was changed but no reflection is made on what effect the sample changes may have had on the results. **Were the methods reliable?** Reliable. Data was collected by focus groups and interviews. However, the results are not discussed alongside other studies.	**Are the findings convincing?** Somewhat convincing. Overall very good but could have used more quotes (and indication of numbers with same views). **Are the conclusions adequate?** Adequate. Implications are clearly defined in relation to policy and local government.		

33. Malley J, Towers A, Netten AP et al. (2012) An assessment of the construct validity of the ASCOT measure of social care-related quality of life with older people. Health and quality of life outcomes 10, 21

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Methodology A survey of older people receiving publicly funded home care services was conducted by face-to-face interview in several sites across England. Data were collected face-to-face through computer-aided personal interviews in people's homes during 2009 in ten geographically dispersed locations across England. The interviews gathered socio-demographic information and details about service receipt and informal support. **Objectives of the study clearly stated?** Yes The study aims to demonstrate the construct validity of the ASCOT attributes. The study involves testing the ASCOT variables against measured attributes. **Design** 2.13 Response rate?	**Data suitable for analysis?** Yes. Data were responses to aspects of the ASCOT toolkit. **Clear description of data collection methods and analysis?** Yes. Methodology is very clear in what was done by the authors and why. **Methods appropriate for the data?** Yes. Authors used: chi-squared tests and analysis of variance, as appropriate, to test the construct validity of each attribute. **Statistics correctly performed and interpreted?** Yes **Response rate calculation provided?** Yes See page 4: In total, 566 contacts	**Is the setting similar to the UK?** Yes. England. **Is there a clear focus on [population]?** Yes. **Is there a clear focus on [intervention]?** Yes. **Are the questions relevant?** Yes. **Overall assessment of external validity** ++	**Internal validity** ++ **Overall assessment of external validity** ++

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Page 4: 53% responded to the survey - 301/566 contacts. **Describes what was measured, how it was measured and the outcomes?** Yes. The paper describes clearly in the methodology section which measures were being tested and why. **Measurements valid?** Yes. Measures are those from the ASCOT toolkit. **Measurements reliable?** Partly. ASCOT measures used. Authors comment in the conclusions that more work needs to be done to test the reliability of the measures in relation to older people. **Measurements reproducible?** Yes. Should be as a clear description is provided of how the study was carried out and who the respondents were.	were attempted from a sample of 778, producing 301 (53%) complete interviews. **Methods for handling missing data described?** Yes. Page 4: Non-responders were categorised as refusals (n = 18, 3%), deceased (n = 4, 1%) and not contactable (n = 243, 43%). **Difference between non-respondents and respondents described?** Yes. Page 4: Non-responders were categorised as refusals (n = 18, 3%), deceased (n = 4, 1%) and not contactable (n = 243, 43%). **Results discussed in relation to existing knowledge on subject and study objectives?** Yes. The results are discussed and interpreted in the context of the study participants and the wider applicability of future use of ASCOT with older people and other groups.		

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Overall validity rating**
Basic data adequately described? Yes a good table (1) is provided in the paper about the socio-demographic characteristics of the respondents. **Results presented clearly, objectively & in enough detail for readers to make personal judgements?** Yes. Results are provided for each item in comparison with other QoL measures such as GHQ-12 – see table 4. **Results internally consistent?** Yes. Analysis included testing the internal consistency between items using correlations.	**Limitations of the study stated?** Yes. The authors report the following limitations with this study (p12): "Firstly, the sample data only included older people receiving publicly funded home care services. As a result it is only possible to draw conclusions about the feasibility of using the measure and its validity for this client group in this setting. Secondly, the sample obtained here was not ethnically diverse, so we cannot demonstrate the validity of the measure amongst black and minority ethnic (BME) groups. It would therefore be of value to repeat this analysis with other client groups and, given the potential for some members of BME groups to have very specific preferences related to their cultural heritage, on a more ethnically diverse sample. Future work should also consider the reliability of the items." **Results can be generalised?** Partly. There are problems with the sample - a bias on older people and an inclusion of a significant minority of proxy views that make generalisation of these findings somewhat problematic.		

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	Appropriate attempts made to establish 'reliability' and 'validity' of analysis? Partly. The whole point of the paper is to test the construct validity of the ASCOT measures being tested. The authors suggest more work is needed to test the reliability of the various items being tested.		

34. Mathie E, Goodman C, Crang C et al. (2012) An uncertain future: the unchanging views of care home residents about living and dying. Palliative medicine 26, 734–43

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Methodology Mixed methods The study used a prospective design with a mixed method approach, and data were collected during 2008–2009. This paper reports on interviews with a subsample of care home residents across six care homes. The other parts to this study, not reported in this paper are: The aspect of care home culture was measured by a tool to establish the attitudes and belief systems of the care homes, and espoused approach to end-of-life care. Review of care notes four times over a year (the data for	**Qualitative comp 1** Which component? Interviews with care home residents. **Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?** Yes. The interviews provided residents with an opportunity to talk about what was significant to them about living and dying in a care home.	**Does the study's research question match the review question?** Partly. The study asked residents questions about their background, their health, life in the care home, health services received, the context and process of care, and their thoughts about their future and about death. The aim of the study was to understand how living in a care home influenced older people's views, experiences and expectations of end-of-life care and symptom relief.	**Overall assessment of internal validity** ++ **Overall assessment of external validity** + **Overall validity score** +

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
which are provided elsewhere) of all residents who had capacity to understand the aim of the study and consented to taking part. Separate interviews with nine care home managers who were invited to participate in the study by letter. **Is the mixed-methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed-methods question?** Yes. **Is the integration of qualitative and quantitative data (or results) relevant to address the research question?** N/A Paper only reports on the interviews with care home residents. **Is appropriate consideration given to the limitations associated with this integration, such as the divergence of qualitative**	**Is the process for analysing qualitative data relevant to address the research question?** Yes. 'Data analysis of the interviews used the computer package NVIVO to map the data. The analysis involved three stages. First, there was a process of familiarization and 'decontextualization' and segmenting of data into separate and defined categories that were close to the participants' own categories. Second, comparison was made within and between categories, which enabled the identification of preoccupations, differences and themes. The third stage was the identification of relationships and exploration of tentative hypotheses. Credibility of analysis was sought through searching for rival explanations, peer debriefing within the research team, and discussion with the PIR group. In addition, the PIR members tested and confirmed the validity of the findings at the end of the study by running three discussion groups with the care home residents' (p736).	**Has the study dealt appropriately with any ethical concerns?** Yes. The research aimed to be as inclusive as possible, giving all residents opportunity to take part in the study, including those living in any dementia units. All residents who had capacity to understand the aim of the study and consented to taking part had their care notes reviewed four times over a year (the data are not provided in this paper), and a self-selected sub-sample agreed to be interviewed three times. Consent to interview was checked consistently throughout the data collection period. **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Partly. In as much as the study discusses aspects of care and support in the context of end of life care, there is clear relevance to the scope. But	

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
and quantitative data (or results)? N/A	**Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data were collected?** Yes. 'The authors state that the study cannot claim to be representative of all residential care homes in England despite the fact that the sample selected was fairly typical of those found in the industry... To differing degrees, care staff acted as gatekeepers to residents and the older people participating may have been more articulate and not in as poor health or cognitively impaired as those who did not participate' (p741). The study made the assumption that being resident in a care home, watching other residents dying and going through periods of ill health would, over time, shape how residents talked about their own mortality and their priorities for end-of-life care. But, the findings contradicted this, nor did the culture or approach to EOLC in the six homes appear to shape residents' views. Preoccupations and priorities for end-of-life care fell into four main themes (and subgroups): Living in the Past (1 a, 1 b), Living in the Present (2 a,	a lot of the reporting is on residents' past lives, current experiences, their health and health services received, and thoughts about their future and about death. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. Older people living in care homes. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. The six care homes varied in their characteristics. There was a range of occupancy (27–60), size and religious affiliation. In terms of approaches to end-of-life, one care home had formal end-of-life procedures, and another had its own final wishes forms. The other care homes all had funeral arrangement forms and reported that they dealt with end-of-life decisions 'as and when' (p736). **Does the study relate to at least one of the activities covered by**	

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
	2 b), Thinking about the Future (3 a, 3 b, 3 c, 4 a) and Actively Engaged with planning the future (4 b) (p736). **Is appropriate consideration given to how findings relate to researchers' influence, for example, through their interactions with participants?** No.	**the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Partly. Not all the views are about the use of services. So as well as perceived and actual experiences of care and support, participants also discuss issues such as their past lives and feelings about the future and death. **Does the study have a UK perspective?** No. The authors warn that 'care must be taken when extrapolating these findings to the wider population. To differing degrees, care staff acted as gatekeepers to residents. This study is limited in that the older people participating may have been more articulate and not in as poor health or cognitively impaired as those who did not participate' (p741).	

35. Miller E, Cooper S, Cook A et al. (2008) Outcomes important to people with intellectual disabilities. Journal of Policy and Practice in Intellectual Disabilities 5(3), 150–158

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
Methodology Qualitative study – Data collection was qualitative with service users with intellectual disabilities (and a small proportion of carers supporting the service user) who are accessing various services. The relevant method of data collection is in the form of interviews.	**How well was the data collection carried out?** Appropriately. Consent was approved and the choice of recording was offered to interviewees. Interviews lasted between 30–90 minutes. The option of conducting interviews in people's own homes was given, which was taken up by the majority of interviewees.	**Does the study's research question match the review question?** Yes. Views and experiences of people with ID who are asked about the importance of process outcomes. All interviewees are accessing a relevant service.	**As far as can be ascertained from the paper, how well was the study conducted?** + Large-scale study (87 interviews) with good, diverse geographical representation. But lack of context or characteristics of participations impacts on the validity of findings.
Is a qualitative approach appropriate? Appropriate. Ascertaining views and experiences through interviews and focus groups. Noted as suitable for collecting data from service users with intellectual disabilities as reported by previous studies (Fraser and Fraser 2001).	**Are the data 'rich'?** Given the little information on characteristics, data is not rich because the diversity of perspective is not analysed.	**Has the study dealt appropriately with any ethical concerns?** Partly. Ethical approval not reported. Good research ethics, ascertaining consent.	**Overall assessment of external validity** ++ Very relevant to question one as the paper presents direct relevant process outcomes in the scope: wellbeing, engagement with services, choice and control.
Is the study clear in what it seeks to do? Clear. Outcomes important to people with ID.	**Is the analysis reliable?** Somewhat reliable. Qualitative data from the interviews was analysed using NVivo. The analysis and approach appears inductive, applying an initial coding frame with original outcomes to expand and include issues that occurred in interviews. The research team then recorded	**Were service users involved in the study?** Partly. Co-produced with the advocacy group Central England People First. This is not without tensions and these are discussed in the paper (page 151).	**Overall score** + Well-linked finding and discussion. Aim was to understand what the fundamental outcomes to people with ID are, and the findings support previous studies framework in reporting quality of life outcomes and process outcomes.

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
How defensible/rigorous is the research design/methodology? Defensible Researchers are well grounded and governed by previous research conducted by the Social Policy Research Unit at York University. The interview schedule was co-designed with the CEPF having been tested in focus groups prior to second stage (i.e. on which this paper is based), where the research team gathered evidence in the interviews across 5 sites. **Is the context clearly described?** Services were selected where health and social care staff were working together to deliver an integrated service at the operational level. But contextual information was not detailed enough. There is little clarity about the characteristics of the participants in interviews conducted by either the research team or by focus groups held by the CEPF.	patterns but little information is provided. It is important to note that no analysis of data for the interviews conducted by CEPF, so unclear how this data is interpreted or incorporated in the findings. **Are the findings convincing?** Somewhat convincing. Relevant findings following a similar format to other studies but they are brief. Each process outcome is supported by a direct quote collated from interviews. The authors report considerations from the limited information ascertained in focus groups. (Page 155). **Are the conclusions adequate?** Adequate. Aim was to understand what the fundamental outcomes to people with ID are, and the findings support previous studies' frameworks in reporting quality of life outcomes and process outcomes. Partnership is a key conclusion: 'Using an outcomes-focused tool based on this work, we identified that changes in the way services are delivered to people with ID have resulted in improved	**Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. People with Intellectual Disabilities (ID) – this is the terminology used in the study. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. A range of settings including statutory adult intellectual disabilities teams, day centres, and supported living. Also included are people's own homes. **Does the study relate to at least one of the activities covered by the guideline?** Yes. Adult social care.	

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
Was the sampling carried out in an appropriate way? Not sure – No information about how sampling was carried out. **Were the methods reliable?** Somewhat reliable Clear design and methodology; however, despite this large-scale study (87 interviews) having good, diverse geographical representation, the characteristics of study participants have not been clearly described. User researchers played a key role in identifying outcomes and designing research tools for this project, but the authors acknowledge that with hindsight, it would have been more useful to involve them in discussing the approach to the research, especially the nature of their role before the funding application stage.	outcomes, including opportunities for supported independent living, where they exist' (p157).	**(For views questions) Are the views and experiences reported relevant to the guideline?** Yes – to ascertain the views and experiences of service users on what outcomes they prioritise. **Does the study have a UK perspective?** Yes. Scotland and England.	

36. Murphy J, Gray CM, Cox S (2007) The use of Talking Mats to improve communication and quality of care for people with dementia. Housing, and Care & Support 10, 21–27

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Methodology Qualitative study **Is a qualitative approach appropriate?** Somewhat appropriate The study deals with improvements to the ability to communicate about their own wellbeing using Talking Mats, as compared to other methods, used for people with dementia. The method used of video-taping the engagement and communication with the service users and then evaluating the tapes and comparing the methods does seem appropriate, although this does mean that a lot of the scoring could be subjective. The report does not state what techniques were used to evaluate how well people communicated using the different methods. **Is the study clear in what it seeks to do?** Mixed. The study's aims are clearly stated. However, I am concerned that the second part of the research question ('Are Talking Mats effective for all people with dementia, or do only those in the	**How well was the data collection carried out?** Not sure/inadequately reported Almost nothing is stated in the report about how the data was collected and evaluated. **Are the data 'rich'?** Poor. No data from the study, i.e. the different interview methods, are provided. Only the findings are presented. The data cannot be described as 'rich'. **Is the analysis reliable?** Not sure/not reported. The methods used to analyse the different ways of communicating are not described, and so their reliability cannot be assessed. **Are the findings convincing?** Somewhat convincing. It seems likely to be true that the Talking Mats can help people with dementia to communicate about their wellbeing. However, not enough data is provided about the process of reaching the findings for them to be considered wholly convincing.	**Does the study's research question match the review question?** Partly. The study deals with the experience of one group of people using adult social care services (i.e. people with dementia), and considers one method of enabling them to communicate better (Talking Mats). It also considers whether the method enables everyone with dementia to communicate better, or only those in the early stages. Cost effectiveness is not considered, although the technique is described several times as 'low technology communication', which seems to imply that it will also be low cost. **Has the study dealt appropriately with any ethical concerns?** Partly. There is no statement in the report about getting ethical clearance for the study. However, the report does provide the following description of how they dealt with the issue of consent by participants: 'The problem of obtaining informed consent for research from people with dementia was addressed by using a three-stage	**As far as can be ascertained from the paper, how well was the study conducted?** - The objectivity of the study seems to be compromised by the research question appearing to assume what the answer will be. No details are provided about the methods used to compare the different methods of communication being considered, or examples that might illustrate how one method was better than another. **Overall assessment of external validity** + The study does have some relevance to the wider population of people with dementia being provided with social care, as it states that the Talking Mats method does enable them to communicate better about their wellbeing, enabling care more appropriate to their needs to be provided. However, the study itself acknowledges that the number of participants is too low for the findings to be generaliseable. Also, since little information is provided about how the technique was actually used it

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
earlier stages of the illness benefit?') appears to anticipate that the answer to the first part, about whether the mats actually work, will be yes. **How defensible/rigorous is the research design/methodology?** Somewhat defensible. What is stated about the research method is fine, but there are gaps. Most obviously, there is no description of how people's ability to communicate about their wellbeing was evaluated, only that it was carried out by two researchers and a final year psychology student. Given the research question's own apparent assumption that the research method is going to be a success, in my view there needs to be more detail about how this evaluation was carried out before its objectivity and its results can be accepted. **Is the context clearly described?** Unclear. From statements within the report, it would appear that the context of the study was that it was carried out with residents of a care home who had dementia. However the	**Are the conclusions adequate?** Somewhat adequate. The findings of 15 months of research are reported as three bullet points. Considerably more space is devoted to policy and practice implications, some of which seems speculative and not directly linked to the evidence, e.g. that Talking Mats may improve communication between people who do not share the same first language.	consent procedure. This involved providing accessible information using visual clues, plain English and verbal explanations, approaches to staff and family members as well as to the people with dementia themselves, and a policy of ongoing consent whereby checks were made at every visit to ensure that the participants were happy to continue' (p24). **Were service users involved in the study?** No. Only as participants - not involved in designing or carrying out research. **Is there a clear focus on the guideline topic?** Yes. The study does explore one possible method for 'improving the experience of care for people using adult social care services'. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. The population of the study were	would be hard to replicate the study on the basis of the information provided. Relevance to the guideline topic is also limited, since service users communicating about their own wellbeing is not one of the matters covered. **Overall score** -

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
care home setting is not explicitly stated. **Was the sampling carried out in an appropriate way?** Not sure. Sampling method not described. **Were the methods reliable?** Somewhat reliable The method of comparing the Talking Mats method of communication with two other discussion methods by video-taping them and then comparing them seems like a good way to proceed, except that the methods used to compare the ways of communicating cannot be described as reliable as it is not described in detail at all.		all people aged 18 and older who use adult social care services. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. The setting appears to be an adult social care home (although this is not specifically stated, it can be inferred). **Does the study relate to at least one of the activities covered by the guideline?** Partly The aim of the study was to enable people to communicate better about their own wellbeing. Although this could assist care workers with better meeting their needs, the aim was not for service users to communicate about their experiences or about their views of the services they were receiving. **(For views questions) Are the views and experiences reported relevant to the guideline?** No The views being solicited in the study were about the participants' own wellbeing, which is not what	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
		is being addressed in the guideline. **Does the study have a UK perspective?** Yes. Two of the three researchers are from the University of Stirling, and although the location of the study is not stated, the introductory sections place it entirely in a UK context.	

37. Norah Fry Research Centre (2010) 'It's all about respect': people with learning difficulties and personal assistants. Bristol: Norah Fry Research Centre

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
Methodology Qualitative study – 'This stage of the project involved visits to 6 direct payment schemes to carry out group, individual and pair interviews with: 19 people with learning difficulties; 14 personal assistants or support workers; 9 managers of direct payment support schemes or provider organisations; and 8 parents or carers'. Service user interview data provided in tables.	**How well was the data collection carried out?** Not sure. Not adequately reported. **Are the data 'rich'?** Not sure - Poorly contextualised and no information about the analysis. **Is the analysis reliable?** Not sure/not reported.	**Does the study's research question match the review question?** Yes. Service users with learning disabilities experience of social care and receiving direct payments. **Has the study dealt appropriately with any ethical concerns?** No.	**As far as can be ascertained from the paper, how well was the study conducted?** - The methodology is not adequately reported, thus making findings difficult to contextualise and draw conclusions. **Overall assessment of external validity** +

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
Is a qualitative approach appropriate? Appropriate. As this is a stage 2 report and survey data includes people with learning disabilities and PA's. **Is the study clear in what it seeks to do?** Clear – clear aim **How defensible/rigorous is the research design/methodology?** Not sure. Not adequately reported. **Is the context clearly described?** Clear. Partially clear characteristics of participants and their disability including their current living situation. The author does not include a level of information about age, ethnicity and sexuality. **Was the sampling carried out in an appropriate way?** Not sure.	**Are the findings convincing?** Not sure. **Are the conclusions adequate?** Not sure	Not reported. The research project was initiated by the Centre for Inclusive Living, an organisation run by disabled people and the research is funded by the Big Lottery. The Norah Fry Research Centre is also a partner of the project. It is important to note that research governance surrounding consent is not discussed, nor if the project sought ethical approval from a relevant research committee. However, the researchers ensured that they only met PA's in the company of the person they were supporting, as they felt it to be the most ethical approach. **Were service users involved in the study?** Yes. Two researchers from a self-advocacy group developed the interview schedule and played a central role in interviewing, 'one or other of them led every interview apart from two' (p1). **Is there a clear focus on the guideline topic?** Yes.	Very relevant to research question. **Overall score** - Although the study is relevant, due to poor research design, it is hard to draw many conclusions from findings.

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
Not adequately reported. **Were the methods reliable?** Not sure. Not adequately reported.		Service user experience. **Is the study population the same as at least one of the groups covered by the guideline?** Yes Adults with learning disabilities. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. A range of settings in the statutory, voluntary and private sector, including day centres, People First (self-advocacy group) with members who use direct payments (DP), support provider organisation, and a social services department. **Does the study relate to at least one of the activities covered by the guideline?** Yes. Direct Payments.	

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
		(For views questions) Are the views and experiences reported relevant to the guideline? Yes. The aim is to 'find out more about what makes good support for people with learning disabilities, particularly those who use direct payments or have one-to-one support through organisations or agencies' (p1). This is conducted through individual and group interviews with 19 people with learning disabilities, in some instances supported by their PA or Carer or Family member. **Does the study have a UK perspective?** Yes – UK.	

38. Patmore C, Qureshi H, Nicholas E (2000) Consulting older community care clients about their services. Research, and Policy and Planning 18(1)

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Methodology Qualitative study 88 older users of Social Services community care were interviewed	**How well was the data collection carried out?** Somewhat appropriately. Data collection methods are not	**Does the study's research question match the review question?** Yes. Study is based on a two-part	**As far as can be ascertained from the paper, how well was the study conducted?** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
in groups, individually, or via telephone conference where senior service managers were favoured as interviewers. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear. Authors clearly discuss purpose of the study with adequate and appropriate reference to the literature. **How defensible/rigorous is the research design/methodology?** Defensible. Study design involving interviews in a variety of formats and settings is appropriate to the research question and to the user group, allowing greater opportunity for people to be involved. **Is the context clearly described?** Clear	clearly described, so it is not possible to say if this was systematic. However, the authors describe the process of recruiting participants to the study and ensuring that a diversity of older people is included. **Are the data 'rich'?** Mixed. Data is author representation of the views of users. **Is the analysis reliable?** Not sure/not reported. No discussion on data analysis, including how researcher(s) themed and coded transcripts/data. **Are the findings convincing?** Convincing. SPRU is well reputed and has published extensively in this area. **Are the conclusions adequate?** Adequate	question. The second part asks 'What were appropriate methods for gathering the views of older service users about outcomes achieved through their own services'? **Has the study dealt appropriately with any ethical concerns?** Yes. The authors discuss the issue of ensuring inclusivity in the research. For instance, the problems in recruiting older people for groups irrespective of preparation and resources were an issue. A research assistant was appointed to visit prospective interviewees. An Older People's Advisory Group provided peer guidance on initial communications, focus group venues and transport arrangements. **Were service users involved in the study?** Yes **Is there a clear focus on the guideline topic?** Yes **Is the study population the same as at least one of the**	**Overall assessment of external validity** ++ **Overall score** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Authors describe the different contexts of the study participants in terms of where they were located and other characteristics such as health condition. **Was the sampling carried out in an appropriate way?** Appropriate Researchers were mindful in recruiting a diverse range of older population groups, including: service users receiving high and low levels of home care; housebound older people; people who attended day care; people with physical disabilities; people with dementia; and people from minority ethnic groups. **Were the methods reliable?** Not sure. Methods are not made explicit. This paper reports findings on one aspect (views of older people) from a larger study involving other groups including carers and professionals (Patmore 1998).		**groups covered by the guideline?** Yes Older people **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Settings include day care and community care. **Does the study relate to at least one of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. Views of older people. **Does the study have a UK perspective?** Yes.	

39. Peace S, Katz J, Holland C et al. (2016) The needs and aspirations of older people with vision impairment: report for Thomas Pocklington Trust. Milton Keynes: Open University. Faculty of Health and Social Care

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
Methodology Qualitative study **Is a qualitative approach appropriate?** Appropriate. Central topics included a range of health, housing and social care issues which were suited to a qualitative study design using a questionnaire format. **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology?** Defensible. **Is the context clearly described?** Clear. Characteristics of the participants and settings are clearly defined, and observations were made in a variety of circumstances and from a range of respondents. **Was the sampling carried out in an appropriate way?** Appropriate.	**How well was the data collection carried out?** Appropriately. Interviews aimed to last about an hour to 90 minutes and most were undertaken either in the person's home or in an agreed 'public place'. These were tape-recorded and minuted. **Are the data 'rich'?** Mixed. User views are quite sparse overall. Much of the findings are based on author narrative. **Is the analysis reliable?** Somewhat reliable. Data analysis was undertaken via framework analysis (Spencer et al. 2003) using a template based on the original interview schedule covering topics including demographics, vision, health, housing and living arrangements, ADL, and support. However, the authors do not elaborate on the process of data analysis. **Are the findings convincing?** Convincing. The research team's experience	**Does the study's research question match the review question?** Partly. Study seeks to understand preferences for where people with vision impairment would like to live and with what kinds of support, so it partly matches review question. **Has the study dealt appropriately with any ethical concerns?** Yes. Informed consent was discussed prior to the interview after which participants signed a consent form. Most of the interviews were tape-recorded with the permission of participants and, where appropriate, photographs of equipment or housing adaptations were taken, again with the participants' permission (p59). **Were service users involved in the study?** Yes. Older people with vision impairments were involved in the study.	**As far as can be ascertained from the paper, how well was the study conducted?** + **Overall assessment of external validity** + **Overall score** +

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
The potential delays in gaining ethical approval meant that study participants were not accessed through the NHS or social services but through recommended national VI organisations and local vision charities, e.g. RNIB/Action in Bristol, London and Birmingham and the HQ of The Macular Society in Andover. The study uses a purposive sample with: • focus on respondents in late old age (over 85 years) • participants with a range of eye conditions • adequate representation from minority ethnic groups. Authors note that because of the shorter life expectancy of this population and increased rate of Vi compared to the white indigenous population, a small number of people aged below 70 were included in addition to a substantial number under 85. **Were the methods reliable?** Reliable. The interviews aimed to last about an hour to 90 minutes and most took place either in the person's home, or in an agreed 'public	of studying the needs and aspirations of older people with high support needs form the basis for this study (Katz et al. 2011. A Better Life: what older people with high support needs value, Research Findings, JRF). Findings are clearly and coherently presented. **Are the conclusions adequate?** Adequate. The conclusions are adequate; however, authors note that study findings cannot be generalised to all older people with vision impairments as the study sample was accessed through organisations for people with VI.	**Is there a clear focus on the guideline topic?** Partly. Although the study examines the preferences of older people with VI and what kinds of support they prefer, the reporting of social care issues was limited. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. Older people with vision impairment. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. People were interviewed in a range of community settings, including their own homes and 'centres for the blind'. **Does the study relate to at least one of the activities covered by the guideline?** Yes.	

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
place'. Seven interviews were carried out in 'centres for the blind'. Interviewing at home was the preferred option as it allowed researchers to get a clearer understanding of the participant's environment.		The study includes user views on accessing and using assistive technology. **Are the views and experiences reported relevant to the guideline?** Yes. The study includes user views on accessing and using assistive technology. **Does the study have a UK perspective?** Yes. Based in England.	

40. Pizzola L, Martos Z, Pfisterer K et al. (2013) Construct validation and test–retest reliability of a Mealtime Satisfaction Questionnaire for retirement home residents. Journal of Nutrition in Gerontology and Geriatrics 32(4), 343–359

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Methodology **Cross-sectional study:** Survey with the purpose of determining tool reliability and validity. **Objectives of study clearly stated?** Partly.	**Measurements and outcomes clear?** Yes. **Measurements valid?** Partly. Construct validity of Mealtime Satisfaction Questionnaire ascertained via comparison with Philadelphia Geriatric Center Morale	**Is the setting similar to the UK?** Yes. Canadian study but residential care setting for older people likely to be similar. **Is there a clear focus on [population]?** Yes. Population is adults with social	**Internal validity** - **External validity** -

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Overall validity rating**
The purpose of the study stated as being to investigate reliability and validity of a Mealtime Satisfaction Questionnaire. However, the conclusions of the study also relate to how to improve satisfaction with mealtimes and quality of life, which were not stated in the original objectives. **Clearly specified and appropriate research design?** Partly. See commentary relating to aims of study. **Subjects recruited in acceptable way?** Partly. Although important to note that participants could only participate if they were 'cognitively well' enough to read the consent information and questionnaire. This means that some population groups, e.g. older people with dementia or those with visual impairments, are likely to be have been excluded from the study. **Sample representative of defined population?**	Scale (PGCMS). However, reliability and validity of this instrument is not reported. **Setting for data collection justified?** Yes. **All important outcomes and results considered?** Partly. Study does not investigate making improvements to mealtimes and whether this improved scores on the MSQ or PGCMS. **Tables/graphs adequately labelled and understandable?** Yes. **Appropriate choice and use of statistical methods?** Yes. **In-depth description of the analysis process?** Yes. **Are sufficient data presented to support the findings?**	care needs (older adults in residential care). **Is the intervention clearly [intervention]?** Unclear. The tool is a method for gathering views and experiences but is about a relatively specific aspect of experience. **Are the outcomes relevant?** Unclear. Outcomes only partially relevant. The main aim of the review question was to look at effective methods for gathering user views and experiences and using these to change practice. This study examines the internal properties of a particular scale, but does not look at how the findings of the tool can be used in practice.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Partly. See comments relating to exclusion criteria above.	Partly. See below. **Results discussed in relation to existing knowledge on the subject and study objectives?** Yes **Results can be generalised?** Partly Results could be generalised to similar population in similar setting but unlikely to be applicable beyond this. **Do conclusions match findings?** Partly. One of the study findings does not appear to be supported by the evidence. The study showed an association between mealtime satisfaction and quality of life at a particular time point. Based on this, the study authors further suggest that, to improve quality of life, satisfaction with meal times should be measured and improved upon. However, this conclusion is not strictly supported by the findings of the study. No steps were taken within the study to improve mealtime satisfaction. It is therefore unclear whether improvement		

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	in mealtime satisfaction would indeed lead to improved quality of life.		

41. Popham C and Orrell M (2012) What matters for people with dementia in care homes? Aging & Mental Health 16, 181–188

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Methodology Qualitative study Care homes managers were interviewed to seek their views on the most important factors in the environment when caring for people with dementia. Focus groups in each home, facilitated by the researcher (CP), were used to gather the views of residents with dementia, family carers and staff as to what aspects of the environment they considered most important. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear.	**How well was the data collection carried out?** Appropriately. **Are the data 'rich'?** Mixed. Data based on a small sample. Not rich in quotes. Findings from various participants merged into themes. **Is the analysis reliable?** Somewhat reliable. Recordings of focus groups and interviews were transcribed and analysed using the 'Long Table Approach' as described by Krueger and Casey (2000). In this technique transcripts are printed out, identified by colour coding for focus group or interview and home. The printouts are cut up	**Does the study's research question match the review question?** Yes. Includes views of residents with dementia. **Has the study dealt appropriately with any ethical concerns?** Yes. Ethical approval was obtained from the University College London Research Ethics Committee. **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes.	**As far as can be ascertained from the paper, how well was the study conducted?** + **Overall assessment of external validity** + **Overall score** +

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
How defensible/rigorous is the research design/methodology? Somewhat defensible. This was a small study based on a convenience sample of homes in Greater London. **Is the context clearly described?** Clear. **Was the sampling carried out in an appropriate way?** Not sure Not clear how sampling was carried out within the homes, i.e. how residents, staff or family carers were selected; only the selection of the care homes is described. **Were the methods reliable?** Reliable. Data was collected by interviews and focus groups and compared to other research.	into separate comments and the comments grouped according to the emerging themes generated. Thus the most frequently mentioned topics could be identified for each group and as a whole. **Are the findings convincing?** Convincing. The authors describe how the themes were developed and which participants contributed to them. **Are the conclusions adequate?** Adequate. Yes and links are made to previous research.	**Is the study population the same as at least one of the groups covered by the guideline?** Yes. People with dementia. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. **Does the study relate to at least one of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. Resident views about the care home environment but data based on a small sample and not rich in quotes.	

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
		Does the study have a UK perspective? Yes.	

42 Rainbow Ripples and Butler R (2006) The Rainbow Ripples report: lesbian, gay and bisexual disabled people's experiences of service provision in Leeds. Leeds: Rainbow Ripples

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Methodology Qualitative study involving: i. In-depth interviews with Lesbian, Gay and Bisexual (LGB) disabled people, ii. Interviews with key service providers, and iii. A questionnaire survey of a broad range of service providers. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear.	**How well was the data collection carried out?** Appropriately. Each interviewee was interviewed at a location of their choice, either face to face or by telephone. Interviewees signed consent forms beforehand explaining the purpose of the research, what would happen to the data provided and what they could expect to get back from the research. Each LGB disabled interviewee was paid £15 as a small thank you for their time and involvement (p32). **Are the data 'rich'?** Rich. Contexts of the data described in	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** Yes. The research's design and methodology was agreed by the University of Hull's internal ethics committees, and was conducted in accordance with the current 'Statement of Ethical Practice for the British Sociological Association' (British Sociological Association 2002).	**As far as can be ascertained from the paper, how well was the study conducted?** ++ **Overall assessment of external validity** ++ **Overall score** ++

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
How defensible/rigorous is the research design/methodology? Defensible. In order to meet the aims of the project, researchers undertook three stages of research. These were: i. In-depth interviews with Lesbian, Gay and Bisexual (LGB) disabled people, ii. Interviews with key service providers, and iii. A questionnaire survey of a broad range of service providers. **Is the context clearly described?** Clear. Characteristics of the participants and settings clearly defined and observations made in a wide variety of settings. **Was the sampling carried out in an appropriate way?** Somewhat appropriate. 'Interviewees ranged from people with little obvious control in their lives, who were using segregated services - such as day or residential care, or were dependent on relatives for personal support - to	detail, as is diversity of perspective and content. **Is the analysis reliable?** Reliable. **Are the findings convincing?** Convincing. While recruiting an LGB disabled researcher to undertake the research, 'Rainbow Ripples, Leeds Lesbian, Gay and Bisexual Disabled People's Group' have acted as the steering group. They have been involved in the design of the fieldwork tools, analysis and writing of the resulting reports and training materials. The authors point out that the 'project has, in this sense, been inspired by, involved and aimed to assist LGB disabled people from its initiation' (Authors, p23). **Are the conclusions adequate?** Adequate. Authors acknowledge that one limitation of the study was that finite resources, budget and time meant that the research had to be confined to those individuals living and/or spending a significant	**Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes. This is the first study to look in detail at a wide range of LGB disabled people's experiences of a wide range of services including those provided by social care. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. LGB disabled people. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Various settings included in the research, including individuals' own homes and residential settings. **Does the study relate to at least one of the activities covered by the guideline?**	

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
LGB disabled people who had attributes associated with independence and control - such as being home owners. LGB disabled people in these situations may feel more confident in coming forward for interview, so this may not be a representative sample' (Authors, p46). **Were the methods reliable?** Reliable Data collected by more than one method, therefore findings could be triangulated. Furthermore, results were overseen by a steering group made up of LGB people from Rainbow Ripples organisation.	amount of their time within the boundaries of Leeds City Council. Despite this shortcoming, the conclusions are adequate.	Yes. The study covered a range of service provision including Education and Training; Transport; and Employment. Areas relevant to the guideline include: Technical Aids and Equipment; Personal Assistance; and Advocacy (advice and support). **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes. Study set in Leeds, but findings potentially have a UK-wide perspective.	

43. Redley M, Clare I, Luke L et al. (2010) Mental Capacity Act (England and Wales) 2005: The emergent Independent Mental Capacity Advocate (IMCA) service. British Journal of Social Work 40, 1812–1828

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Overall validity rating**
Methodology Mixed methods	**Qualitative comp 1** SEMI-STRUCTURED INTERVIEWS	**Does the study's research question match the review question?** Yes.	**Overall assessment of internal validity** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
The quantitative data were collected by asking each participating advocacy organisation to complete a 22-item checklist describing each individual referred to the pilot IMCA and associated casework. Qualitative data were collected by a series of interviews with managers and practitioners about their experiences and perceptions of IMCA casework (Authors, p1818). **Is the mixed-methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed-methods question?** Yes. Quantitative data collection was important by way of gathering info on type and nature of referrals and provided context for the semi-structured interview findings with health and social professionals. **Is the integration of qualitative and quantitative data (or results) relevant to address the research question?**	1) Face-to-face semi-structured interviews with the IMCA managers, IMCA caseworkers and the person responsible for promoting the IMCA service. 2) Semi-structured phone interviews - with the decision-makers in health and social care who had worked with an IMCA, and the interviews with the healthcare practitioners who had not worked with an IMCA (Authors, p1818). **Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?** Yes. Face-to-face semi-structured interviews with the IMCA managers, IMCA caseworkers and the person responsible for promoting the IMCA service - sixty and ninety minutes duration. Questions included participants' views and experience of: the IMCA role; promoting the IMCA service in health and social care services; the complexities of IMCA casework; working with decision-makers; the difference between statutory and generic non-instructed advocacy; and the perceived effectiveness of	Studies are excluded if they are about models/approaches reporting provider views only. But (in this case) where advocates are directly representing service users, e.g. where service user lacks the mental capacity to be involved in the service use tool development, study is included. **Has the study dealt appropriately with any ethical concerns?** Yes. Ethical approval was granted by the NHS Cambridge Research Ethics Committee on the basis that no attempt would be made to interview individuals lacking the capacity to give or withhold consent to participate in the research (Authors, p1817). **Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes.	**Overall assessment of external validity** ++ **Overall validity score** +

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Overall validity rating**
Yes. Integration of quantitative and qualitative data provides a complete picture and answers the research question. **Is appropriate consideration given to the limitations associated with this integration, such as the divergence of qualitative and quantitative data (or results)?** N/A	a statutory advocate in supporting the best interests of adults lacking decision-making capacity. Semi-structured phone interviews - with the decision-makers in health and social care who had worked with an IMCA, and the interviews with the healthcare practitioners who had not worked with an IMCA. Interviews lasted between ten and forty minutes. Questions included participants' views about whether the involvement of a statutory advocate had provided, or might provide, additional support both to people lacking capacity and to professionals making substitute decisions (Authors, p1818). **Is the process for analysing qualitative data relevant to address the research question?** Yes. Interview data were recorded with key phrases or expressions included verbatim. Emerging themes were identified and coded. Codes and subsequent analysis were modified and agreed via the researchers' participation network meetings attended by IMCA caseworkers and their managers, hosted by the Department of Health, where representatives	**Is the study population the same as at least one of the groups covered by the guideline?** Yes. Study relates to professionals working with individuals who lack mental capacity. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Advocacy organisations in the voluntary sector. Other health and social care practitioners are mentioned but organisation details not made explicit. **Does the study relate to at least one of the activities covered by the guideline?** Yes. Advocacy in the form of representing to substitute decision-makers the views of adults who lack capacity. **(For views questions) Are the views and experiences reported**	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	from each organisation could discuss with civil servants, and the research team, challenges concerning raising awareness of the pilot IMCA services among practitioners in health and social care, different interpretations of the IMCA role as set out in the MCA, and complicated IMCA casework. Data analysis involved identifying key issues around IMCA practice (e.g. the assessment of a client's capacity and whether family members might be appropriate to consult) and how these were described and characterised. These descriptions became the basis for hypothetical models of IMCA practice. The models were tested and refined in later interviews and at the monthly network meetings, and then used to code the data (Authors, p1819). **Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data were collected?** Yes. 'The purpose of these findings from the pilot Independent Mental Capacity Advocate (IMCA) service was to inform the development of	**relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	statutory advocacy, introduced in English legislation for the first time under the 2005 Mental Capacity Act' (Authors, p1823). **Is appropriate consideration given to how findings relate to researchers' influence, for example, through their interactions with participants?** No. Researchers do not explain how they might have influenced study design and analysis or how the findings relate to their perspective, role and interactions with study participants. **Quantitative component (descriptive)** **Which component?** Quantitative data – a 22-item checklist describing each individual referred for an IMCA and associated casework. **Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed-methods question)?** Yes.		

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	This was a convenience sample of social care and health staff from a range of organisations. **Is the sample representative of the population under study?** No. The authors stress: 'It should be borne in mind that the data presented here are derived from a pilot service, whose organisations were selected for the pilot in part because they were already judged able to deliver an IMCA service. Hence, the quantitative data may not be an accurate representation of the true proportions of IMCA cases with respect to decision types and the demographics of the client groups. In contrast, the managers and IMCA caseworkers interviewed for the qualitative data probably represent some of the most able advocates because the organisations from which they came had been selected by the Department of Health to take part in the pilot' (Authors, p1823). **Are measurements appropriate (clear origin, or validity known, or standard instrument)?** Yes.		

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	Quantitative data - each participating advocacy completed a 22-item checklist describing type and nature of referral to pilot IMCA service. Checklist items included: – 'prospective clients' demographics (including the reason for their lack of capacity and main means of communication) – the profession of the person making the referral and the type of decision – whether or not the prospective client was considered eligible for an IMCA – the nature of casework including the numbers of meetings with the client, the total number of hours spent on the case, time from referral to decision, and whether health or social care notes were accessed – items to measure the outcome of each client's case and specifically whether the IMCA had been able to obtain information about his or her wishes or values – whether a written report had been submitted, and – whether the IMCA challenged the decision maker's best-interests decision' (Authors, p1817).		

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	Checklist items were piloted with representatives from each of the seven organisations, and the persons responsible for administering the questionnaire were given face-to-face guidance in its use. The final version of the checklist (MS Access database format) was completed monthly and returned electronically to the research team. **Is there an acceptable response rate (60% or above)?** Not reported in this paper.		

44. Riazi A, Bradshaw SA, Playford, editors (2012) Quality of life in the care home: a qualitative study of the perspectives of residents with multiple sclerosis. Disability and rehabilitation 34, 2095–102

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Methodology Qualitative study Participants were interviewed individually in their care homes. **Is a qualitative approach appropriate?** Appropriate. Yes and used grounded theory.	**How well was the data collection carried out?** Appropriately. Yes the study clearly sets out in detail how the recruitment, sampling and data collection was carried out. **Are the data 'rich'?** Rich. Lots of quotes given to support	**Does the study's research question match the review question?** Partly. The study is mostly about quality of life but includes questions about the care home environment, and choice and control, which are relevant to this review.	**As far as can be ascertained from the paper, how well was the study conducted?** ++ **Overall assessment of external validity** ++

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Is the study clear in what it seeks to do? Clear. The aim of this study was to explore how residents with MS perceive their QoL in the care home and to develop a conceptual model of QoL for care home residents with MS. **How defensible/rigorous is the research design/methodology?** Defensible. Design is appropriate for a views question. **Is the context clearly described?** Clear. Yes the settings are clearly described (p2096): Care homes offering nursing care and/or personal care, with both high and low proportion of MS residents were approached. Homes were within a 100-mile radius of London, UK. They differed in size, setting (urban/rural) and organization type (large vs. independent homes). **Was the sampling carried out in an appropriate way?** Appropriate.	themes - direct from residents. However, not clear which setting / care home the residents were from. **Is the analysis reliable?** Reliable. More than one researcher coded the themes and checked the themes. Themes were complete when saturation was reached, and then there was a search for new topics. **Are the findings convincing?** Convincing. Yes clearly presented including age and gender of participant for context. **Are the conclusions adequate?** Adequate. The conclusions relate back to the research questions well.	**Has the study dealt appropriately with any ethical concerns?** Yes. Participants who could not give consent and those who could not follow the interview questions did not take part. **Were service users involved in the study?** Yes. Residents of care homes. **Is there a clear focus on the guideline topic?** Yes. Views and experiences of residential care settings. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. Adults using social care services. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes.	**Overall score** ++

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Data collection and analysis was repeatedly checked for accuracy and elimination of bias in the following ways (p2096): Each interview was recorded and transcribed verbatim. Data collection and analysis were conducted concurrently until data saturation was reached [23]. That is, we finished interviewing residents when we were sure that the same instances of data were being repeated over and over [23], and no new "experiences" were being reported by participants regarding their QoL. Alternating between collection and analysis allowed confirmation of coding categories while they were being developed [24]. The transcripts were read repeatedly by two investigators (Siobhan A. Bradshaw and Afsane Riazi). These two investigators independently coded the transcripts using open coding, by assigning codes to the text based on words or phrases that captured meaning in the data [24] (Figure 1). **Were the methods reliable?** Reliable. The main method was qualitative		Residential care. **Does the study relate to at least one of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes. Care homes from a 100-mile radius of London.	

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
interviews. Themes were derived and checked by multiple interviewers. “Participants were interviewed individually in their care homes. Informed consent was obtained from all participants. Prior to interview, the cognitive ability of the resident was determined by the researcher (Siobhan A. Bradshaw), reflecting on conversation during the consent process and their general demeanour, though no formal cognitive evaluation was undertaken at this stage in order to be as inclusive of participants as possible. Participants who could not give consent and those who could not follow the interview questions did not take part”. (Authors: page 2098).			

45. Social Care Institute for Excellence (2009) Personalisation for Someone with a Learning Disability. SCIE TV Transcript. London: SCIE

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
Methodology Other - This is not a research study. There is no clearly stated methodology; however, the video features face-to-face qualitative interviews with family members, and	**How well was the data collection carried out?** Not sure/inadequately reported.	**Does the study’s research question match the review question?** Partly.	**As far as can be ascertained from the paper, how well was the study conducted?** -

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
scenarios from the life of a woman with learning disabilities. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Mixed. This is not a research study. There is no clearly stated research objective; however, the video is clear about its aims. **How defensible/rigorous is the research design/methodology?** Not sure. **Is the context clearly described?** Unclear. **Was the sampling carried out in an appropriate way?** Not sure. **Were the methods reliable?** Not sure	**Are the data 'rich'?** Rich. **Is the analysis reliable?** Somewhat reliable. The video features direct reports from family members, and proxy reports of the person's experience via their family members. The person who uses services is central to the video. **Are the findings convincing?** Somewhat convincing. **Are the conclusions adequate?** Not sure.	This is not a primary research study. The video does, however, focus on areas relevant to review questions on (RQ1) improving experience, and (RQ2+3) barriers and facilitators. It also includes someone from a population that is in scope for this review. **Has the study dealt appropriately with any ethical concerns?** No. This is not a primary research study. The transcripts do not provide details of methodology or approach to recruitment for participation, or support of people in the video. **Were service users involved in the study?** Yes. The video includes a woman who uses services and her family members. **Is there a clear focus on the guideline topic?** Yes.	This is not a research study. It does feature rich experience data, highly relevant to our topic but it includes only one case study. **Overall assessment of external validity** + **Overall score** -

Internal validity - approach and sample	**Internal validity - performance and analysis**	**External validity**	**Overall validity rating**
		This is explicitly about improving the experience and life of someone who uses social care support, by providing a personalised package of care. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. The person has a learning disability, communication needs and sensory impairment. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. The person is supported to live in her own home, rather than having to go into residential care. **Does the study relate to at least one of the activities covered by the guideline?** Yes. The video focuses on providing personalised support, enabling	

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
		choice and control and promoting independence. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

46. Social Care Institute for Excellence (2010) Working With Lesbian, Gay, Bisexual and Transgendered People - People with learning disabilities: A gay man's story. SCIE TV Transcript. London: SCIE

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Methodology Other – This is not a research study. There is no clearly stated methodology; however, the video features face-to-face, qualitative reports from someone with a learning disability. **Is a qualitative approach appropriate?** Appropriate.	**How well was the data collection carried out?** Not sure/inadequately reported. **Are the data 'rich'?** Rich. The video provides first-hand accounts of experience from someone using social care. **Is the analysis reliable?** Not sure/not reported.	**Does the study's research question match the review question?** Yes. The video features scenarios from the life of a man with social care needs and face-to-face qualitative data provided by him. The video focuses on areas relevant to our review questions on (RQ1) improving experience, and (RQ2+3) barriers and facilitators.	**As far as can be ascertained from the paper, how well was the study conducted?** - **Overall assessment of external validity** - The video is a case study, not research but is relevant to our population and scope.

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Is the study clear in what it seeks to do? Unclear. This is a case study and not research study. **How defensible/rigorous is the research design/methodology?** Not sure. No details are provided about methods for this case study. **Is the context clearly described?** Clear. The context for this work is clear: it seeks to describe the experiences of a man using social care support with specific needs related to his learning disability and his sexuality. **Was the sampling carried out in an appropriate way?** Not sure. **Were the methods reliable?** Not sure.	**Are the findings convincing?** Somewhat adequate. The man's testimony about what worked and didn't work in supporting him in the way he wanted is compelling. **Are the conclusions adequate?** Somewhat adequate. The video concludes with a summary from an academic about not making assumptions and providing personalised support.	**Has the study dealt appropriately with any ethical concerns?** No. The video is a case study and not research. No details are provided about sampling or ethics. **Were service users involved in the study?** Yes. The video features a man with learning disabilities who uses social care support. **Is there a clear focus on the guideline topic?** Yes The video focuses on the man's experience of support: what worked well and what worked less well. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. The man has a learning disability, social care needs and needs for support in relation to his sexuality.	**Overall score** -

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
		Is the study setting the same as at least one of the settings covered by the guideline? Yes. The video focuses on the man in the context of his home and community. **Does the study relate to at least one of the activities covered by the guideline?** Yes. The video focuses on experience of being supported by care workers. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

47. Social Care Institute for Excellence (2012) Challenging behaviour and learning disabilities – independent living. SCIE TV Transcript. London: SCIE

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Methodology Other. This is not a research study. There is no clearly stated methodology. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear. The case study film seeks to provide practical suggestions for providing people with personalised support. **How defensible/rigorous is the research design/methodology?** Not sure. There is no methodological detail provided in the transcript. It is a case study film that is presented as part of a suite of resources on the topic. **Is the context clearly described?** Clear.	**How well was the data collection carried out?** Not sure/inadequately reported. There is also no detail of this type in the methods. **Are the data 'rich'?** Rich. **Is the analysis reliable?** Not sure/not reported. **Are the findings convincing?** Somewhat convincing. **Are the conclusions adequate?** Somewhat adequate. This is a short case study film and therefore conclusions are limited; however, the conclusions that are presented are clear and concise.	**Does the study's research question match the review question?** Partly. This is a case study video on SCIE's website. It is part of a suite of resources on learning disabilities and behaviour that challenges. No detailed methodological information is provided in the transcript of the case study video. The population group, type of support and service setting is relevant to the guideline. The content is relevant, particularly to RQ1 and RQ3. **Has the study dealt appropriately with any ethical concerns?** No. This is a case study video on SCIE's website. It is part of a suite of resources on learning disabilities and behaviour that challenges. No detailed methodological information is provided in the transcript of the case study video.	**As far as can be ascertained from the paper, how well was the study conducted?** - There is also no detail within the transcript about methods. **Overall assessment of external validity** - The case study is relevant to our topic and population but includes indirectly reported user views and experiences. There is also no detail within the transcript about methods. **Overall score** -

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Was the sampling carried out in an appropriate way? Not sure. There is also no detail of sampling within the transcript. **Were the methods reliable?** Not sure. There is also no detail within the transcript about methods.		**Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes. The population group, type of support and service setting is relevant to the guideline. The content is relevant particularly to RQ1 and RQ3. **Is the study population the same as at least one of the groups covered by the guideline?** Yes **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Relevant settings: home and community. **Does the study relate to at least one of the activities covered by the guideline?** Yes.	

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
		The case study focuses on practical ways to provide support that responds to people's needs and wishes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

48. Social Care Institute for Excellence (2014a) Challenging behaviour and learning disabilities -improving services. SCIE TV Transcript. London: SCIE

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Methodology Other – This is not a research study. There is no clearly stated methodology; however, the video features face-to-face, qualitative interviews with people with learning disabilities, those who support them, those who manager services and an academic expert.	**How well was the data collection carried out?** Not sure/inadequately reported. **Are the data 'rich'?** Mixed.	**Does the study's research question match the review question?** Partly. This is not a primary research study. The video does, however, focus on areas relevant to our review questions on (RQ1) improv-	**As far as can be ascertained from the paper, how well was the study conducted?** - This is not a primary research study. The transcripts do not provide details of methodology or approach to recruitment for participation in the video.

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Is a qualitative approach appropriate? Appropriate. **Is the study clear in what it seeks to do?** Mixed. This is not a primary research study; however, the video has clear aims and key messages. **How defensible/rigorous is the research design/methodology?** Not sure - Not applicable **Is the context clearly described?** Clear. **Was the sampling carried out in an appropriate way?** Not sure. This is not a primary research study. There is no detail about how participants were recruited. **Were the methods reliable?** Not sure.	**Is the analysis reliable?** Not sure/not reported. **Are the findings convincing?** Somewhat convincing. **Are the conclusions adequate?** Somewhat adequate. There are brief conclusions that summarise the key learning points from the video about how to support people in a person-centred way.	ing experience, and (RQ2+3) barriers and facilitators. It also includes populations that are in scope for our work. **Has the study dealt appropriately with any ethical concerns?** No. This is not a primary research study. The transcripts do not provide details of methodology or approach to recruitment for participation in the video. **Were service users involved in the study?** Yes. The video includes direct and proxy reports of views and experiences of people who use services. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least one of the groups covered by the guideline?** Yes.	**Overall assessment of external validity** + **Overall score** - This is not a primary research study.

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
This is not a primary research study. There is no detail of methods for conducting the interviews that are featured.		**Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Residential care and support in other community settings **Does the study relate to at least one of the activities covered by the guideline?** Yes. The video relates to people's activities of daily living. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. The video reports practitioners' views and experiences of supporting communication needs of people with learning disabilities and behaviour that challenges. It also reports service users' experiences of being supported in this way. **Does the study have a UK perspective?** Yes.	

49. Social Care Institute for Excellence (2014b) Dignity in Care – Privacy. SCIE TV Transcript. London: SCIE

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Methodology Other – This is not a research study. There is no clearly stated methodology; however, the video features face-to-face, qualitative accounts from people who use services and workers who provide support. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Unclear. **How defensible/rigorous is the research design/methodology?** Not sure. **Is the context clearly described?** Clear.	**How well was the data collection carried out?** Not sure/inadequately reported. **Are the data 'rich'?** Poor. **Is the analysis reliable?** Not sure/not reported. **Are the findings convincing?** Somewhat convincing. **Are the conclusions adequate?** Inadequate.	**Does the study's research question match the review question?** Partly. This is not a primary research study. The video does, however, have some relevance to a key outcome of interest - dignity - and is, by inference, relevant to our review questions on (RQ1) improving experience, and (RQ2+3) barriers and facilitators. It also includes populations that are in scope for our work. **Has the study dealt appropriately with any ethical concerns?** No. This is not a primary research study. The transcript does not provide details of methodology or approach to recruitment, or ongoing support for people participating in the video.	**As far as can be ascertained from the paper, how well was the study conducted?** - The video features film footage of people using services but the narrative reports are from people who provide support. This is not a research study so there is no information about methods or sampling. **Overall assessment of external validity** - **Overall score** -

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
Was the sampling carried out in an appropriate way? Not sure **Were the methods reliable?** Not sure		**Were service users involved in the study?** Yes People who use services feature in the video by way of illustrative clips of their day-to-day lives. **Is there a clear focus on the guideline topic?** Partly. This is not a primary research study. The video does, however, have some relevance to a key outcome of interest - dignity - and therefore is broadly relevant to experience of support. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. The video features adults who use social care support. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes.	

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
		The video features people who live in and work in residential care settings. **Does the study relate to at least one of the activities covered by the guideline?** Yes. The video focuses on how workers can support people in a way that maximises dignity and respect. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. The experiences are reported by workers and managers. **Does the study have a UK perspective?** Yes.	

50. Stevens Alice K, Raphael H, Green Sue M (2015) A qualitative study of older people with minimal care needs experiences of their admission to a nursing home with Registered Nurse care. Quality in Ageing & Older Adults 16, 94–105

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Methodology Qualitative study A qualitative inductive methodology using a grounded theory approach was employed in order to gain insight from the participants' perspective. **Is a qualitative approach appropriate?** Appropriate. Yes for gaining insights, views and experiences of transitions into residential care. **Is the study clear in what it seeks to do?** Clear. Yes it seeks to explore the experiences of older people with minimal care needs gaining admission to care homes. A qualitative study using a grounded theory method was undertaken. **How defensible/rigorous is the research design/methodology?** Defensible. A qualitative study using a grounded theory method was undertaken. The core methods of data collection with simultaneous	**How well was the data collection carried out?** Appropriately. The study took place in one geographical region in the south of the UK. Within a grounded theory study, it is undesirable to determine sample size at the outset (Cutcliffe 2000); hence participant numbers were guided by the needs of the data collection and the analysis. Initial sampling was purposive. As data were collected and analysed theoretical sampling techniques were employed (Charmaz 2006). Theoretical sampling can also refer to questions within an interview; therefore, as data collection and analysis progressed, the interviews became more focused on areas of theoretical relevance that emerged during the analysis (Glaser 1992). **Are the data 'rich'?** Rich. Yes lots of quotes from direct users about their views/experiences. **Is the analysis reliable?** Reliable.	**Does the study's research question match the review question?** Yes. The study includes views and experiences of transitions to residential care and what helped and/or hindered that process. **Has the study dealt appropriately with any ethical concerns?** Yes. Page 96: A large national provider of residential care agreed that care home residents could be approached via the care home manager. Ethical approval was obtained from the local NHS Research Ethics Committee and governance approvals from the local trust. Written informed consent was obtained from all participants. **Were service users involved in the study?** Yes. Older people leaving hospitalisation and entering residential care. **Is there a clear focus on the guideline topic?**	**As far as can be ascertained from the paper, how well was the study conducted?** ++ **Overall assessment of external validity** ++ **Overall score** ++

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
data analysis, theoretical sampling, constant comparison, field notes and memo writing were employed, thus ensuring the developing theories were "grounded" in the data. **Is the context clearly described?** Clear. The settings and methods of recruitment and inclusion / exclusion criteria are all clearly described. **Was the sampling carried out in an appropriate way?** Appropriate. The study took place in one geographical region in the south of the UK. Within a grounded theory study, it is undesirable to determine sample size at the outset (Cutcliffe 2000); hence participant numbers were guided by the needs of the data collection and analysis. Initial sampling was purposive. As data were collected and analysed, theoretical sampling techniques were employed (Charmaz 2006). Theoretical sampling can also refer to	Each interview was recorded and transcribed verbatim into a word-processing file. Non-verbal communication, for example, displays of emotion during the interview, was also recorded in memos and field notes. During the initial coding, the data were broken down, "fractured" and codes and labels that depicted meaning were assigned to words or phrases (Glaser 1992; Charmaz 2006). "Fracturing" facilitated the distancing from the data and conceptualisation which is a necessary procedure for theory development (Charmaz 2006). During analysis, the data were constantly compared to other data, allowing the codes to be reviewed and refined. This ensured that the emerging categories and their properties had relevance and "fit" (Glaser 1992). Theoretical memos informed category generation and posed questions of the data. Relevant literature informed the emerging categories and is discussed in the results section. As analysis progressed, coding moved towards being "selective", focusing on those codes	Yes. Users of residential care - direct views and experiences. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. Older people using residential care/making transitions into residential care. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Transitions to residential care. **Does the study relate to at least one of the activities covered by the guideline?** Yes. Views and experiences of using residential care. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. Views and experiences of using	

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
questions within an interview; therefore, as data collection and analysis progressed the interviews became more focused on areas of theoretical relevance that emerged during the analysis (Glaser 1992). **Were the methods reliable?** Reliable. Grounded theory supported by field notes and interactive analysis.	that related to emergent main categories in order to identify a core category that linked the data (Glaser 1992). Only data that held relevance for the emerging theory continued to be incorporated. As the categories became integrated and reduced, only the most relevant remained and were linked to form the core category. **Are the findings convincing?** Convincing. Very clearly described and linked to the evolving key themes from the research. **Are the conclusions adequate?** Adequate. Yes they link well with the aims of the research.	adult social service care. **Does the study have a UK perspective?** Yes.	

51. Stewart F, Goddard C, Schiff R et al. (2011) Advanced care planning in care homes for older people: a qualitative study of the views of care staff and families. Age and Ageing 40, 330–335

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Methodology Qualitative study	**How well was the data collection carried out?**	**Does the study's research question match the review**	**As far as can be ascertained from the paper, how well was**

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Is a qualitative approach appropriate? Appropriate. **Is the study clear in what it seeks to do?** Clear aims and objectives and research question. Detailed and appropriate reference to relevant literature. **How defensible/rigorous is the research design/methodology?** Defensible. Study design appropriate to the research question. Clear description of rationale/justification for the sampling, data collection and data analysis techniques. **Is the context clearly described?** Clear. **Was the sampling carried out in an appropriate way?** Appropriate.	Appropriately. Care homes were identified through the Commission for Social Care website and the local Care Home Support Team. In each home, the manager and a randomly selected nurse and care assistant were invited to take part. In care homes providing personal care only, a visiting community nurse was invited to participate. Participating homes were grouped into four mutually exclusive subsets: (i) nursing or dual-registered without the Gold Standard Framework for Care Homes (GSFCH), (ii) nursing or dual-registered in early stages of the GSFCH, (iii) nursing or dual-registered in later stages of the GSFCH and (iv) residential. A care home was randomly selected from each subset in order to achieve a purposeful sample. Care home managers provided the names of residents and their family members or friends who they felt would be capable of being interviewed.	**question?** Yes. **Has the study dealt appropriately with any ethical concerns?** Yes. The study was approved by King's College Research Ethics Committee (REF: 07/H0808/136 & 07/Q0703/89). Written informed consent was obtained from all participants who took part. **Were service users involved in the study?** No. The authors acknowledge that a limitation of this research is the absence of residents' views. Fourteen of 41 potential residents were interviewed, but only one resident shared their views about advanced care planning during the interview and the other 13 residents did not. Therefore, the authors were not able to include residents' views as part of this study.	**the study conducted?** ++ **Overall assessment of external validity** ++ **Overall score** ++

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
In each home, the manager and a randomly selected nurse and care assistant were invited to participate. In care homes providing personal care only, a community nurse who visited the home was invited to take part. The aim was to recruit four residents and their family members (if available) from each type of home and an additional four family members to represent residents with cognitive impairment. **Were the methods reliable?** Somewhat reliable.	**Are the data 'rich'?** Rich. **Is the analysis reliable?** Reliable. The Interviews were analysed using the framework analysis approach, which allowed the exploration of new themes whilst content coding categorical questions and allowing comparison of themes between participants. It comprises five stages: (i) familiarisation; (ii) identifying a thematic framework; (iii) indexing; (iv) charting; and (v) mapping and interpretation. **Are the findings convincing?** Convincing. Clear and coherent findings. The themes of the qualitative analysis were organised around (i) benefits, (ii) barriers, and (iii) facilitators. **Are the conclusions adequate?** Adequate. The study describes limitations:	**Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. Though not directly involved, the study is about older people in care homes. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Care homes. **Does the study relate to at least one of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes.	

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
	Residents views were excluded, as only one resident was able to offer any opinion on ACP. Reasons suggested include: the questions regarding ACP coming towards the end of a relatively intense interview schedule, and also the difficult nature of the subject. Interviewing family members and friends of existing care home residents and also comparing their views to those of staff is that, unlike staff, they may have not yet experienced the outcome of ACP practices. As such it may have been more useful to interview relatives of deceased residents who have a more global view of the process. Views of GPs are missing and they are significant members of the multi-disciplinary team.	Explores views from care home staff and the family of residents in care homes for older people. **Does the study have a UK perspective?** Yes.	

52. Stewart J and McVittie C (2011) Living with falls: House-bound older people's experiences of health and community care. European Journal of Ageing 8, 271–279

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Methodology Qualitative study	**How well was the data collection carried out?**	**Does the study's research question match the review**	**As far as can be ascertained from the paper, how well was**

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
A qualitative research design, using an interpretative phenomenological analysis (IPA) approach. **Is a qualitative approach appropriate?** Appropriate. Yes – interviews are the appropriate methodology for eliciting views data from a small sample of people – in-depth analysis. **Is the study clear in what it seeks to do?** Clear. It is clear in that it sets out to examine the experiences of eight housebound, community-living older people. This group is argued to be under-represented in the research literature. **How defensible/rigorous is the research design/methodology?** Somewhat defensible. Correct method for addressing the research aims. However, sampling was rather opportunistic because letters were sent to potential participants (who had been identified by their community physiotherapist) discharged	Appropriately. Recruitment and interviews took place over autumn and winter of 2006. Consent was obtained before any interviews took place. **Are the data 'rich'?** Mixed. Some quotes on service use but as the study was not explicitly about opinions of using services, some of the themes and quotes are not directly relevant to this review. **Is the analysis reliable?** Reliable. For the data analysis, emerging themes were repeatedly checked for fit against further instances, with themes being further developed as necessary. This initial analysis was conducted by the first author. Thereafter both authors checked the emerging themes against instances occurring in the data set. **Are the findings convincing?** Somewhat convincing. As this is a small sample from one area of the UK, this study cannot say how much this reflects	**question?** Partly. It is about the views and experiences of a community of older people after they have had a fall. However, the data themes include discussion of how this has impacted on their use of services and therefore their views of health and social care. **Has the study dealt appropriately with any ethical concerns?** Yes. At the time the interviewer worked within community-based health services and was accordingly familiar with the health status and concerns of those who agreed to take part in the study. It is stated that this knowledge allowed the establishment of easy rapport between interviewer and interviewees in the research process, allowing interviewees to talk openly about their experiences. Interviewer audio-recorded with the consent of the participants and later transcribed. To ensure confidentiality, participants' names were changed to pseudonyms. Ethical	**the study conducted?** + **Overall assessment of external validity** + **Overall score** +

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
from the service within the previous 6 weeks and the authors waited for these people to reply - either of which did reply and became part of the study. Apart from the discharge criteria, there is no information about why these people were chosen or recruited - it seems the study took whoever replied to their letters. **Is the context clearly described?** Clear. The sample is clearly described and the background context is given for the participants. However, because the interventions were tailored to the individuals, the authors say they cannot report on the rehab programmes each individual received. **Was the sampling carried out in an appropriate way?** Somewhat appropriate. The sampling was random in that letters went out and the study waited to see who would reply. However, this could mean those who did reply were those individuals who had more to say about using services post fall,	views of other people after falls in other areas of the UK. But the results are presented well for a small-scale in-depth study. **Are the conclusions adequate?** Adequate. The conclusions relate back to the aims very well and offer some suggestions about what could be improved for future service delivery.	approval for the study being granted by the local NHS research ethics committee. **Were service users involved in the study?** Yes. Participants were users of community home help social services. **Is there a clear focus on the guideline topic?** Yes. Users of home help social services. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. Older people using home help services. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Own home is one of the settings of this review.	

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
which could be a biased picture. **Were the methods reliable?** Reliable. Interviews were carried out appropriately – recorded with consent.		**Does the study relate to at least one of the activities covered by the guideline?** Yes Social services use included even though about falls. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. Views of adults using home help/community based social services. **Does the study have a UK perspective?** Study set in Scotland.	

53. Swain J (2005) Independent Evaluation: Developing User Involvement in Leonard Cheshire. Final Report. Newcastle: Northumbria University

Internal validity - performance and analysis	Internal validity - approach and sample	External validity	Overall validity rating
Methodology National, regional, local reports/assessments/evaluations	**Report identifies who is responsible for intellectual content?** Yes. John Swain. Professor of Disability and Inclusion School of Health, Education and Community Studies	**Is the setting similar to the UK?** N/A Setting is Leonard Cheshire, an organisation that provides social care services including Care-at-Home, residential homes and the	**Internal validity rating** - **External validity rating** +

Internal validity - performance and analysis	Internal validity - approach and sample	External validity	Overall validity rating
Clearly stated aims or brief? Yes. Aims to: 'To conduct a review of and support the development of service user involvement at all levels and within all areas of Leonard Cheshire activity' (p5). **Stated methodology?** Yes. The research has been conducted as an 'independent evaluation' by a research team from Northumbria University. Involved two stages. Stage one – Mapping the Evaluation included: a) Initial contact with stakeholders within Leonard Cheshire including service users, Leonard Cheshire managers, trustees, directors and volunteers, Disabled People's Forum Staff and SURE representatives b) A literature review of relevant research. c) Qualitative and quantitative analysis of documentation provided by Leonard Cheshire.	Northumbria University, Newcastle upon Tyne. **Are they reputable?** Yes. **Any limits clearly stated?** No. **Clear authorial standpoint?** No. **Work appears balanced?** Unclear.	Employability scheme. Not all findings may translate to other contexts. **Is there a clear focus on [population]?** Yes. Adults included are in receipt of a range of social care provision, so populations correspond with those stipulated in the scope. **Is there a clear focus on [intervention]?** N/A **Are the questions relevant?** Yes. Despite this evaluation being about user involvement, much of the views material covers the quality of social care provision within Leonard Cheshire. Relevant views material has been extracted from both stage one and stage two of this evaluation. Stage One views material - gathered through focus groups and semi-structured interviews. Key questions were developed with the participants around topics of: user involvement within the organisation; impact on	**Overall score** -

Internal validity - performance and analysis	Internal validity - approach and sample	External validity	Overall validity rating
d) Part of Phase One involved collecting the views and experiences of service users and providers through focus groups and semi-structured interviews. Stage Two – This final phase aimed to: a) Develop the recommendations of the conclusion of the Interim Report. b) Conduct 6 'case studies' of local developments within Leonard Cheshire in relation to user involvement. c) Focus on examples deemed to be good practice by members of the Steering Group in terms of the barriers and facilitators to user involvement. d) Consider strategies to embed the recommendations of the evaluation into the development of user involvement in Leonard Cheshire. Five case studies were conducted with a focus on the development of good practice in user involvement.		the lives of service users; and the effectiveness of key strategies within the organisation – including training, mentoring, information, support to users in learning difficulties services. User involvement topics included: governance; central committees; regional involvement; local services; and staff and volunteer recruitment. Stage Two - from the five case studies, case study two and case study three provide views material. **Overall assessment of external validity** +	

Internal validity - performance and analysis	Internal validity - approach and sample	External validity	Overall validity rating
Peer-reviewed? Unclear. The authors do not refer to peer review. They make reference to the management of the project being undertaken by a Steering Committee whose role was to ensure the evaluation remains independent and that the research is collaborative, 'that is conducted ‘with’ rather than ‘on’ the organisation' (p6). **Edited by reputable authority?** Unclear. **Date** Clearly stated date relating to contents? Yes. **Significance** **Meaningful content?** Partly. Content is meaningful up to a point in that it appears to reflect general messages about service user involvement in services. However, service user views (from Stage one of the evaluation) do not distinguish who is making a			

Internal validity - performance and analysis	Internal validity - approach and sample	External validity	Overall validity rating
statement or in which settings these are based, therefore making it difficult to draw any conclusions without this vital context. **Adds context?** Partly. **Strengthens or refutes a current position** Partly. Without detailed contextual information that makes explicit the details of service users and settings that the quotes are extracted from, it is difficult to make a proper assessment of the findings. **Enriches research area?** Partly. Lack of contextual information within quotes makes it difficult to assess findings.			

54. Swinkels A and Mitchell T (2009) Delayed transfer from hospital to community settings: the older person's perspective. Health & social care in the community 17, 45–53

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Methodology Qualitative study Study used a phenomenological approach to facilitate researcher's exploration and interpretation of participants' perceptions of delayed transfer from hospital. Phenomenology is concerned with the complex description that arises from people's detailed stories of their experiences. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology?** Defensible Conversational interviews (Van Manen 1990, Denzin and Lincoln 2003) were used to gain participants' perspectives. The researchers believed that this method would engage participants, help them feel at ease and in so doing, promote communication. A semi-structured interview	**How well was the data collection carried out?** Appropriately. Conversational interviews (Van Manen 1990, Denzin and Lincoln 2003) were used to collect participants' views. The researchers believed that this method could engage participants, help them feel at ease and thereby promote communication. A semi-structured interview guide consisting of eight questions was used as a basis for exploring patients' perceptions of delayed transfer of care. Audiotaped interviews were carried out in private with patients in separate rooms or private spaces next to wards. Interviews lasted for as long as participants wished to talk. **Are the data 'rich'?** Rich. The study included a diversity of views, which can be clearly traced back to who said them and what level of need they were at. **Is the analysis reliable?** Reliable. Data analysis in phenomenology aims to 'preserve the uniqueness	**Does the study's research question match the review question?** Yes. The interview schedule includes questions on: What has been done to help your transfer out of hospital? (Perception of management of transfer process); What do you think you need to help you leave hospital? (Perception of needs). **Has the study dealt appropriately with any ethical concerns?** Yes. Decisional capacity or competence to make decisions may vary from day to day, or even from hour to hour, in some older people (Kayser-Jones and Koenig 1994, Grout 2004, Brindle and Holmes 2005). This issue arose where one researcher spent considerable time discussing the research with a participant and obtained consent, but when the researcher returned to interview the person 4 days later, they did not recognise her and denied having seen the consent form. This situation demonstrates the	**As far as can be ascertained from the paper, how well was the study conducted?** ++ **Overall assessment of external validity** + **Overall score** +

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
guide, comprising eight questions, was used as a basis for exploring patients' perceptions of delayed transfer of care (Table 2). Audiotaped interviews were conducted in private with patients in side rooms or enclosed areas adjacent to wards. In addition, field notes were taken at each interview to record the time, location and context of each interview, together with researchers' overall impressions of the body language and demeanour of individual participants. **Is the context clearly described?** Clear. **Was the sampling carried out in an appropriate way?** Appropriate. A purposive sampling strategy was used to identify a wide range of potential participants, aged 65 years and over, from different categories of delay (e.g. waiting for assessment, a care package or a placement in a residential or nursing home).	of each lived experience of the phenomenon while permitting an understanding of the meaning of the phenomenon itself' (Banonis 1989, p.168). Researchers transcribed their own interviews and annotated these with memos and reflections during this process. Transcripts were imported into NVivo (version 2.0) data analysis software. Each researcher initially coded their own interviews and then met together to discuss the development of data categories. These discussions were key to ensuring that the categories were defined and comparable across and between researchers and transcripts. Then themes were developed to house the data categories and explored by both researchers to ensure compatibility, fit and rigour (Koch and Harrington 1998). This highly iterative phase of the analysis process highlighted both the uniqueness and similarities of participant's experience and required some data to be revisited, recoded and recategorised.	importance of continually checking out participants' understanding of the research and revisiting consent. **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. Older people awaiting hospital discharge. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. **Does the study relate to at least one of the activities covered by the guideline?** Yes. Hospital ward.	

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
Were the methods reliable? Somewhat reliable. Only one method of data collection was employed, i.e. conversational interviews (Van Manen 1990, Denzin and Lincoln 2003). A semi-structured interview guide was used to explore patients' perceptions of delayed transfer of care and these were audiotaped.	**Are the findings convincing?** Convincing. **Are the conclusions adequate?** Adequate. Employing a phenomenological approach helped facilitate researchers' exploration and interpretation of participants' perceptions of delayed transfer from hospital. The authors conclude that participants passively relinquished their involvement in discharge planning. Some chose not to be involved because of the perceived expertise of others. Other participants felt disempowered by factors such as ill health, low mood, dependency, lack of information and the intricacies of discharge planning processes for complex community care needs.	**(For views questions) Are the views and experiences reported relevant to the guideline?** Partly. Some are and some not. The relevant aspects are those to do with participants' perceptions of social services and future health and social care needs. **Does the study have a UK perspective?** Yes.	

55. Teale EA and Young JB (2015) A Patient Reported Experience Measure (PREM) for use by older people in community services. Age and Ageing 44, 667–672

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Overall validity rating**
Methodology	**Measurements and outcomes clear?**	**Is the setting similar to the UK?** Yes.	**Internal validity** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Cross-sectional study: Survey the consensus group developed the questionnaire items. Tests for reliability were used using the Mokkan Scale to determine the Loevinger H coefficient. **Objectives of study clearly stated?** Yes. **Clearly specified and appropriate research design?** Yes – to include measures of experiences of intermediate care as an important part of assessing the quality of integrated care. **Subjects recruited in acceptable way?** Partly. The new questions were incorporated into a national audit survey. Recruitment methods states that approximately half of the NHS in England registered to participate in the audit. **Sample representative of defined population?** Unclear. Half of the NHS in England registered to participate in the audit.	Partly. The development of the questions was by an expert consensus panel of survey experts, patients and practitioners. Questions were chosen for their relevance; there is no information about how members of the panel reached their decisions (other than face validity) and what may have been excluded from the original round of suggested questions. 15 people responded out of 29 on the panel; however, the final versions of the PREMs were field tested in three sites prior to adoption in the audit. **Measurements valid?** Yes. Scalability of the IC-PREMs was explored with Mokken analysis (non-parametric item response theory (NIRT) to measure the latent trait, in this case user experience). This property of a set of questions is called uni-dimensionality and is assessed through calculation of Loevinger H statistics. **Setting for data collection justified?** Partly. There were different methods of	**Is there a clear focus on [population]?** Yes. Older people who receive bed-based, or community-based intermediate care. **Is the intervention clearly [intervention]?** No. The intervention "intermediate care" as spanning both health and social care is quite broad, and included people described as bed-based or home based. There may be a range of different interventions and activities within the two groups that can be called intermediate care. **Are the outcomes relevant?** Yes. Patient reported experiences of intermediate care as a component of improving integrated health and social care is relevant to this review.	**External validity** ++

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Not clear why these authorities registered over those that didn't, but likely to represent a range of different localities and a large sample of the population.	recruiting people to complete the questionnaire - face to face with bed-based group and by post for the home-based group, which may have had an effect on the response rates for both groups, with face-to-face being higher. **All important outcomes and results considered?** Partly. Questionnaires with missing data were removed although this was described as generally low, and indicates the acceptability of the questionnaire to people who completed it. **Tables/graphs adequately labelled and understandable?** Yes. **Appropriate choice and use of statistical methods?** Yes. **In-depth description of the analysis process?** Yes. **Are sufficient data presented to support the findings?** Partly.		

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	The NAIC was an anonymous survey and demographic information for individual service users cannot be linked to their PREM responses. **Results discussed in relation to existing knowledge on the subject and study objectives?** Yes **Do conclusions match findings?** Partly. Overall, the H coefficients were low to moderate (the moderate and low cut off points overlapped).		

56. Think Local Act Personal (2009) A service user's personal budgets story. Video transcript. London: TLAP

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Methodology Other Not research. Video evidence transcript from TLAP. Single case. **Is a qualitative approach appropriate?** Not sure.	**How well was the data collection carried out?** Appropriately. Video evidence is appropriate for views/opinions of using SDS (self-directed support) through social services and using personal assistants, which meets the scope criteria.	**Does the study's research question match the review question?** Partly. Not research, so no RQs stated. Video evidence transcript from TLAP. However, video is about views/opinions of using individual budgets through social services	**As far as can be ascertained from the paper, how well was the study conducted?** - Not research. No theoretical basis or sampling or known methods reported.

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Not research. Video evidence transcript from TLAP. **Is the study clear in what it seeks to do?** Unclear. Not research. Video evidence transcript from TLAP. Video clearly about service user expressing opinions. **How defensible/rigorous is the research design/methodology?** Not sure. Not research. Video evidence transcript from TLAP. **Is the context clearly described?** Unclear. No introduction of the case is given but it is clear it is video evidence of a service user describing their experience of using adult social care to employ a PA. **Was the sampling carried out in an appropriate way?** Not sure N/A: Not research. Video evidence transcript from TLAP.	**Are the data 'rich'?** Rich. Yes rich in service user views. **Is the analysis reliable?** Not sure/not reported. N/A: Not research. Video evidence transcript from TLAP. **Are the findings convincing?** Convincing. Yes – direct views from a service user about employing a PA. **Are the conclusions adequate?** Not sure. No conclusions given.	and using personal assistants, which meets the scope criteria. **Has the study dealt appropriately with any ethical concerns?** No. Not research. Video evidence transcript from TLAP. **Were service users involved in the study?** Yes. Single case of a woman reporting on experience of using social care services. **Is there a clear focus on the guideline topic?** Yes. Video is about views/opinions of using individual social care budgets and using personal assistants, which meets the scope criteria. **Is the study population the same as at least one of the groups covered by the guideline?** Yes Adult using social care services.	**Overall assessment of external validity** + Poor research rigour but rich in direct user views and high relevance to review scope. **Overall score** - Poor on research methods/rigour but rich on direct user views. However, transcript is very short and no background section explaining context.

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Were the methods reliable? Not sure. N/A: Not research. Video evidence transcript from TLAP.		**Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Own home setting. **Does the study relate to at least one of the activities covered by the guideline?** Yes. Using social care services - individual budgets. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. Video is about views/opinions of using individual budgets and using personal assistants, which meets the scope criteria. **Does the study have a UK perspective?** Yes.	

57. Think Local Act Personal (2010a) A service user's personal budget story. Video transcript. London: TLAP

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
Methodology Other Not research so no aims stated. Video evidence from TLAP. Transcript of one case study. **Is a qualitative approach appropriate?** Not sure. Not research. Video evidence transcript from TLAP. **Is the study clear in what it seeks to do?** Unclear. Not research. Video evidence transcript from TLAP. Video clearly about service user expressing opinions. **How defensible/rigorous is the research design/methodology?** Not sure. Not research. Video evidence transcript from TLAP. **Is the context clearly described?**	**How well was the data collection carried out?** Appropriately. Video evidence is appropriate for views/opinions of using SDS (self-directed support) through social services and using personal assistants, which meets the scope criteria. **Are the data 'rich'?** Rich. Yes rich in service user views. **Is the analysis reliable?** Not sure/not reported. N/A: Not research. Video evidence transcript from TLAP. **Are the findings convincing?** Convincing Yes – direct views from a service user about employing a PA. **Are the conclusions adequate?** Not sure. No conclusions given.	**Does the study's research question match the review question?** Partly. Not research so no RQs stated. Video evidence transcript from TLAP. However, video is about views/opinions of using SDS (self-directed support) through social services and using personal assistants, which meets the scope criteria. **Has the study dealt appropriately with any ethical concerns?** No. Not relevant: not research. **Were service users involved in the study?** Yes Single case of a man reporting on experience of using social care services. **Is there a clear focus on the guideline topic?** Yes. Video is about views/opinions of using SDS (self-directed support) through social services and using	**As far as can be ascertained from the paper, how well was the study conducted?** - Not research. No theoretical basis or sampling or known methods reported. **Overall assessment of external validity** + **Overall score** - Poor on research methods/rigour but rich on direct user views. However, transcript is very short and no background section explaining context.

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
Unclear. No introduction of the case is given but it is clear it is video evidence of a service user describing their experience of using adult social care to employ a PA. **Was the sampling carried out in an appropriate way?** Not sure. N/A: Not research. Video evidence transcript from TLAP. **Were the methods reliable?** Not sure. N/A: Not research. Video evidence transcript from TLAP.		personal assistants, which meets the scope criteria. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. Adult using social care services. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Own home setting. **Does the study relate to at least one of the activities covered by the guideline?** Yes. Using social care services: SDS. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. Video is about views/opinions of using SDS (self-directed support) through social services and using personal assistants, which meets the scope criteria.	

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
		Does the study have a UK perspective? Yes.	

58. Think Local Act Personal (2010b) A Service user's Personal budget story. Video transcript. London: TLAP

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Methodology Other Not research. Video evidence transcript from TLAP. Single case. **Is a qualitative approach appropriate?** Not sure. Not research. Video evidence transcript from TLAP. **Is the study clear in what it seeks to do?** Unclear. Not research. Video evidence transcript from TLAP. Video clearly about service user expressing opinions. **How defensible/rigorous is the research design/methodology?**	**How well was the data collection carried out?** Appropriately. Video evidence is appropriate for views/opinions of using personal assistants, which meets the scope criteria. **Are the data 'rich'?** Rich. Yes rich in service user views. **Is the analysis reliable?** Not sure/not reported. N/A: Not research. Video evidence transcript from TLAP. **Are the findings convincing?** Convincing.	**Does the study's research question match the review question?** Partly. Not research, so no RQs stated. Video evidence transcript from TLAP. However, video is about views/opinions of using personal assistants, which meets the scope criteria. **Has the study dealt appropriately with any ethical concerns?** No. Not research. Video evidence transcript from TLAP. **Were service users involved in the study?** Yes. Single case of a man reporting on	**As far as can be ascertained from the paper, how well was the study conducted?** - Not research. No theoretical basis or sampling or known methods reported. **Overall assessment of external validity** + Poor research rigour but rich in direct user views and high relevance to review scope. **Overall score** - Poor on research methods/rigour but rich on direct user views. However, transcript is very short and

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
Not sure. Not research. Video evidence transcript from TLAP. **Is the context clearly described?** Unclear. No introduction of the case is given but it is clear it is video evidence of a service user describing their experience of using adult social care to employ a PA. **Was the sampling carried out in an appropriate way?** Not sure. N/A: Not research. Video evidence transcript from TLAP. **Were the methods reliable?** Not sure. N/A: Not research. Video evidence transcript from TLAP.	Yes – direct views from a service user about employing a PA. **Are the conclusions adequate?** Not sure. No conclusions given	experience of using social care services. **Is there a clear focus on the guideline topic?** Yes. Video is about views/opinions of using personal assistants to provide help/support, which meets the scope criteria. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. Adult using social care services. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Own home setting. **Does the study relate to at least one of the activities covered by the guideline?** Yes. Using social care services – PAs. **(For views questions) Are the views and experiences reported**	no background section explaining context.

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
		relevant to the guideline? Yes. Video is about views/opinions of using personal assistants, which meets the scope criteria. **Does the study have a UK perspective?** Yes.	

59. Think Local Act Personal (2012a) Making it Real. Video transcript. London: TLAP

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Methodology Other Not research. Video evidence transcript from TLAP. Single case **Is a qualitative approach appropriate?** Not sure. Not research. Video evidence transcript from TLAP. **Is the study clear in what it seeks to do?** Unclear. Not research. Video evidence transcript from TLAP. Video	**How well was the data collection carried out?** Appropriately. Video evidence is appropriate for views/opinions of using personal assistants, which meets the scope criteria. **Are the data 'rich'?** Rich. Yes rich in service user views. **Is the analysis reliable?** Not sure/not reported. N/A: Not research. Video evidence transcript from TLAP.	**Does the study's research question match the review question?** Partly. Not research, so no RQs stated. Video evidence transcript from TLAP. However, video is about views/opinions of using personal assistants, which meets the scope criteria. **Has the study dealt appropriately with any ethical concerns?** No. Not research. Video evidence transcript from TLAP.	**As far as can be ascertained from the paper, how well was the study conducted?** - Not research. No theoretical basis or sampling or known methods reported. **Overall assessment of external validity** + Poor research rigour but rich in direct user views and high relevance to review scope.

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
clearly about service user expressing opinions. **How defensible/rigorous is the research design/methodology?** Not sure. Not research. Video evidence transcript from TLAP. **Is the context clearly described?** Unclear. No introduction of the case is given but it is clear it is video evidence of a service user describing their experience of using adult social care to employ a PA. **Was the sampling carried out in an appropriate way?** Not sure. N/A: Not research. Video evidence transcript from TLAP. **Were the methods reliable?** Not sure. N/A: Not research. Video evidence transcript from TLAP.	**Are the findings convincing?** Convincing. Yes – direct views from a service user about employing a PA. **Are the conclusions adequate?** Not sure. No conclusions given.	**Were service users involved in the study?** Yes. Single case of a man reporting on experience of using social care services. **Is there a clear focus on the guideline topic?** Yes. Video is about views/opinions of using personal assistants to provide help/support, which meets the scope criteria. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. Adult using social care services. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Own home setting. **Does the study relate to at least one of the activities covered by**	**Overall score** - Poor on research methods/rigour but rich on direct user views. However, transcript is very short and no background section explaining context.

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
		the guideline? Yes. Using social care services – PAs. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. Video is about views/opinions of using personal assistants, which meets the scope criteria. **Does the study have a UK perspective?** Yes.	

60. Think Local Act Personal (2012b) Making it Real - A woman with Alzheimer’s . Video transcript. London: TLAP

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Methodology Other Not research. Video evidence transcript from TLAP. Single case. **Is a qualitative approach appropriate?** Not sure.	**How well was the data collection carried out?** Appropriately. Video evidence is appropriate for views/opinions of using personal assistants, which meets the scope criteria.	**Does the study’s research question match the review question?** Partly. Not research, so no RQs stated. Video evidence transcript from TLAP. However, video is about views/opinions of using personal	**As far as can be ascertained from the paper, how well was the study conducted?** - Not research. No theoretical basis or sampling or known methods reported.

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
Not research. Video evidence transcript from TLAP. **Is the study clear in what it seeks to do?** Unclear. Not research. Video evidence transcript from TLAP. Video clearly about service user expressing opinions. **How defensible/rigorous is the research design/methodology?** Not sure. Not research. Video evidence transcript from TLAP. **Is the context clearly described?** Unclear. Not much of an introduction of the case is given but it is clear it is video evidence of a service user describing their experience of using adult social care to employ a PA. **Was the sampling carried out in an appropriate way?** Not sure.	**Are the data 'rich'?** Rich. Yes rich in service user views. **Is the analysis reliable?** Not sure/not reported. N/A: Not research. Video evidence transcript from TLAP. **Are the findings convincing?** Convincing. Yes – direct views from a service user about employing a PA. **Are the conclusions adequate?** Not sure. No conclusions given.	assistants, which meets the scope criteria. **Has the study dealt appropriately with any ethical concerns?** No. Not research. Video evidence transcript from TLAP. **Were service users involved in the study?** Yes. Single case of a woman reporting on experience of using social care services. **Is there a clear focus on the guideline topic?** Yes. Video is about views/opinions of using personal assistants to provide help/support, which meets the scope criteria. **Is the study population the same as at least one of the groups covered by the guideline?** Yes Adult using social care services.	**Overall assessment of external validity** + Poor research rigour but rich in direct user views and high relevance to review scope. **Overall score** - Poor on research methods/rigour but rich on direct user views. However, transcript is very short and no background section explaining context

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
N/A: Not research. Video evidence transcript from TLAP. **Were the methods reliable?** Not sure. N/A: Not research. Video evidence transcript from TLAP.		**Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Own home setting. **Does the study relate to at least one of the activities covered by the guideline?** Yes. Using social care services – PAs. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. Video is about views/opinions of using personal assistants, which meets the scope criteria. **Does the study have a UK perspective?** Yes.	

61. Towers AM, Smith N, Palmer S et al. (2016) The acceptability and feasibility of using the Adult Social Care Outcomes Toolkit (ASCOT) to inform practice in care homes. BMC Health Serv Res 16, 523

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Methodology Mixed methods Survey analysis of the current SCRQoL, as measured by ASCOT. Focus group discussions (with staff initially and then residents and their families) to provide feedback on changes in practice. **Is the mixed-methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed-methods question?** Yes. The mixed-method research design of qual and quant methods is appropriate to addressing the various aims of the study. **Is the integration of qualitative and quantitative data (or results) relevant to address the research question?** Unclear It is unclear how the different components were integrated. The paper seems to present each component separately.	**Qualitative comp 1** Which component? Focus group interviews to provide feedback on QoL assessments from researchers and get staff to reflect on what works well. **Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?** Partly. Views of staff on what works well are important but would have been better to include views of residents about same issues alongside this. **Is the process for analysing qualitative data relevant to address the research question?** Unclear. Not clear how the qualitative data was analysed and incorporated into the results. **Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data were collected?** Partly. Some analysis was undertaken to	**Does the study's research question match the review question?** Yes. Relevant for RQ4. Paper is evaluating a toolkit for measuring/monitoring people's views of QoL within residential care home settings. **Has the study dealt appropriately with any ethical concerns?** Yes. Researchers spent time in each home talking to residents, explaining the study and assessing their capacity to consent. Throughout the study researchers continuously monitored whether or not residents agreed to participate. Consent was considered a continuous process and researchers continuously assessed residents' willingness to be involved in the study. **Were service users involved in the study?** Yes. Residents of care homes completed the SCRQoL measures - some with assistance from staff (those lacking capacity).	**Overall assessment of internal validity** + **Overall assessment of external validity** + **Overall validity score** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Is appropriate consideration given to the limitations associated with this integration, such as the divergence of qualitative and quantitative data (or results)? Partly The authors state in the paper that the qualitative data was to provide feedback and reflection on what works well. In the discussion and conclusions section, the authors report if the staff views diverged or were in agreement with the views presented by the authors. However, not much discussion is given to comparing the qual and quant aspects of the research.	compare the two care home settings but this was related to the quantitative analysis of the SCRQoL. No analysis was undertaken of the qualitative data by setting/context. **Is appropriate consideration given to how findings relate to researchers' influence, for example, through their interactions with participants?** Yes. The role of researchers is presented in the discussion section. For example, the authors reflect that "had staff collected the data and made their own ratings of residents' lives, using ASCOT, it may have had more impact on care practice than a feedback intervention and would also have had sustainability beyond the life of the study, providing potential for ongoing benefits for residents and staff." **Quantitative component (descriptive)** **Which component?** Analysis of the SCRQoL survey at two time points.	**Is there a clear focus on the guideline topic?** Yes. Relevant evidence for addressing RQ4. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. Older people using social care services in residential care home settings. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Residential care home settings. **Does the study relate to at least one of the activities covered by the guideline?** Partly. While the focus is heavily on QoL, the paper is relevant to the review as it discusses changes in practice related to feedback provided on QoL within the care homes. **(For views questions) Are the views and experiences reported**	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed-methods question)? Yes. **Is the sample representative of the population under study?** No. Results are based on a very small sample, which the authors comment was due to the difficulties recruiting and retaining homes to the research. Attrition rate was 16% (one care home was removed from the study at Time 2). The two residential care homes only accepted female residents (85% of the total sample was female). This made the sample unusual. **Are measurements appropriate (clear origin, or validity known, or standard instrument)?** Yes. Measures are taken from the validated ASCOT toolkit. **Is there an acceptable response rate (60% or above)?** Partly. The authors state the response rates are acceptable. However,	**relevant to the guideline?** Partly. There are NO direct quotes provided from the residents but the staff reflections of the ASCOT toolkit and how this changed practice are relevant for this review. **Does the study have a UK perspective?** Yes. Study of two residential care homes in England.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	they varied from 23% in one of the nursing homes to 54% in one of the residential care homes. Additionally, attrition rate was 16% and one care home was removed from the study at Time 2.		

62. Trappes-Lomax T and Hawton A (2012) The user voice: older people's experiences of reablement and rehabilitation. Journal of Integrated Care 20, 181–194

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Methodology Qualitative study Semi-structured face-to-face interviews in 2002/3, with 42 participants (mean age 81.4 years) using interpretative phenomenological analysis (IPA). **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear. The interview schedule focused on the three main stages of the rehabilitative pathway: 'Going There'	**How well was the data collection carried out?** Appropriately. Those agreeing to take part were contacted by telephone to arrange a mutually convenient time and place for interview. Three participants were interviewed in residential care, one in an acute hospital during a planned admission. In total, 38 were interviewed at home, six with a spouse or other family carer. Participants were reminded of the aim of the study and not pressured to be involved, while given the option to withdraw at their discretion with no effect on their entitlement to services. All provided signed consent forms.	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** Yes. Ethical approval was granted by the North and East Devon Local Research Ethics Committee. **Were service users involved in the study?** Yes.	**As far as can be ascertained from the paper, how well was the study conducted?** ++ **Overall assessment of external validity** ++ **Overall score** ++

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
(reason for/experiences of admission, expectations of care); 'Being There' (perceptions of the setting, experiences of care); and 'Leaving There' (experiences of discharge, formal and informal support once back at home). **How defensible/rigorous is the research design/methodology?** Defensible. **Is the context clearly described?** Clear. **Was the sampling carried out in an appropriate way?** Appropriate. All participants in the previous trial (n=206) had been patients in one of ten community hospitals. All received initial rehabilitation input in the community hospitals. They had then been discharged either straight home (the control group) or to one of several L/A short-term residential rehabilitation units (the intervention group). In total, 64 of these original participants were confirmed by GPs to be well enough to be approached again.	**Are the data 'rich'?** Rich. Narrative is full of rich quotes from users where contexts of the data are clearly described. **Is the analysis reliable?** Reliable. Data was analysed using IPA, as recommended for relatively large samples (Smith et al. 1999). This is based on systematic analysis of common themes arising from the transcripts. A provisional coding framework was developed by the researchers, working jointly on data from the first interview and separately for three more. Carer transcripts were coded separately. The coding was checked in two stages by an independent IPA researcher and a research psychologist. The last stage involved sending interviewees a summary of results and asking for feedback on this. Seven replies were received, which provided further detail on individual experiences, but none conflicted with the feedback. **Are the findings convincing?** Convincing.	**Is there a clear focus on the guideline topic?** Yes. User views about reablement and rehab. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Rehabilitation services in community hospitals, local authority short-term residential units and people's own home. **Does the study relate to at least one of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. Views of people in rehabilitation	

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
In total, 42 (65%) responded to written invitations to take part in the follow-up qualitative study. **Were the methods reliable?** Reliable.	Findings clearly and coherently presented. **Are the conclusions adequate?** Adequate Authors state that findings mirror other studies of user experience and related evidence about assessment, institutionalisation and psychological factors.	services in community hospitals and local authority short-term residential units as well as people's own homes. **Does the study have a UK perspective?** Yes.	

63. Turnpenny A, Caiels J, Whelton B et al. (2016) Developing an easy read version of the adult social care outcomes toolkit (ascot). Journal of Applied Research in Intellectual Disabilities, Advance online publication. doi: 10.1111/jar.12294

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Methodology Mixed methods The study combined survey development and pre-testing methods with approaches to create accessible information for people with intellectual disabilities. A working group assisted researchers in identifying appropriate question formats, pictures and wording. **Is the mixed-methods research design relevant to address the qualitative and quantitative re-**	**Qualitative comp 1** Which component? Eight focus groups with a total of 32 participants with an intellectual disability and/or autism were conducted to gain feedback on the first revision of the ASCOT-ER. Each focus group tested two or three domains – using the approach described in the Methods section – and each domain was tested at least twice in different focus groups.	**Does the study's research question match the review question?** Yes. RQ4 is about testing and evaluating the effectiveness of tools to support, with the collection of views and experiences of people using, adult social care services. This paper reports on the process of adapting and improving the ASCOT tool for use by people with intellectual disabilities and autism.	**Overall assessment of internal validity** + **Overall assessment of external validity** + **Overall validity score** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
search questions (or objectives), or the qualitative and quantitative aspects of the mixed-methods question? Yes. **Is the integration of qualitative and quantitative data (or results) relevant to address the research question?** Yes. **Is appropriate consideration given to the limitations associated with this integration, such as the divergence of qualitative and quantitative data (or results)?** No. This is not mentioned within the analysis. The results of the qualitative and quantitative sections are dealt with separately.	**Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?** Yes. **Is the process for analysing qualitative data relevant to address the research question?** Yes. Working group and focus group discussions were summarised in detail after each meeting. Notes were thematically analysed to check for misunderstandings, inconsistent interpretations, concept coverage and adequacy of images. The findings from these were incorporated into the revisions of the questionnaire. **Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data were collected?** No. No details given about this.	**Has the study dealt appropriately with any ethical concerns?** Partly. The study received ethical clearance. However, it is reported levels of needs and abilities of respondents were mixed (some of them lived independently with minimal help, and others had more support. Two people were unable to read) and this factor does not seem to have been explicitly taken into account in either the methods of working with the participants or in the tools used. **Were service users involved in the study?** Yes. People with intellectual disabilities or autism using social care services. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least one of the groups covered by the guideline?** Yes.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	Is appropriate consideration given to how findings relate to researchers' influence, for example, through their interactions with participants? Yes. Interviewers' contributions can shape interviews by providing confirmation, functional remarks, expansive probes and feedback, and keep respondents motivated.	**Is the study setting the same as at least one of the settings covered by the guideline?** Yes. **Does the study relate to at least one of the activities covered by the guideline?** Yes. **(For effectiveness questions) Are the study outcomes relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

64. Valdeep G, Husain F, Vowden K (2014) Satisfaction with social care services among Black and Minority ethnic populations: exploring satisfaction with adult social care services amongst Pakistani, Bangladeshi and white British people. London: National Centre for Social Research

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Methodology Qualitative study In-depth interviews and focus groups designed to explore whether lower satisfaction was re-	**How well was the data collection carried out?** Somewhat appropriately. Initial sampling criteria included specific local authority areas (Newham, Redbridge, Birmingham and Leeds); however, this was	**Does the study's research question match the review question?** Yes.	**As far as can be ascertained from the paper, how well was the study conducted?** +

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
lated to how social care is delivered to or received by BME groups. **Is a qualitative approach appropriate?** Somewhat appropriate. Yes but not grounded in any theory. Purposeful sampling was conducted. **Is the study clear in what it seeks to do?** Clear. The aims of the study are very clear. **How defensible/rigorous is the research design/methodology?** Defensible. The methods used are very clearly described and appropriate to addressing the research aims. **Is the context clearly described?** Clear. **Was the sampling carried out in an appropriate way?**	later relaxed to include other areas within London. P19: During recruitment, compromises in relation to some criteria (such as area) and final numbers interviewed had to be made. P20: The intention had been to conduct two phases of research: interviews with service users and then follow-up interviews with a relative. However, the authors say that after finding that many of the initial service interviews had been conducted with relatives, it was decided that the phase of interviewing relatives was not necessary. **Are the data 'rich'?** Mixed. A reasonable amount of direct user views but also quite a lot of quotes from relatives - this is probably because the authors say that in cases where the service user could not directly be interviewed, the interview was carried out with their relative. **Is the analysis reliable?** Reliable. P23: The interviews were tran-	**Has the study dealt appropriately with any ethical concerns?** Yes. Prior to starting project work, an application was made to the Social Care Research Ethics Committee and approval was given. Throughout the project the authors maintained contact with the Social Care REC to discuss ethical issues that arose and to apply for amendments, as needed. Additionally, all interviewers had enhanced Criminal Records Bureau (CRB) clearance. The project was carried out in accordance with ISO 20252. **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least one of the groups covered by the guideline?** Yes.	**Overall assessment of external validity** ++ **Overall score** +

Internal validity - approach and sample.	**Internal validity - performance and analysis.**	**External validity.**	**Overall validity rating.**
Somewhat appropriate. Purposeful sampling was done. The sample locations were selected to capture variations in socio-economic status and local and regional differences in terms of provision of social care. The researchers chose areas with large Pakistani and Bangladeshi communities using data available from the Office for National Statistics and deliberately chose two areas with a higher concentration of people of Bangladeshi origin and two with more people of Pakistani origin. **Were the methods reliable?** Reliable.	scribed verbatim and analysed using the Framework method, developed by NatCen. Framework is a qualitative data analysis method, which uses a 'matrix' approach to conduct theme and case-based analysis. Using Framework, the authors say they "adopted a comprehensive approach to the data analysis ensuring systematic and consistent treatment of every piece of data collected to ensure reliable and valid interpretation." The authors say that use of their analytical framework meant the interpretations were grounded in the data "and not imposed by the research team". There is no theoretical basis stated for the sampling, analysis or interpretations drawn. **Are the findings convincing?** Convincing. Yes because the authors have been very clear in attributing statements and quotes to the different groups interviewed so it is very clear to see which ones relate directly to service users. **Are the conclusions adequate?** Somewhat adequate.	**Is the study setting the same as at least one of the settings covered by the guideline?** Yes. **Does the study relate to at least one of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
	In most instances it is clear how conclusions link up to the findings sections but this is not for all of the conclusions.		

65. Ward L and Banks L (2017) Older people's experiences of sight loss in care homes. Brighton: Social Science and Policy Research Centre

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
Methodology Qualitative study **Is a qualitative approach appropriate?** Appropriate. Study aims to fill a gap on research with older people with sight loss in residential care homes by giving a voice to people experiencing sight loss in residential care. **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology?** Defensible. Stratified, purposive sampling methods were used to ensure a	**How well was the data collection carried out?** Not sure / inadequately reported. It was not clear what methods of data collection were used. For example any adaptions made for individual participants to assist in interviews, where the interviews were held, methods for obtaining informed consent. **Are the data 'rich'?** Rich. **Is the analysis reliable?** Reliable. Experts by experience were involved in the analysis and meanings in the data. **Are the findings convincing?** Somewhat convincing. Although barriers to good care	**Does the study's research question match the review question?** Yes. The experiences of people with sight loss of health and social care were a priority for the guideline committee. **Has the study dealt appropriately with any ethical concerns?** Yes. An experts by experience panel considered any ethical dimensions to the research. **Were service users involved in the study?** Yes. An experts by experience panel was employed to oversee and develop the interview questions and	**As far as can be ascertained from the paper, how well was the study conducted?** + **Overall assessment of external validity** ++ **Overall score** +

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
range of users' views and experiences were represented. **Was the sampling carried out in an appropriate way?** Somewhat appropriate. However, only care homes meeting all standards in the most recent assessment (307 care homes and 363 nursing homes) were selected (i.e. functioning well). However the aim of the research was to identify good practice rather than barriers to good care. All but one of the care homes were in London boroughs, this is out of 14503 registered care homes in England. The majority of CQC inspections report either good or needs improvement. **Were the methods reliable?** Reliable.	were identified, the care homes were already selected for providing good quality care based on CQC inspection report, so it is may be that the whole range of barriers to good care experienced by older people in care homers with sight loss are not identified from this sample, hence the recommendations only really apply to improving quality of care in already high performing care homes. **Are the conclusions adequate?** Somewhat adequate.	any ethical dimensions to the research. The panel was also involved in interpreting the findings. A project advisory group was also brought together from stakeholders from the sight loss and care sectors. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. Study includes the direct views and experiences of people using social care services. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Residential care homes. **Does the study relate to at least one of the activities covered by the guideline?** Yes. Experiences of care and support in residential care homes for people with sight loss.	

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
		Are the views and experiences reported relevant to the guideline? Yes. **Does the study have a UK perspective?** Yes.	

66. Westwood S (2016) 'We see it as being heterosexualised, being put into a care home': gender, sexuality and housing/care preferences among older LGB individuals in the UK. Health & Social Care in the Community 24, e155–e163

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
Methodology Qualitative study - Semi-structured interviews. **Is a qualitative approach appropriate?** Appropriate. The study seeks to explore in depth the views of LGB people about what they would prefer in terms of adult social care residential provision that would meet their needs, including a need to feel safe. A qualitative approach is an appropriate method for doing this. **Is the study clear in what it**	**How well was the data collection carried out?** Appropriately. 'Interviews were audio recorded and then transcripts were prepared for analysis. These were sent to participants for verification and/or corrections. The final version, approved by each participant, was then used for analysis'. (Page 156). **Are the data 'rich'?** Rich. **Is the analysis reliable?** Somewhat reliable. The analysis was carried out using	**Does the study's research question match the review question?** Partly. The study deals with service user preferences rather than service user experience, since only 10 of the 60 interviewees were currently living in sheltered accommodation. No information is given about whether the remainder were using any adult social care services. **Has the study dealt appropriately with any ethical concerns?** Yes.	**As far as can be ascertained from the paper, how well was the study conducted?** + **Overall assessment of external validity** - There is only limited relevance to the service user experience of adult social care services, as none of the participants describe such experiences. However, they do provide their views about their preferences for receiving adult social care in a residential setting, and one of the options for this would be residential provision by

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
seeks to do? Clear. The study has a clear aim, which is to explore the views of LGB people about how elderly residential provision could meet their needs. **How defensible/rigorous is the research design/methodology?** Somewhat defensible. The use of semi-structured interviews was an appropriate method for carrying out this study, as it allowed for interviewer flexibility in exploring the participants' opinions and views. The study was self-selecting, as recruitment was carried out using online advertising, social networks, opportunistic and snowball sampling. Although for qualitative research, representativeness is not of primary importance, it is worth noting that the sample does seem particularly weighted in some areas. Only 1 out of 60 participants were non-white, the majority were described as being 'well educated and relatively affluent' (p156), and al- though this was a study about preferences for supported housing and care, only 1 in 6 of the participants was actually living in supported housing,	thematic approaches, which is appropriate to the methodology. However, there is no mention of the researcher's analysis being checked by any other parties. **Are the findings convincing?** Convincing. The findings are clearly presented and coherent. There is no reason to doubt this is a sound presentation of the data that emerged from the interviews. **Are the conclusions adequate?** Somewhat adequate. Despite some reservations about sampling, the report does present a useful picture of the concerns of LGB people about going into residential care settings. It may have benefited from having more voices from LGB people with experience of the care settings being considered, and greater diversity in the ethnic and social backgrounds of the interviewees.	'The project was approved by the Ethics Committee at Keele University. Ethical issues (researching hidden populations, insider/outsider dynamics and anonymity in sensitive research) were addressed in the Methodological section of the final thesis (Westwood 2014, pp.107–116) and were also explored in Westwood (2013).' (Page 156). **Were service users involved in the study?** No. Only as interviewees - no indication that they were involved in designing, data collection or analysis. **Is there a clear focus on the guideline topic?** Partly. Only 10 out of 60 interviewees are described as being service users, i.e. they live in sheltered accommodation. The remainder are expressing their preference for the type of service (supported housing provision) they would like if and when they need it. **Is the study population the same as at least one of the**	adult social care services. **Overall score** -

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
and interviewees may have had little knowledge about supported living arrangements. **Is the context clearly described?** Not sure. The study does not describe the context in which the interviews were carried out. **Was the sampling carried out in an appropriate way?** Somewhat appropriate 'Participants were recruited via online advertising, marketing via social networks, opportunistic and snowball sampling, i.e. word of mouth recommendation, which was of particular importance in accessing less networked individuals' (p156). This may have led to a lack of representation of some perspectives, e.g. the participants are described as being all white British except 1, and generally well educated and affluent. **Were the methods reliable?** Reliable.		**groups covered by the guideline?** Partly. All participants in the study are adults, and although the study does not state whether they are using adult social care services, the research question concerns their prospective use of residential care services, either sheltered housing or residential or nursing care. **Is the study setting the same as at least one of the settings covered by the guideline?** Partly. There is no report in the study of the majority of participants currently using adult social care services, as 50 of the 60 interviewees are still living independently, and the other 10 are living in sheltered accommodation, which is a 'housing' provision not adult social care. However, the settings of interest for the study are residential settings for elders, which can be provided by housing (sheltered housing), adult social care (residential homes) or health (nursing care).	

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
		Does the study relate to at least one of the activities covered by the guideline? Partly. The study does provide information about what LGB service users would wish if they entered elderly residential care, and how it could be ensured that the right care was delivered to them so that their social and emotional needs and wellbeing were supported. However, as the study does not provide data of people's experiences of using adult social care services, only what their preferences would be if they were provided with these services, this question is only partly met. **Are the views and experiences reported relevant to the guideline?** Partly. The study presents views about what preferences would be in terms of being provided with residential elderly care, by adult social care and other service providers (housing and health). There was some presentation of participants' experiences of living in sheltered accommodation, and of the experiences of people known to the	

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
		participants who had lived in residential care settings. **Does the study have a UK perspective?** Yes.	

67. Williams V and Robinson C (2000) 'Tick this, tick that': The views of people with learning disabilities on their assessments. Journal of Learning Disabilities 4(4), 293–305

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
Methodology Qualitative study - This study contains three points of data collection; however, note this is hard to interpret because unclearly written. Point 1 titled 'Individual planning': The research team met with 46 people with learning disabilities who have individual programme plans (IPPs) and are in receipt of a day service. 25 people were then interviewed following an IPP, rather than a community care assessment because the researchers wanted to investigate 'how this process contributed to their own	**How well was the data collection carried out?** Somewhat appropriately. The authors create accessible guides to conduct interviews with the participants; however, there is no information about consent, place of interview or rationale. **Are the data 'rich'?** Not sure. Not adequately reported. **Is the analysis reliable?** Not sure/not reported.	**Does the study's research question match the review question?** Yes. Views and experiences of people with learning disabilities of assessment process - community care assessment and the IPP. **Has the study dealt appropriately with any ethical concerns?** No. Not reported.	**As far as can be ascertained from the paper, how well was the study conducted?** - The authors do not note any limitations in their paper. This poor (-) quality study is using an outdated assessment framework and legislation, originally the NHS and Community Care Act (1990), succeeded by the Care Act (2014). Need to be mindful of interpreting findings because the sample age group is between 14 and 47, and the authors do not distinguish between each participant when reporting. Compounding the lack of information on participants, it is

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
choices and empowerment' (p295). Point 2 titled 'method': 51 families were approached who had a person with learning disabilities over the age of 11. This was then reduced to 45 interviews being carried out because one refused and five were under the age of 11. Point 3 titled 'method' and 'one year on' in findings: The research team then approached the original 45 interviewed for a follow-up approximately a year later to find out the outcomes after their assessment, but 6 responded and were interviewed. **Is a qualitative approach appropriate?** Appropriate. Provides an opportunity to gather data about people with learning disabilities' direct experience of their assessment through researchers conducting qualitative interviews.	Data not convincing due to lack of information provided. Additionally, the authors make a lot of statements which are not adequately supported by previous research, such as: 'People with learning disabilities are constantly surrounded by others who are judging them, and their whole life can seem to them like an educational journey, with intermittent progress reports sent to their parent' (p298). **Are the findings convincing?** Not sure. Not adequately reported. **Are the conclusions adequate?** Not sure. Based on the lack of methodology and analysis, findings are difficult to interpret. Unsure of how authors have interpreted the data.	**Were service users involved in the study?** No. Not reported. **Is there a clear focus on the guideline topic?** Yes. Service user views – Adults with learning disabilities. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. Adults with learning disabilities. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Social care. **Does the study relate to at least one of the activities covered by the guideline?** Yes. Assessment process.	impossible to ascertain if findings are representative geographically and across the service users' level of need. The authors are not clear about how each phase is reported in findings, some participants are only asked certain questions but the amount of participants who respond does not correlate with number of interviews conducted. **Overall assessment of external validity** + Relevant findings to people with learning disabilities' view on their assessments and the outcomes; however, outdated legislation. **Overall score** -

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
Is the study clear in what it seeks to do? Clear. **How defensible/rigorous is the research design/methodology?** Not sure. Not adequately reported. **Is the context clearly described?** Not sure. Not adequately reported. **Was the sampling carried out in an appropriate way?** Not sure. Not adequately reported. **Were the methods reliable?** Somewhat reliable. One method of data collection - qualitative interviews, over three phases. The use of follow up a year later is good; however, there is no information about the methodology or response rate. Out of 45 interviews conducted, 6 responded.		**(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. Views of those who are in receipt of social care, having underwent an assessment and are currently supported through adults services. **Does the study have a UK perspective?** Yes. UK.	

68. Willis P, Maegusuku-Hewett T, Raithby M et al. (2016) Swimming upstream: the provision of inclusive care to older lesbian, gay and bisexual (LGB) adults in residential and nursing environments in Wales. Ageing and Society 36, 282–306

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
Methodology Qualitative study The study used 5 focus group interviews with care and nursing staff and managers, and individual interviews with older LGB people. **Is a qualitative approach appropriate?** Appropriate. Most appropriate method for ascertaining the views and experiences being sought. **Is the study clear in what it seeks to do?** Clear. The study sets out its aims clearly. **How defensible/rigorous is the research design/methodology?** Defensible.	**How well was the data collection carried out?** Appropriately. Data collection was carried out by conducting semi-structured interviews with the LGB people who came forward, either with individuals or in 4 cases with couples. Interviews were between 1 and 3 hours long, average length 2 hours, and the resulting transcripts were thematically coded. Three focus group interviews were conducted with 14 care staff, and 2 focus groups were held with the 27 managers. The groups lasted 45–90 minutes, and were co-facilitated by 2 members of the research team. **Are the data 'rich'?** Rich. **Is the analysis reliable?** Reliable.	**Does the study's research question match the review question?** Yes. The study does consider what the barriers are to LGB people being provided with residential care, which recognises and supports their needs, and how this service provision could be improved. **Has the study dealt appropriately with any ethical concerns?** Yes. 'The project received ethical approval from the NHS Wales National Research Ethics Service (reference 11/WA/0217), local R&D approval from Abertawe Bro Morgannwg, Cardiff and Vale and Betsi Cadwaladr University Health Boards, and University ethics approval.' (Page 303). **Were service users involved in the study?**	**As far as can be ascertained from the paper, how well was the study conducted?** ++ A well conducted study that lays out a convincing case in its initial background statement for why this is an important issue. **Overall assessment of external validity** + Although the prospective service users who participated in the study do not have experience of the service about which they are being interviewed, the study does provide a lot of contextualising information, both in terms of the views and experiences of the staff and in terms of the findings from other studies, so that the relevance and applicability of their views is demonstrated.

Internal validity - approach and sample	**Internal validity - performance and analysis**	**External validity**	**Overall validity rating**
Since the study did not include the views and experiences of LGB people living in residential care settings, the interviews with focus groups of staff and managers provided a context for the views and concerns expressed by the LGB participants in the study. The study would have benefited from including some voices of LGB people actually living in residential care. However, given the hetero normative environment described in these places, it could have been difficult to identify LGB people resident in them who were open about their sexual identity. Though this could have added another dimension to the study, it still 'works' by giving voice to what the group of LGB people interviewed would want from residential care, and then juxtaposing that with practitioners' descriptions of the current situation in such accommodation. **Is the context clearly described?** Clear.	The study reports that for service user interviews 'Transcripts were thematically coded in NVivo using an interpretative phenomenological framework whereby the focus was on the participant's understanding of their social world, identities and expectations of future care. During the analysis we were mindful of not obscuring attention to the heterogeneity of older LGB people's lives – we do not want to convey an artificial image of participants' lives as following uniform trajectories and neglect differences on the basis of other social identities such as age, gender and ability' (pp.289–90). NVivo was also used to analyse the transcripts of the focus group interviews with practitioners, and the study describes how themes emerged from the interviews, with team members checking each other's analysis. **Are the findings convincing?** Convincing. The findings are clearly presented, coherent and plausible.	Yes. **Is there a clear focus on the guideline topic?** Partly. Although it deals with adult social care residential provision for older people, it does presents service user preferences rather than experiences, as none of the LGB interviewees was living in residential care. **Is the study population the same as at least one of the groups covered by the guideline?** Partly. The study population includes adults who are prospective rather than actual users of adult social care services. The study population also includes care staff and managers. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes.	**Overall score** +

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
The report starts with a thorough discussion of the social and research context in which the study took place. The context for the service user interviews was their own homes. The context for the focus groups with practitioners and managers is not described, although the focus groups with managers are described as dovetailing with a regional networking event, meaning greater numbers of managers could attend. **Was the sampling carried out in an appropriate way?** Somewhat appropriate. LGB adults interviewed were recruited using purposive and snowballing methods, i.e. they were self-selecting. The authors state that as there is no census data about the numbers of LGB people in the UK, a representative sample would be impossible to achieve. However, this does mean that certain voices or perspectives could be absent, most notably, since all interviewees are white, BME voices.	**Are the conclusions adequate?** Somewhat adequate. The conclusions clearly relate to the data and the analysis carried out on it. However, for the purposes of the guideline it would have been preferable to include some views from LGB people that related actual experiences of using adult social care services.	The settings under consideration are adult social care residential homes for older people. **Does the study relate to at least one of the activities covered by the guideline?** Yes. The study includes the views of prospective service users with the aim of ensuring that the right care is delivered to them. **Are the views and experiences reported relevant to the guideline?** Yes. The study includes the views of LGB people who do not have experience of adult social care provision, and the views and experiences of staff and managers who do. **Does the study have a UK perspective?** Yes. Wales.	

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
Were the methods reliable? Reliable. No reason to doubt the reliability of the methods used.			

69. Willis R, Evandrou M, Pathak P et al. (2016) Problems with measuring satisfaction with social care. Health & Social Care in the Community 24, 587–595

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Methodology Qualitative study In-depth individual interviews with adult service users and informal carers from white British and South Asian ethnic groups in three Local Authority regions. **Is a qualitative approach appropriate?** Appropriate way of finding out in-depth information about survey responses. **Is the study clear in what it seeks to do?** Clear.	**How well was the data collection carried out?** Somewhat appropriately. The study provides quite a lot of information to indicate that data was collected appropriately: interviews were conducted in 3 languages according to participants' preferences, using semi-structured interviews with mostly open-ended questions, apart from one closed-ended question about satisfaction ratings. However, the report does not provide information about questions asked other than the satisfaction question, and does not state where interviews were carried out. **Are the data 'rich'?**	**Does the study's research question match the review question?** Yes. The study concerns the way user satisfaction is measured, and in particular whether user satisfaction surveys are an adequate way of measuring user satisfaction. **Has the study dealt appropriately with any ethical concerns?** No. Given the study was funded by NIHR, it is highly unlikely that there was no ethical clearance, but there is no discussion in the paper of ethical issues or clearance.	**As far as can be ascertained from the paper, how well was the study conducted?** + No information provided gives cause for concern about the way the study was conducted. However, there are areas in which more information could have been provided, e.g. where and how the interviews were carried out, what was actually asked of participants, more detailed comparison of responses from the 2 ethnic groups in the study. **Overall assessment of external validity**

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
How defensible/rigorous is the research design/methodology? Defensible. **Is the context clearly described?** Unclear. The study does provide the social and research context in which the study was carried out. However, it provides no information about the context or setting in which the interviews which provide the data for the study were carried out. **Was the sampling carried out in an appropriate way?** Appropriate. The researchers used purposive and snowballing sampling methods to recruit participants from the 2 ethnic groups in the study. 'Service users and carers were recruited through several means. First, invitation letters were posted by Local Authority Social Services departments to service users and carers. Second, gatekeepers of interest groups were approached for advice on how to recruit participants. Permission was given for the research team to visit temples, mosques, churches, carer groups,	Mixed. The study presents rich data to illustrate their findings that user satisfaction survey do not adequately convey the experiences of people using adult social care services, e.g. how they may be satisfied with some aspects of the service received but not others. However, very little rich data is provided to illustrate the other matter under consideration, whether there are differences in satisfaction between South East Asian and white British service user satisfaction ratings. **Is the analysis reliable?** Reliable. ‘Data were analysed using thematic analysis (Braun & Clarke 2006) and the principles of open coding, constant comparison, negative case analysis and memo writing (Mason 2002). In addition, some a priori codes derived from the literature review were used. Data were not forced into these a priori codes; instead, they were used as reminders to look for instances of theoretical importance in the data. The NVivo 10 software program was used to facilitate data storage, categorisation and	**Were service users involved in the study?** No. Only as interviewees, not involved in designing, carrying out or analysing the study. **Is there a clear focus on the guideline topic?** Yes. The main focus of the study is user satisfaction, in 2 domains: a comparison between a BME group of service users and a white British group; and interviews about what it is that people who use adult social care services are satisfied and dissatisfied with about the services, and hence what does not get captured by survey questionnaires. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. The participants include 46 people who use adult social care services, as well as 36 carers.	+ A useful exploration of the views and experiences of people who use adult social care services, in terms of satisfaction with the services, which highlights the important data, which is not captured by user satisfaction surveys. Study also compares the experiences of majority and minority ethnic groups. However, it is quite a short study, so does not present a wealth of data, and does not provide details about how ethical issues were dealt with. **Overall score** +

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Overall validity rating**
social groups, etc. in order to introduce the project to potential participants. Finally, people who had taken part in the study were asked if they would mind passing on the researchers' details to their friends and family members' (p591). **4.3 Were the methods reliable?** Reliable.	retrieval. Two coders independently coded the transcripts, and compared their coding. Codes and themes were developed through discussion with the project team, and checked by returning to the transcripts' (Authors, p591). **Are the findings convincing?** Convincing. **Are the conclusions adequate?** Adequate. The conclusions seem clearly linked to the data from the participants.	**Is the study setting the same as at least one of the settings covered by the guideline?** Yes. 'Services used included domiciliary care, residential care, day centres and carers' groups, among others' (p591). **Does the study relate to at least one of the activities covered by the guideline?** Yes. The study relates to the views of people who use adult social care services and of carers relating to what parts of the service they are satisfied and dissatisfied with. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes. Hampshire, Portsmouth and Southampton.	

70. Willis R, Khambhaita P, Pathak P et al. (2016) Satisfaction with social care services among South Asian and White British older people: the need to understand the system. Ageing and Society 36, 1364–1387

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
Methodology Qualitative study **Is a qualitative approach appropriate?** Appropriate. Appropriate way for studying views and experiences of 2 different ethnic groups. **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology?** Defensible. Methods appropriate to research requirements. **Is the context clearly described?** Clear. 'Interviews were carried out at a place and time convenient to the participant, e.g. the participant's own home, their day centre or the university' (p1369). **Was the sampling carried out in**	**How well was the data collection carried out?** Appropriately. Interviews carried out by 2 researchers, of whom 1 was British Indian and 1 was white Irish. The British Indian interviewer was able to conduct interviews in Hindi and Gujarati, and both interviewers conducted interviews in English. As both interviewers were female, gender matching with male participants was not possible. The advisory panel helped develop the topic guides for the interviews, which were piloted before being finalised, and were designed not to include implicit assumptions about South Asian participants having worse experiences of adult social care. **Are the data 'rich'?** Rich. **Is the analysis reliable?** Reliable. NVivo software was used to assist with the process of coding the interview transcripts. 'Two members	**Does the study's research question match the review question?** Yes. Appropriate way to collect and compare views and experiences of adult social care services, and explore the reasons for satisfaction or dissatisfaction with these services. **Has the study dealt appropriately with any ethical concerns?** Yes. 'Ethical approval was granted by the Social Care Research Ethics Committee and the University of Southampton Research Ethics Committee, and research governance approval was granted by the three Local Authorities in the study area'. (Page 1368). **Were service users involved in the study?** No. Only as interviewees, not involved in designing, carrying out or analysing the study, or in making recommendations.	**As far as can be ascertained from the paper, how well was the study conducted?** ++ **Overall assessment of external validity** ++ **Overall score** +

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
an appropriate way? Appropriate. 'Recruitment packs were translated into relevant South Asian languages (Hindi, Gujarati, Bengali). Local authorities posted recruitment packs directly to existing service users. Researchers promoted the project at organised groups, e.g. day centres, lunch clubs, social clubs, temples and churches. The research fellow volunteered at a culturally specific carers' group. An information stall was held at the Southampton Mela, an Asian arts festival, and another at a pre-Christmas arts and crafts fair. Two of the research team speak a range of South Asian languages, which helped facilitate recruitment events. Posters advertising the project were placed in shops, libraries, GP surgeries and pharmacies. Finally, the snowballing technique was used, where participants were asked to suggest members of their social network as potential participants' (p1368). The result was a sample from a variety of religions and no religions, with a wide variety of ages and with a variety of medical con-	of the research team coded the interviews, held coding meetings and revised the coding strategy. After coding, themes were proposed and tested in the data. Analysis meetings with the whole research team refined the themes, and the team collaborated in writing up the findings. Themes were discarded if they did not have enough evidence to support them. Other themes were strengthened and amended through the process of exploring the data, and discussion within the team' (p1370). **Are the findings convincing?** Convincing. The findings are clearly presented, and are coherent and consistent, including extracts from the data to support findings and conclusions. **Are the conclusions adequate?** Adequate. The conclusions are clearly linked to the evidence presented and the analysis.	**Is there a clear focus on the guideline topic?** Yes. The study deals with the experiences of 2 groups of service users of different ethnicities. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. Forty-six service users and 36 carers. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. 'Participants used the following services provided by or funded through the local authority: day centres, lunch clubs, domiciliary care, meals-on-wheels, care homes, respite care, received direct payments, had an adaptation made to their home, and culturally specific day centres, lunch clubs and carers' groups. Many of the South Asian participants used culturally specific services but some	

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
ditions and disabilities, using a variety of different adult social care services. **Were the methods reliable?** Reliable. No reason to doubt the reliability of the methods used.		also used mainstream services' (p1368). **Does the study relate to at least one of the activities covered by the guideline?** Yes. The study deals with the aspects of adult social care services that are valued by people being provided with the service, as well as the views of people using the services and their carers about being provided with the right care. **Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes. Hampshire, Portsmouth and Southampton.	

71. Wilson CB and Davies S (2009) Developing relationships in long term care environments: the contribution of staff. Journal of clinical nursing 18, 1746–55

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
Methodology Qualitative study 'The study employed a constructivist design where the different perspectives held by participants were explored and shared to develop a joint construction of how relationships influenced their experiences' (p1746). **Is a qualitative approach appropriate?** Appropriate. 'This paper draws from a study that adopted a constructivist approach (Guba & Lincoln 1989) to explore relationships in care homes from the perspective of residents, families and staff. A constructivist approach was relevant in the context of this study, since it assumes that each participant may hold a different perspective on their relationships, influenced by the time, the context and by others with whom they share relationships. In a constructivist inquiry, the interaction between the researcher and participants shapes what emerges from the investigation and knowledge is then created	**How well was the data collection carried out?** Appropriately. 'Data were collected over two years between 2003–2005 across three care homes using participant observation, interviews with residents, families and staff and focus groups. As the interaction between the researcher and participant was a major part of this study, data collection was carried out by one researcher for consistency. Participant observation was undertaken on different days at different times within each home in time slots between 4–12 hours each day. Being a participant in the home included being involved in activities such as helping residents at meal times, having conversations with residents and participating in care routines. The range of activities supported the triangulation of data sources and credibility of the study. During these periods of observation, field notes were tape recorded verbally and then transcribed verbatim within the next 24 hours during which time simultaneous notes were made	**Does the study's research question match the review question?** Partly. The aim of this study was to consider how relationships in care homes influence the experience of older people, their families and staff. **Has the study dealt appropriately with any ethical concerns?** Yes. Seeking informed consent was an on-going process and consent was continuously negotiated through strategies such as obtaining verbal consent prior to each visit as well as seeking written consent at various times such as before a taped interview. As the study progressed, people who seemed to hold differing views were also invited to be involved to ensure a breadth of views within each home. This study was reviewed by a local Research Ethics Committee and organisational approval was granted by the local Primary Care Trust.	**As far as can be ascertained from the paper, how well was the study conducted?** + **Overall assessment of external validity** + **Overall score** +

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
jointly through this interaction (Rodwell 1998)'. **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology?** Defensible. Participant observation and interviews enabled a hermeneutic circle* to be created between residents, families and staff. Data collection and analysis were conducted in parallel using a constant comparative method. Focus groups: Care home 1 = 2 with residents; Care home 2= 1 with families; Care home 3 = 1 with residents Interviews with residents - 16 across all care homes Participant observation (hours) = 156 across all care homes Interviews with staff = 25 Interviews with families = 18 *Theory of interpretation and understanding that no observation or description is free from the effects of the observer's experiences, pre-suppositions, and projections of his or her personal	in a reflexive diary. Interviews were used to support the hermeneutic process of developing shared meanings between the participants and the researcher (Guba & Lincoln 1989). This was achieved through semi-structured interviews that were prearranged, tape-recorded and transcribed. Following each interview, a reflexive diary was used to document thoughts and observations about this process and the data that emerged, enabling the researcher to feed back thoughts and observations to participants as the research progressed, ensuring conformability of the study (Lincoln and Guba 1985)' (p1749). **Are the data 'rich'?** Rich. **Is the analysis reliable?** Reliable. As data were collected, and transcription and coding were undertaken in parallel within each care home. Units of meaning were sorted into categories for each home. On completion of data	**Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Partly. The focus of the study is on the development of relationships in care homes and the impact that this has on experiences. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. Older people. **Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Care home setting. **Does the study relate to at least one of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences re-**	

Internal validity - approach and sample.	Internal validity - performance and analysis.	External validity.	Overall validity rating.
values and expectations. Hermeneutic is Greek for interpreter. **Is the context clearly described?** Unclear **Was the sampling carried out in an appropriate way?** Appropriate 'Three care homes were chosen to reflect variations in size, location and residents. Purposive sampling was undertaken within homes to ensure that participants were able to illuminate the research question (Stake 2000)'. **Were the methods reliable?** Reliable.	collection, the final stage of 'filling in patterns' included searching for convergent and divergent opinion, seeking explanation for these discrepancies. This process was recorded in a methodological log to capture decisions as the research design emerged, providing an audit trail to ensure dependability (Lincoln and Guba 1985) (p1749). **Are the findings convincing?** Convincing **Are the conclusions adequate?** Adequate This study progresses our understanding of the development of relationships between staff, residents and families in care homes by considering how the staff may support or constrain these relationships through their approach to care delivery.	**ported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

72. Yeung EYW, Partridge M, Irvine F (2016) Satisfaction with social care: the experiences of people from Chinese backgrounds with physical disabilities. Health & Social Care in the Community 24, e144–e154

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
Methodology Qualitative study - Individual interviews with 26 people from Chinese backgrounds with physical disabilities aged 18–70 who use adult social care services, followed up by focus group interviews with the same individuals in 3 groups. **Is a qualitative approach appropriate?** Appropriate. The aim of the study was to record the views and experiences of a particular minority group of adult social care service users, so the qualitative approach was the appropriate method for doing this. **Is the study clear in what it seeks to do?** Clear. The study has a clear focus - finding out whether the experience of Chinese adult social care service users reflects the lower satisfaction levels of BME users of these services, and to hear the voices of Chinese people with physical disabilities and impairments using these services. **How defensible/rigorous is the**	**How well was the data collection carried out?** Appropriately. The interviews were carried out by 2 bilingual and 1 English-speaking researchers using a topic guide with a series of open-ended questions to guide the interviews. The researchers describe the process of the interviews: 'We began the interviews with questions such as: 'what is your experience of social care?' and 'how did you first come into contact with social care?' These open-ended questions provided room for participants to freely articulate their experiences. The interviews lasted between 30 and 80 minutes and took place either in Chinese community centres or participants' homes [...] We stopped recruiting participants once data saturation had been reached. Interviews were carried out in the preferred language of participants' (page 146). After initial data analysis, all participants were invited to take part in focus group to discuss initial findings. As a result, 14 participants took part in 3 focus group, 2 in Cantonese and 1 in English. Researchers state that these	**Does the study's research question match the review question?** Yes. The study is very relevant to the review question, as it deals with the service user experience of adult social care service users from the Chinese community. **Has the study dealt appropriately with any ethical concerns?** Yes. 'Ethics approval was obtained from the National Social Care Research Ethics Committee and informed consent was sought before data collection commenced. Pseudonyms were used in this paper to protect participants' identity' (page 145). The researchers further report that 'We did not encounter any major ethical dilemmas throughout the research process. However, a number of participants appeared to be emotionally upset when they talked about their experiences of living with a physical disability, and the demand placed on their families to look after them. When participants showed signs of distress, we offered them the option to take a break, have the	**As far as can be ascertained from the paper, how well was the study conducted?** ++ **Overall assessment of external validity** ++ **Overall score** ++

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
research design/methodology? Defensible. The study began with semi-structured individual interviews with Chinese people who use adult social care services, and then took the findings from these interviews to focus groups so that the researchers' interpretation of them could be validated and clarified. The sample was recruited by sending recruitment material to all local authority adult social care teams and distributing leaflets and posters to Chinese community centres and supermarkets in major cities. Most recruits came via the Chinese community centres, with some recruits contacting the research team directly. **Is the context clearly described?** Clear. The individual interviews were carried out in participants' homes and in Chinese community centres, and the focus groups were held in Chinese community centres. The researchers state that 'Contextual information that could not be recorded in the interviews and focus groups was captured in our field notes' (p146), although the report	groups 'helped to verify our interpretation and generate new understanding of their experiences' (p146). **Are the data 'rich'?** Rich. **Is the analysis reliable?** Reliable. The researchers have ensured they accurately captured what participants were saying by inviting the participants to attend focus groups where the researchers' initial analysis of the individual interviews could be discussed. The interviews and focus groups were recorded and transcribed, with data analysis being carried out in the language used in the original interview, to ensure that meaning was not lost in translation. Thematic analysis of the interviews used the words that were used in the interviews in coding them. The bilingual researchers then translated Chinese codes and themes, with constant reference to source material to ensure accurate representation. **Are the findings convincing?** Convincing.	interview re-scheduled or withdraw from the study. All participants chose to continue the interview as they felt that it was important to have their experiences shared and voices heard. Participants were given information about bilingual counselling services should they wish to seek support from them' (p146). **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes. The study deals with adult social care service user experience of the Chinese community. **Is the study population the same as at least one of the groups covered by the guideline?** Yes. All the interviewees were people using adult social care services because of a physical disability or impairment.	

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
does not supply field note information. **Was the sampling carried out in an appropriate way?** Appropriate. The study used purposive sampling to recruit participants, which is not problematic since this is a qualitative study and need not be representative of Chinese people using adult social care services in general so long as views about the experience of using these services is captured. They recruited participants by contacting all local authority adult social care teams, and sending leaflets and posters to Chinese community centres and supermarkets in major cities. Some participants contacted the research team directly - the study does not state how these participants had become aware of the study, but presumably it was through seeing promotion materials or word of mouth. **Were the methods reliable?** Reliable. There is no reason to consider the methods as being unreliable.	There is no reason to doubt that the researchers have presented a convincing and accurate depiction of the experiences of Chinese people using adult social care services. **Are the conclusions adequate?** Adequate. The study concludes that 'experiences of social care among people from Chinese backgrounds are influenced by structural and cultural factors. It is an on-going struggle especially for those who are not proficient in English, to negotiate access and organisation of their social care. The findings clearly show that many participants remain confused about the organisation of social care and they can be easily lost in the system' (p152). It suggests that social care services need to be better informed about the tensions between reluctance to accept outside support and the demands that caring places on family networks. They should also be aware of the Chinese community's reluctance to complain when a person's social care needs are not being adequately met. The report	**Is the study setting the same as at least one of the settings covered by the guideline?** Yes. Twenty-three participants were living at home and 3 were living in residential care. Eight were receiving day centre care, 12 domiciliary care, with 1 receiving both, 1 getting home care and 1 waiting to be assessed. **Does the study relate to at least one of the activities covered by the guideline?** Yes. The study deals with the views of people receiving social care services on how well the services meet their needs and support their wellbeing. **Are the views and experiences reported relevant to the guideline?** Yes. The study solely concerns the experiences of a particular group of adult social care services users. **Does the study have a UK perspective?** Yes.	

Internal validity - approach and sample	Internal validity - performance and analysis	External validity	Overall validity rating
	suggests developing a 'clear communication strategy that takes account of the verbal and written languages used by the diverse set of Chinese communities in England' (p152), e.g. by working collaboratively with Chinese welfare organisations to address cultural and linguistic needs and ensure fair access and treatment.	It presents the views of members of the Chinese community living in the UK.	

Findings tables

Review question 1: Which aspects of the experience of using adult social care services are positive or valued by people who use services?
Review question 2: For people who use adult social care services, what are the barriers related to improving their experience of care?
Review question 3: For people who use adult social care services, what would help improve their experience of care?
Review question 4. What methods and approaches for gathering, monitoring and evaluating the experiences of people using adult social care services are effective and cost-effective?

1. Abbott D, Ottaway H, Gosling J et al. (2017) Lesbian, gay, bisexual and transgender, queer and intersex (LGBTQI+) disabled people and self-directed social care support. Bristol: University of Bristol

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim The study aims were to: 'Understand more about the specific social care needs of LGBTQI+ disabled People and how they are, or could be, supported by adult social care professionals through self-directed social care. • Improve social care professionals' understanding of and approaches to the social care needs of LGBTQI+ Disabled People, thereby improving outcomes for service users. • Gain insight from support workers and personal assistants (PAs) of potentially helpful and empowering ways of supporting and interacting with	**Participants** People receiving social care **Sample characteristics** • Sex 53% identified as female, 30% as male, 15% as non-binary. • Sexual orientation Lesbian, Gay, Bisexual, Transgender, Queer and Intersex (LGBTQI+) Disabled adults described themselves as follows: 34% lesbian/gay woman 26% a gay man 32% bisexual 20% identified as trans • Disability Respondents could choose from eight categories to describe their disability/impairment: 'mobility impairment' was most commonly selected (33%), followed by 'long-term health impairment' (22%), 'cognitive impairment'	**Framework areas** Respect, dignity and control; Personalised support; Active participation in lived experience of care; Care and support for people's needs **Narrative findings** More than half of those surveyed said that they never or only sometimes revealed their sexual orientation or gender identity to their PAs. Less than one third said that they were 'very comfortable' discussing their support needs regarding being LGBTQI+ with their PAs. 'There was a full range of being out to PAs: not out, out to some and out to all. Some that were out or out to all talked about how pleasurable and important it was to be open about their sexuality or being trans. Some interviewees said that they were not immediately out to PAs but adopted a 'wait and see' policy'. (Authors: page 2). Several people said they were unhappily resigned to the idea of not being fully out because of their anxiety about the reaction of the PA and the implications on their care and support: "I have the bloody right to be who I am in my own home. You know, if I can't be myself in my own house, I'm really screwed, you know. Because I need people working for me who can handle queers coming in and out of the house, who can handle maybe that one of my friends who used to be a girl is now a	**Overall score** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
LGBTQI+ Disabled social care recipients and overcoming challenges or barriers' (Authors: page 2). **Methodology** Mixed methods 1.Qualitative interviews with 20 LGBTQI+ disabled people 2.A focus group of PAs 3. A survey of 56 LGBTQI+ disabled adults who use self-directed social care in England. **Country** UK England **Source of funding** NIHR School for Social Care Research.	(14%) and 'mental health difficulties' (13%). **Sample size** 56 LGBTQI+ disabled adults	guy this week, who can handle going out to protests with me, who can handle turning up at LGBTQI+ events with me, you know." (Study participant: page 2) "If I fire someone I've got to have an alternative before I can do that. You can't just find people in two or three hours. It's meant I've had to put up with more bad behaviour if I hadn't had to think, 'Well what's the alternative?'" (Study participant: page 2) Over a third said that they had faced discrimination or had poor treatment from their PAs because of their sexual orientation or gender identity. Most interviewees talked about difficult experiences with PAs and other social care staff regarding their package of support, at times discriminatory, even abusive. Agencies were seen as slow to respond. Some interviewees were very discreet at home: "If I had a copy of 'Gay Times' I would probably make an effort to make sure it wasn't there... especially when you've got a new carer coming in... just in case they're homophobic." (Study participant: page 3). Over 90% said that their needs as a LGBTQI+ disabled person were either overlooked or only partly considered during assessment or review. Less than a third said they felt comfortable talking about these needs with staff in their local authority. Assessments failed to emphasise the whole person, by ignoring sexual orientation or gender identity. One person describing the process of filling in an assessment form, said:	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		“I picked it up, signed it and wrote the date in the box, and I said to her, [social worker] 'Oh, what's this?' And there was a box about my sexuality, and she had not asked me. And I said, 'Oh, what's this bit? You haven't filled it.' She said, 'Oh, I never bother with that. I don't think it's really relevant.' But actually it's important that we are represented within these things, and that people know that trans people and queer people are being seen. I just said to her, 'Well I'm going to fill it in.' It felt a bit too much like sweeping it under the carpet. And I don't want to be swept under the carpet.” (Study participant: page 4). Some people were worried that being too open may negatively affect the outcome of assessments: “I do worry if a care manager was very religious or whatever that they may not give me a totally fair assessment if they're judging my life or lifestyle.” (Study participant: page 4). In terms of being supported to do LGBTQI+ 'things' (e.g. go to an event/bar, support to maintain friendships and relationships), 22% said that their PAs did not assist them. When asked further, 40% said it was because they were not out to their PAs; 40% said they were uncomfortable with their PAs supporting this; and 20% said that their PAs had refused to help with such activities. Also, positive examples were cited by participants: “My PA was delighted to come on Pride with me. My PAs, I'm very open with them about my work, my lifestyle, about my orientation and about my gender. I	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		need people to work with me that respect my independence and who are happy to see me participating in my community doing things that enrich me. I need my PA to come to Pride and go with the flow and not care that some man may come and kiss him on the cheek. My PA enjoyed Pride, he was glad to go.” (Study participant: page 4). Many people expressed the desire for more LGBTQI+ PAs. In the qualitative interviews and survey, people described the benefits and challenges of self-directed social care support. Having control over support arrangements was the most commonly mentioned reason for a preference for self-directed support. Previous experiences with agency workers were negative: “You have different people all the time, you've got strangers coming into your house. I wanted to be able to choose. It's transformative if you get the right person.” (Study participant: page 4). Most of the interviewees spoke about the desire to have more support for 'social hours' to reduce isolation. A repeated theme in the research was the difficulty of recruiting and retaining good quality PAs. The reasons included a lack of guidance and support with recruitment processes and a lack of support and information regarding managing disagreement or conflict within support relationships/arrangements.	

2. Abbott S, Fisk M and Forward L (2000) Social and democratic participation in residential settings for older people: realities and aspirations. Ageing and Society 20, 327–340

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim To explore the range and diversity of views held by older people living in sheltered housing and residential care settings about independence and involvement. **Methodology** Qualitative study Qualitative interviews - quota samples **Country** UK NW England, W Midlands and Wales	**Participants** Older people receiving social care Older people in sheltered housing or residential settings **Sample characteristics** Sex 25 men; 97 women interviewed Sample age Two-thirds of sample aged over 85 years **Sample size** 122 interviews were carried out. **Costs?** No	**Framework areas** Respect, dignity and control Care and support for people's needs **Narrative findings** Page 334: The authors discuss that an important impact of moving into residential care for some people is the loss of paid work and / or running of their own homes. Some participants spoke of strategies for overcoming this loss. The authors report that: "A significant minority of residents spoke of a variety of practical ways in which they participated in the running of the house. It was important to be able to offer help (for example, laying the table at lunch-time, helping with the washing-up, gardening, etc.), and suggested that these activities increased their self-esteem." (Authors) "The house-keeper's husband went into hospital suddenly and she was going to call someone to get the tea. But I said that I'd do it… and felt quite proud to be involved. (F, 76) (Respondents). The authors go on to say that: "Staff had recognised the value of practical participation and in several houses there was a rota for laying the table: 'to make them feel involved' (staff)." And (on p336) the authors state that residents had positive aspirations "to be involved more strategically in the running of the residence". Page 335: Other residents spoke about the benefits of personalisation: "I wish we could call each	**Overall score** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		other by our first names, it's more friendly. But the committee don't approve. (F, 86)". Page 336: The authors note that none of the care homes had a formal complaints procedure in place and that most staff expected that residents would identify problems by talking to staff, and that complaints would be dealt with by informal discussion. One care home had a committee that did meet with residents twice yearly specifically to deal with complaints. In another care home, "the chairperson took advantage of a weekly tea-party to invite 'bouquets and brick-bats'" (Authors). Page 338: The authors mention that information issues were a problem but rarely mentioned. One resident said: "They put things on the notice board but I can't read it…I have to rely on someone telling me…people don't always think to tell me. (F, 85)". Page 338: The authors argue that "there was substantial evidence of limited choice (particularly concerning meals), an absence of clear processes for redress, and limited opportunities for representation". However, the authors argue that as opportunities for involvement (such as resident representation on care home committees) was not even highlighted as an issue for many residents; there needs to be 'ownership' of the problem before it can be resolved. They argue that "A necessary although not sufficient first step in achieving a more participative culture is for organisations and individuals providing sheltered housing or residential care to learn how to encourage and attend to dissenting as well as majority voices among their residents". (Authors).	

3. Barnes C and Mercer G (2006) Creating user-led disability services in a disabling society. Bristol: Policy Press

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim Drawing on evidence from a range of sources, including material from the first national study of user-controlled services (Creating Independent Futures 2000), this book provides a critical evaluation of the development and organisation of user-controlled services in the UK and identifies the key economic, political and cultural factors that shape their further development. Chapter seven discusses users' experiences using mainstream, community-based support services and contrasts this with disabled people's experiences of user-led services, with in-depth examination of the issues specific to user-led services	**Participants** People receiving social care Professionals/practitioners **Sample characteristics** *Sex* 53% female *Disability* 65 individuals described themselves as having a physical impairment. Eight people reported emotional distress. Eight people had learning difficulties. Eight had sensory impairments. *Ethnicity* 93.3% described themselves as one of the following: English (48%) Scottish (24%) British (10.7%) Welsh (9.3%) Irish (1.3%) The remaining 6.7% described themselves as African Caribbean, White European or Jewish (p67). *Sample age* Nearly half of sample were aged 35–54 Four people aged 18–24 Five people aged over 65 *Level of need*	**Framework areas** Respect, dignity and control Personalised support Info and comms Active participation in lived experience of care Care and support for people's needs **Narrative findings** Services accessed by the disabled participant spanned the statutory, private and voluntary sector. The majority (68) of the sample of 76 individuals was still accessing services from LA social service departments, including input from a social worker and/or case manager, home adaptations, home helps and day centre placements. Generally, individuals criticised these mainstream organisations for not being responsive to their needs. Centre for Independent/Integrated/Inclusive Living (CIL) organisations are seen as significantly more responsive to people's needs, despite their lack of resources. MAINSTREAM PROVISION i. Assessments Most assessments were led by professionals and most participants felt that these were not personalised. 'They just don't work to the services that you require...they suit themselves. They don't listen...Mind you, I suppose that they are short of staff and that's their way..."look we've got other people to attend to", but that's not what people want to hear (Participant 1,	**Overall score** ++

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
that users believe distinguish them from mainstream provision. **Methodology** Qualitative study Interviews in nine case study sites **Country** UK **Source of funding** Voluntary/Charity National Lottery. Author states funding received for two years from January 2000 (p63).	36 participants lived with their partner, family or friends, while 33 lived alone and six lived in residential homes (p67). **Sample size** 76 disabled people. **Costs?** No.	page 117). “It was a fight to get any sort of assessment to begin with. Their assessments were budget led” (Participant 2 , page 117). This situation confirmed for participants the importance of moving towards self-assessment. The Authors explain that there is no evidence that this has led to a disproportionate use of services (Authors, p117). ii. Home-helps The limitations on home-help input was a significant anxiety, where many interviewees talked about difficulties caused especially with regards to lifting and handling and domestic tasks. Reliability of home-helps, including agency staff and volunteers was particularly problematic: ‘...there might be 400 of you in an area and 40 people coming out to do the care. So you have to allow for this and be flexible. What happens in reality is that you're up at half past seven (in the morning) waiting for your care workers and sometimes at a quarter to on in the afternoon you are still sitting there waiting for her’ (Particpant 2, p118). This was especially problematic for people whose health conditions fluctuated from day to day, e.g. those with multiple sclerosis or severe emotional distress, as the level of support needed would vary accordingly. High staff turnover and variable quality of support were other issues that were cause for anxiety: ‘You didn't know who was coming to see you and a lot of different people come and they would come in and tell you what they would do, they didn't know what to do with me, how to lift me or anything’ (Participant 3, p119). iii. Lack of control	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		Several interviewees felt that they had no control and that they were expected to be grateful for services: ‘There was no control...I was very much worked on, I was an object more than a subject’ (Participant 4, p119). iv. Complaints Participants also pointed out that complaints were often not dealt with properly and individuals were often labelled as 'trouble makers' (Authors, p119). ‘You're put down as a whiner, or you're a moaner, the fact that you mightn't have had a shower for three or four days – “well, it doesn't really matter dear, you’re not really going anywhere today, are you?”’ (Participant 2, p120). ACCESSING USER-LED SERVICES i. Referrals The authors note that it is significant that the majority of people interviewed were signposted to user-led organisations by professionals in statutory services. Referrals were proportionately higher in those areas where links were strong between user-controlled organisations, local social services department or health authority, e.g. as in Cardiff, Glasgow and Surrey: ‘I would say that that particular office at social services was quite proactive in helping me get in touch with the direct payment scheme’ (Participant 5 , p120). But there was no automatic system of referral by health authorities or allied health professionals for disabled people: ‘When I started to become ill and	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		went to the hospital, he [the consultant] gives you a prognosis, I was left absolutely devastated. There was no information in the hospital whatsoever, and I wasn't in a state to ask. Basically I went home not aware of any group whatsoever...You're by yourself, you don't know where to go' (Participant 6, p123). ii. Use of services and choice and control Two main themes were identified in comparisons between professionally led and user-led organisations: choice and control. Participants were explicit about the fact that user-led organisations offered them more choice of services and increased control over how these services were delivered: 'I have transferred from a social services' help at home to a direct payment scheme via the [user -controlled organisation]. We were struggling with the kind of help we were having... [The independent living support worker from the organisation] came to see us with my social worker. We discussed the whys and wherefores, and we thought we would at least attempt to use this direct payment scheme...From day one the impact was just totally different. It totally turned our lives around' (Participant 7, p124). iii. Support groups Some people used direct payments from other agencies but attended PA employers' support groups run by the case study organisation: 'Nobody was able to help me with the Independent Living [Fund]...I was at	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		my wits end when I discovered the [CIL]. M...[a disabled support worker] has been exceptionally helpful. I was over today to talk to her about the payment of Income Tax and National Insurance. I actually had to call the taxman. He didn't know anything about carers, about people like me employing carers...' (Participant 8, p125). iv. Use of Direct payments Also mentioned regularly by participants, was social workers and other professionals questioning the competence of disabled people applying for direct payments: 'I went to the social work side and it went so far, and basically it was binned at a certain level. I didn't get the support to follow it through, or the information. So I went back and challenged them and came down here to the CIL...and that's why I've been coming on the training schemes...They bring you up to speed with what's necessary...How do you handle your personal assistants? How do you handle your payroll?...The CIL it can keep you totally on the right track...' (Participant 9, p125). v. Information Access to information was a problem, especially for people with newly acquired impairments: 'It's the "catch-22" situation, in as much as when you need it, when you become disabled or incapable of performing certain functions, it becomes harder and harder to obtain information...' (Participant 10, p126). 49% of	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		the participants had sought out information from the case study organisations. vi. Training Nearly half of the participants saw themselves as both users and members of their local CIL. Training facilities and courses were offered by all the case study organisations: 'The training I received enabled me to be a proficient deliverer of Disability Awareness or Equality Training...' (Participant 11, p127). vii. Counselling and peer support The need for counselling was particularly valued by those disabled people who had recently acquired their impairment and/or recently become aware of disability issues: 'When I came here they gave me confidence to carry on...I know there's a support group here and someone I can come and talk to whereas before I didn't...' (Participant 6, p128). Formal and informal peer support provided by other disabled people active in the case study organisations was identified as helpful in reducing social isolation (Authors, p129). viii. Sensitivity to need Participants felt that user-controlled organisations were much more sensitive to their specific needs: 'When I was on my own without a PA or somebody I could exchange information or confidences with...Well I would have either become a basket case or...a suicidal case...Psychologically the [CIL] gives the individual a sense of identity and a sense of which places to	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		go for help. So it certainly is a lifeline in that respect' (Participant 5, p129). WANTS AND ASPIRATIONS Participants often cited the issue of lack of information about the benefits of user-controlled services and the organisations providing them: 'I certainly think they could improve by making more people aware that the place is here....People like myself, who become disabled, you don't know who to turn to...' (Participant 6, p131). Some participants were very worried that CILs were not attracting younger disabled people. Other problems cited by participants was accessibility of buildings used by CILs, geographical location and access by public transport, and staff shortages which could impact on the efficiency and effectiveness of services (Authors, p132).	

4. Beech R, Henderson C, Ashby S et al. (2013) Does integrated governance lead to integrated patient care? Findings from the innovation forum. Health & Social Care in the Community 21, 598–605

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim This article presents research that examined the integration of services offered at the patient/practitioner interface [referred to as	**Participants** Older people receiving social care Professionals/practitioners Carers/family members	**Framework areas** Respect, dignity and control Continuity of care and transitions (incl. access) **Narrative findings** The care delivery experiences of patients are grouped	**Overall score** ++

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
meso- and micro-level integration by Ling et al. 2010, and also as continuity of care (Heaton et al. 2012)] and in particular the extent to which the actions of frontline staff working within and across organisations supported the drive to reduce the use of emergency hospital bed days by older people. A secondary aim of the research was to assess how closer inter-organisational integration was affecting the delivery of services at the patient/practitioner interface. **Methodology** Qualitative study Qualitative methods within a case study design. **Country** UK	**Sample characteristics** Level of need Patients regarded as eligible for care 'closer to home' services, at the point of and following a health crisis, Three conditions focused on: [Chronic Obstructive Pulmonary Disease (COPD), stroke or falls]. **Sample size** 18 patients (six in each site) with one of three conditions. **Costs?** No.	into the three key phases of their journeys: pre-crisis; crisis; and rehabilitation (including discharge from acute care). A general barrier was concerns voiced by patients on the suitability of arrangements for organising continuing care, while family members reported being excluded from discussions about care arrangements and the roles they were expected to play (p600): BARRIER The pre-crisis phase Although some patients had been quite well before their health crisis, many had suffered significant periods of ill health. In particular, patients who had fallen and patients with breathing problems gave examples of having delayed help-seeking or reporting accidents, being reluctant to 'bother' professionals (in particular GPs). Such decisions delayed or averted contact with primary and community care services at when they might have acted to prevent crises. For example, 14 of 18 individuals said that they had suffered a previous fall, but in many cases had not reported these to health professionals. Blockages to connecting 'closer to home' services to patients could be a result of the way mainstream primary and community services were organised. Staff members said that GPs had a key role in offering care during the pre-crisis and crisis phases, but they thought that changes to the GP appointment system had created barriers. Some staff praised out-of-hours rapid response teams for being typically faster to respond than out-of-hours GP services. (Staff, p600) (p601):	

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		FACILITATOR The crisis phase - It has been estimated that up to half of those people who fall and are seen by the ambulance service do not need to be admitted to hospital (Snooks et al. 2006). This research found that very few people were diverted at the point of making an emergency call. Mrs N's patient journey not only highlights a rare example of a successful 'diversion' by paramedics from acute care but also describes the patient's feelings to a perceived poor service from her primary care provider. 'If I press that [alarm], then it answers in the hall there. That's how I got the paramedics you see, because – not being unkind – you can be on the phone for hours trying to ring a doctor and you don't get anywhere. So I ring now for the paramedics'. [Mrs N, Site 3]. Mr H's daughter arranged for home care from his social services department, which then referred him on to community rehabilitation, and Mrs R heard about adult care services from a family member. Her GP subsequently referred her to the intermediate care team: I got a phone call within 24 hours from adult care [actually intermediate care] asking me what was wrong – and maybe 2 days later I was all set up; they were marvellous. [Mrs R, site 3]. BARRIER Two patients (Mr H and Mrs R) spoke of episodes in which they were treated in A&E for fractures and discharged home without suitable arrangements for follow-up care and support. In both cases, family members intervened and contacted community services to arrange this (Authors, p601). Mr H's	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		daughter arranged for home care from his social services department, which then referred him on to community rehabilitation, and Mrs R learned about adult care services from a family member. Her GP subsequently referred her to the intermediate care team. The patient journeys highlighted the important role that family and friends play in providing follow-up care. One issue identified by staff working for care 'closer to home' services in all the sites was that current referral patterns meant that opportunities were being missed to prevent 'avoidable' acute bed use. A key problem was the lack of knowledge of the existence and function of these services by potential referrers. (Authors, p601). (p602): FACILITATOR The rehabilitation phase – In some cases, decision-making about on-going care following an acute attendance or admission resulted in timely transfer and patients were satisfied. For example, Mr K was screened in the hospital's observation ward by intermediate care staff, offered a 6-week package of intensive physiotherapy and transferred to the rehabilitation unit the next day. Decision-making about on-going care following an acute attendance or admission resulted in timely transfer and patients were satisfied. For example, Mr K was screened in the hospital's observation ward by intermediate care staff, offered a 6-week package of intensive physiotherapy and transferred to the rehabilitation unit the next day (Authors, p 602). Many of the patients who received on-going care from rehabilitation services commented on the personalised nature of care provided within a	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		holistic and integrated approach (Authors, p602). (p602): BARRIER The rehabilitation phase – However, many patients and carers were concerned with the quality of acute hospital discharge planning, especially their lack of involvement in this. Two patients from different sites, both frail women in their 80s with COPD, experienced unsuccessful discharges and thought that this was because they were not feeling well enough to go home. (Two female participants in their 80s, p602): ‘I was astonished when the young doctor said, “I think you can go home tomorrow”. I said, “I don’t feel fit. … What about me going to the [rehabilitation unit] for a bit?” And he said “Oh no, you’d be much better at home, get back to normal”. And so it was against my will. I suppose they would say I finally agreed, but there didn’t seem any option but to go home – and it was then I found I wasn’t able to cope. … With hindsight, I was a bit weak to go with it, but I was so weak’ (Miss E, p 602). Other patients who needed extended periods of rehabilitation faced delays in access to bedded rehabilitation with the choice of discharge destination seemingly driven by the availability of community hospital and intermediate care beds (Authors, p602). Common issues across all the phases above included services for preventing health crises were underused because individuals were slow to access care following accidents or when feeling unwell and because health professionals failed to inform patients about preventative services such as falls prevention services. At the time of a health crisis, there was a reliance on ‘traditional’ referral patterns and services, partly due to a lack of knowledge about care	

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		'closer to home' services among key frontline professions and because out-of-hours rapid response services were not always available. Patients spoke about a lack of information and signposting about services that they could themselves use before, during or after a health crisis. Communication between professionals, particularly across organisational boundaries, was a challenge. Patients described having to undergo multiple assessments. Information sharing was impeded by a lack of compatible technologies.	

5. Blake M, Bowes A, Valdeep G et al. (2016) A collaborative exploration of the reasons for lower satisfaction with services among Bangladeshi and Pakistani social care users. Health & Social Care in the Community. Advance online publication. doi: 10.1111/hsc.12411

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim 'This study explored underlying reasons for the expression of dissatisfaction with services among Bangladeshi and Pakistani social care users in England and investigated, using a collaborative approach, how these could be addressed' (p1). **Methodology**	**Participants** People receiving home care - All the service user participants in the study (63) were being provided with adult social care services in their homes. Professionals/practitioners – 24 social care managers, social workers and care workers. **Sample characteristics** Sex – Of the service user participants, 28 were male and 35 female.	**Framework areas** **Personalised support** The study found that 'requests for care did not always translate into the desired care package. Apart from services to address unmet needs (such as loneliness and isolation), more equipment and more time from care and support workers, in particular, were identified as care gaps' (page 5). In order to address this, the report noted that 'our findings confirm that a person-centred approcolsach to meeting the needs of diverse clients is needed irrespective of the service user's ethnicity or cultural background' (p8). I.e. service providers should guard against making assumptions about the sort of service that should be provided, based on the service user's ethnicity.	**Overall score** ++

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
In-depth interviews with social care users. **Country** UK – England. **Source of funding** Government - National Institute for Health Research, School for Social Care Research (NIHR SSCR)	Sexual orientation – Not stated. Disability – Not stated. Ethnicity – Of the service user participants, 20 were Bangladeshi, 24 were Pakistani and 19 were white British. The report makes clear that they are describing ethnic descent not nationality in using these terms. Ethnicity of the social care practitioners is not provided. Sample age - Of the service user participants, 30 are aged 18 to 59 and 33 are aged 60+. Level of need – Not provided. Socioeconomic position – Not provided. **Sample size** Comparison numbers – A comparison is made between the 44 Asian service user participants and the 19 white British participants in terms of how they understood and responded to survey questions, in order to ascertain whether this could be connected to the lower satisfaction level with adult social are described by BME communities. There were also comparisons between the perceptions of	**Info and comms** The study reported that 'Reliability and consistency emerged as two main concerns in relation to communication. Reliability related to social workers keeping appointments and being responsive to users' need for contact. A common complaint was that it was difficult to make contact with social workers generally, and not having an assigned social worker hindered communication. Frequent changes in social workers combined with perceived inadequate handovers meant users had to explain their situation and care needs repeatedly. Those who relied on social workers' knowledge to navigate the care system felt dissatisfied with what was viewed as sporadic communication' (p5). However, the study did find that practitioner assumptions played a role in the minority communities not receiving the same level of service as white British service users in the study: 'There was a perception among local authorities, borne out in practice, that Bangladeshis and Pakistanis with care needs were more likely than other groups to live with their families. This led to an assumption of a preference for 'taking care of their own'. This perception worked in parallel with an expectation within these groups that the family should or would provide care, resistance to 'outsiders' providing care in the home and a perceived stigma associated with seeking care outside the family. This perceived and internalised obligation to provide care meant that these groups were less likely than their white British counterparts to be aware of their entitlements to services' (p6). The study also	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
	the 63 service users and the 24 social care practitioners. **Costs?** No – Not provided.	identified some language and communication barriers: • 'Communication barriers were experienced along the care pathway. Accessing care, especially through local authority automated phone lines, was particularly difficult for Bangladeshi and Pakistani people. • Where language services (interpreter or own language staff) were not available, difficulties were encountered in communications with social workers; in challenging care packages; explaining tasks; and building rapport with care workers. • Factors that mediated the negative consequences of poor communication were levels of education; English language proficiency; the involvement of family members; and the assistance of third parties such as community organisations or providers who advocated on behalf of carers' (p7). • It was also noted that 'A shared language increased satisfaction with care workers; however, this was not essential and the use of body language and signing helped to build rapport between care workers and service users, contributing to higher levels of satisfaction with care' (p7). The study made recommendations related to information and communication: '– Raising awareness of available services through local media and community organisations in order to facilitate access to services and with a view to reducing the stigma associated with accessing services	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		– Effective communication between local authorities and social care providers of service user characteristics, preferences, and cultural and religious needs so that these can underpin the development of an appropriate person-centred package of care [...] – Effective modes of communication for those who are not fluent in English and greater use of better trained and well briefed interpreters with workers who know how to work with an interpreter, as well as more face-to-face contact between provider and service user' (p8). **Continuity of care and transitions (incl. access)** The study made the following recommendation, in order to address the issues raised by changes of social worker and to ensure information was passed on: 'Implementing a service user file, 'Ten things you need to know about me', to be updated by service users as needed and with the support of care workers' (p8). **Care and support for people's needs** The practitioners reported that it could be difficult to assess the needs of service users with poor literacy and English language skills, as this meant they relied on other family members to translate/interpret. However, although the family members already providing care were usually female, the persons with the necessary language skills were usually the males. It was believed that not being able to communicate with the main carer led to some of the dissatisfaction service users experienced. With regard to ethnic matching of	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		care providers with service users, the study noted 'For the most part, an accepted response to cultural diversity (by both providers and service users) was the matching of care providers to the cultural characteristics of service users. A common language; appropriate and respectful forms of address (e.g. addressing older care users as ‘aunty’ instead of using first names); preparation of culturally appropriate food; the gender of care workers; religion (for support with ritual ablution for prayer); and a general cultural understanding to help build rapport and familiarity were identified by service users as important dimensions of ethnic matching' (p7). However 'The salience and relative value of these dimensions was specific to individual service users. For those concerned about preserving the privacy of family discussions, religion matching was more important than language matching. The use of personal budgets to employ family members as carers could facilitate the provision of culturally appropriate care' and 'care user-care provider ethnic matching was not always necessary to improve satisfaction' (p7). Service users stated that ethnic matching was sometimes inappropriate or inadequate, but local authorities sometimes had to compromise when they could not provide an exact match, e.g. matching general geographic location but not language. The study found no evidence of cultural awareness training being provided for staff providing care, but also that there were service users who felt that their care workers did show some level of cultural awareness which contributed to their satisfaction with the service. Overall, the study found that 'Poor understanding by service users and poor communication by	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		service providers of the balance between cultural appropriateness and a formal caregiving relationship hindered care provision that met care users' needs and expectations' (p8). **Narrative findings** CARE PATHWAYS COMMON TO ALL GROUPS: Three aspects played a key role in perceived satisfaction with care: accessing care through the local authority; interaction and communications with social workers; and receiving care from care and support workers. There were common drivers of satisfaction for all three ethnic groups. i. Accessing care Ease of making contact with social workers, the speed of undertaking an assessment and the care package agreed was fundamental to user satisfaction for all three ethnic groups: *'Those that don't ask don't get anything'* (Female service user, Pakistani origin, Leeds, p5). With the exception of services to address unmet needs (such as loneliness and isolation), care gaps were identified in the shape of more equipment and more time from care and support workers. ii. Communication with social workers Reliability and consistency were two main concerns in relation to communication. Reliability included social workers keeping appointments and being responsive.	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		Not having an assigned social worker was also identified: *'We have to contact the social services team in the area to get hold of the actual social worker'.* (Relative of male service user, Bangladeshi origin, Birmingham (p5). iii. Receiving care The nature of care was the most important driver of satisfaction. Service users expressed satisfaction where staff had gone out of their way to provide a service. A lack of time caused dissatisfaction for both service users and carers: *'… One is punctuality, two is the rapport and three is getting the work done properly. She's [my care worker] got all three. If you haven't got all three, then it might be a problem'* (Service user, male, white British, London, p6). SATISFACTION, ETHNICITY AND CULTURE: Common issues led to satisfaction or dissatisfaction among all three population groups. But there were cultural and ethnic differences. Cultural issues were interpreted and expressed differently by service users, by their families (including carers) and by local authorities or providers. i. They 'take care of their own'	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		Service providers assumed that Asian families would prefer to 'take care of their own', consequently making them less aware of their entitlement to services and less likely to seek help, or only do so at crisis point. ii. Family and caring Caring was often a female role supplemented with a small amount of care from the local authority. Where there were language or literacy issues, care providers sometimes could not communicate directly with the women who were the main carers about what the service user's needs were. The authors note that: *‘Disentangling reasons for dissatisfaction is difficult where the wider family is involved – care users, their main carers and those who act as communicators with the care system’* (Authors, p7). iii. Language and communication barriers Accessing care, especially through local authority automated phone lines, was problematic for Bangladeshi and Pakistani people. In the absence of language services (interpreter or own language staff), communications with social workers was hampered; care packages could not be negotiated properly; explaining tasks and building rapport with care workers was problematic. iv. Ethnic matching as a response to cultural and religious difference	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		Service users identified key dimensions of ethnic matching including a shared language; preparation of culturally appropriate food; the gender of care workers; religion (for support with ritual ablution for prayer); and a general cultural understanding to help build rapport and familiarity. Significantly, care user–care provider ethnic matching was not always an essential part of improving satisfaction. For example, white British care workers were perceived to perform practical tasks such as cleaning and changing clothes more effectively than care workers of other ethnicities. v. Meeting service user needs From the provider and local authority perspectives ethnic matching was not always possible so compromises had to be made, for example matching South Asian origin but not language. This contrasted with the view that cultural familiarity could weaken the fundamentally professional (and formal) nature of the care user–care worker relationship. For example, a senior manager, (homecare provider) explained that service users may say: *‘I want someone from my community because she speaks my language. I like it – somebody comes in, in the day and I can speak my language’. Or, ‘I confide in her’. Or, ‘It’s like a daughter coming to the door’. Whereas another service user will turn round and say, ‘It’s my private life. I don’t want somebody to come in and intrude and ask me all questions about – where’s your daughter’?* (Senior manager, homecare provider, p8).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		Care workers were not receiving cultural awareness training, although some were still showing cultural sensitivity, which contributed positively to satisfaction. COLLABORATIVE WORKSHOPS generated a number of suggestions from service users: – Use local media and community organisations to raise awareness of services and reduce stigma. – Good communication between local authorities and care providers about service users' individual needs, so as to develop person-centred care packages. – Service users to be assisted to provide and update a file about their needs. – The support needs of carers within the family (usually women) to be considered. – Improved communication with non-English speakers, e.g. with appropriately trained interpreters, and more face-to-face contact. – Recruit a local care workforce that mirrors the diversity of the service user population. – Training in cultural awareness for social care practitioners (Authors, p8).	

6. Cameron A, Abrahams H, Morgan K et al. (2016) From pillar to post: homeless women's experiences of social care. Health & Social Care in the Community 24(3), 345–352

Research aims.	**PICO (population, intervention, comparison, outcomes).**	**Findings.**	**Overall validity rating.**
Study aim The TARA Project- 'The study was based in a large English city and followed a group of homeless women (without secure housing) and women at risk of homelessness (from tenancy breakdown) to identify how their experiences and needs changed over this time. The aim was to gain a fuller understanding of their needs, including their social care needs, as a means to understand how best to support women to access, and maintain engagement with, support services' (p347). **Methodology** Qualitative study Small-scale longitudinal study over two years. Thirty-eight women were recruited	**Participants** People receiving social care Social care services for homeless people are provided by a various agencies from across the statutory and non-statutory sectors. The authors describe a various range of social care provision including – named key workers based in, or linked to, their accommodation; at specialist services, such as mental health or drug and alcohol services, as well as by accessing support from local voluntary groups, e.g. an organisation working with street sex workers. **Sample characteristics** *Sex* All female participants *Ethnicity* The majority described their ethnicity as white British (27), four women described themselves as white European, two as black African and five as mixed race. *Sample age* Age range from 19 to 59. *Level of need* Homeless women (without secure	**Framework areas** Personalised support Info and comms Continuity of care and transitions (including access) Care and support for people's needs **Narrative findings** This study highlighted the disjointed nature of support for homeless women. There were also positive examples of person-centred services. The findings are summarised under the four headings below. SUPPORTING WOMEN Many of the women had multiple key workers. One woman, said how she was 'getting all the support I need' from workers at a community-based drug treatment service for Black, Asian and Minority Ethnic adults as well as from a generic drugs project and a housing association (p348). But many women found it difficult engaging with multiple services in parallel. Participant 2 commented '…I think it's easier just to have one person to talk to' (p348). In terms of what individuals felt was an effective key worker, Participant 3 explained how she valued the consistent and non-judgemental support from workers based in a voluntary organisation. 'Cos I just gave up, you know. But they've never given up on me, even though I've made mistakes… and I've had my relapses and I've had whatever – their door's always open to me' (p348).	**Overall score** ++

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
with a retention rate of 58% over three rounds of interviews. Interviews explored specific events in women's lives, their current living arrangements and how their experiences and needs, including for social care, changed over time. **Country** UK England **Source of funding** Government National Institute for Health Research (NIHR), School for Social Care Research.	housing) and women at risk of homelessness (from tenancy breakdown). **Sample size** Despite the intention to recruit 40 women, the final sample was 38. At the second stage, 6 months later, 28 women were re-interviewed. At the final stage, 6 months later, 22 women were interviewed (i.e. eventually 16 women dropped out of the study). Of the numbers who dropped out, one woman could not be located; one woman was in a closed detox unit; and another was in prison; with the remaining 13 either wishing to abstain or being too busy. **Costs?** No.	Participant 2 explained that having a worker of a similar age with similar experiences was fundamental to her. Other women valued having a key worker who took a holistic, person-centred approach. Participant 4 explained how her worker from a local drugs project had supported her back into education. Her worker had: '...filled in forms to get funding, and like she knew who to get in contact with . . . which I wouldn't have a clue… and she came to college with me to try and like enrol me' (p348). It was not just key workers from specialist community services who took this approach. Participant 5 said staff in the refuge where she lived had liaised with various services on her behalf, including drug workers and social workers. Other women talked about the support that their key workers had provided in terms of accompanying them to medical appointments and supporting them with practical tasks, such as budgeting their money. Where women did not have a good rapport with their key workers, this was sometimes because the initial contact with a worker had been problematic (Authors, p348). FRAGMENTED SERVICES Women talked about the lack of co-ordination between services. The dispersed locations of services caused problems as described by Participant 3 in her first interview '...it's just when they pass you from pillar to post, from post to pillar… and that's what they're doing with me… the other day I had to go all the way to do an assessment, and then they wanted me to go to yesterday. That all costs money, buses and that …	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		or I have to walk it. And by the time I've done all that, I'm knackered…' (p349). Participant 6 described in her second interview the issue of conflicting advice about which services she could attend. '…If I'm going to one organisation I'd like the information and the advice I'm given to be consistent, so I don't come out even more confused than I already am.' Participant 7 said about services '…they occasionally fail to pass messages on, and that's cos they're all over the place…' (p349). Most of the women were attending one-to-one counselling and/or group sessions as a condition of the support they received, either from their housing agency or specialist support agency, and their experiences were mixed. Participant 8 said counselling had, 'Helped me with my anger like obviously… overdosing, self-harming, things from my childhood' (p349). But others found these sessions 'harrowing and unhelpful', while group sessions were universally thought to be intimidating and difficult to attend (Authors, p349). STATUTORY SOCIAL WORK SERVICES Several women revealed that they had been involved with social work services, either in their own childhood or as a parent involved with the children protection system, but did not feel comfortable discussing their experiences with services (Authors, p349). Despite the complex nature of their needs, none of the	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		women said they were in contact with social workers from adult services (Authors, p350). WOMEN-ONLY SERVICES The history of abuse and sexual violence experienced by women meant that having access to women-only services, including hostels, was often reported. Mixed hostels were seen as hostile environments. Participant 7 spoke of the respite she received at a women's morning at a specialist drugs project and the significant part this played in her care: 'Because it's just somewhere you can go and have a cup of tea and paint your nails and there's people there… if you need some support they can help you sort of thing' (p350). CHANGES TO SERVICES Over the duration of the research, the local authority re-commissioned some of its supported housing contracts; budgets of services were cut and the women-only night shelter closed. Women spoke of consequences such as not being able to have the same key worker anymore. Participant 7 commented: 'They had a whole massive mix up in a load of people had to be let go and they had a budget cut . . . so she isn't a support worker any more, she's got a different role in which is a shame'. She said that staff were having to support more women, appeared more stressed and had less time for individual women (p350).	

7. Clark J (2009) Providing intimate continence care for people with learning disabilities. Nursing times 105, 26–8

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Study aim This study aimed to answer the broad question: 'How do adults with severe and profound learning disabilities experience intimate and personal care?' **Methodology** Qualitative study Participant observation in residential care homes, staff interviews and analysis of documents (including support guidelines and organisational policies) were used to ascertain the personal care experiences of six people with learning disabilities. **Country** UK **Source of funding** Not reported.	**Participants** Older people receiving social care **Sample size** Data was collected over 10 months, during which time the delivery of intimate and personal care provided to six service users by 17 social staff was observed in two residential homes. **Costs?** No.	**Narrative findings** Data findings presented in themes which barriers are discussed within: 1. Naked. Service users were left naked while sitting on the toilet. Authors say this highlights issues of barriers to dignity. 2. Using the toilet as a seat. Not only were service users often left naked on the toilet, but they were also asked to sit on the toilet while other aspects of their care were carried out. Authors question if it is dignified to be shaved or have teeth cleaned while sitting on the toilet. Another key barrier is privacy. The authors argue this practice means it is not possible for residents to use the toilet without being observed by staff. 3. Being left waiting. The study highlights a disjoin between guidelines stating residents are to be asked at regular intervals if they need to use the toilet and what happens in practice, with examples of residents left for long periods without being taken to the toilet. 4. Being watched. The policies and procedures in both homes highlighted the need to maintain privacy and dignity during intimate and personal care. However, while doors were always shut while this care was delivered, other staff and service users often entered the room while someone was on the toilet or in the bath. On one occasion, when a man was on the toilet, at least three other people intruded. 5. Lack of discretion. The study highlights evidence of residents being spoken about in terms of their incontinence in public places such as kitchen areas.	**Overall validity rating** +

8. Colston G (2013) Perspectives on personal outcomes of early stage support for people with dementia and their carers. Edinburgh: Centre for Research on Families and Relationships

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim This research project seeks to identify the personal outcomes of early stage support provided by Alzheimer's Scotland Dundee Early Stage Support Service by conducting semi-structured interviews with individuals living with a diagnosis of dementia who are using the service, as well as their carers and the staff and volunteers who provide the support. Focus here is on the interviews with people with dementia. **Methodology** Qualitative study Semi-structured interviews with people recently diagnosed with dementia. The researcher was also a practitioner/manager of	**Participants** Older people receiving social care Professionals/practitioners Carers/family members **Sample characteristics** *Sex* 5 male. *Disability* People with dementia. *Sample age* 63–76, average age 70. *Level of need* People who have recently been diagnosed with dementia and living in the community and accessing the post diagnostic support service. One man had been using the service for four years, three men for one year and the other man for 18 months. **Sample size** 5 service users and 3 carers. 6 staff and volunteers.	**Framework areas** Active participation in lived experience of care **Narrative findings** The Five Pillars have been adopted as part of Scotland’s National Dementia Strategy and resulted in the Scottish Government making a commitment to ensure that everyone given a diagnosis of dementia is entitled to a year's post diagnostic support. The experiential perspective of individuals was analysed within this context and these pillars are: peer support; community connections; understanding the illness; planning for the future-decision making; planning for the future-future care. Peer support and community connections are the key pillars of support that people with dementia highlight as significant. PEER SUPPORT A male participant uses the service as a continuation of activities he has enjoyed all his life and having the opportunity to meet with others he gets on well with. 'Meet other people the same as me, the staff help as well.’ (Male participant 2, 72). 'Out and about meeting different people that was something, rather than sitting here all day. Meeting other people is the best part of it... . Otherwise it	**Overall score** -

Research aims	**PICO (population, intervention, comparison, outcomes)**	**Findings**	**Overall validity rating**
the service. Questionnaires conducted online with staff and volunteers, and interviews with carers not reported here. **Country** UK Scotland. **Source of funding** Government Funded through the Economic and Social Research Council. This programme also received support from the Scottish Government's Joint Improvement Team.	**Intervention** The model of support that has been developed is based around developing activities and supports for people who are in the early stages of dementia. This support includes individual and group activities and a Positive Dementia Support Group. Activities have depended on individual needs and wishes of those using the service and, for example, swimming, golf, ice skating, decoupage, gym, Tai Chi, allotment, History Group, Men's Group, Football Memories. In respect of this review, the Positive Dementia Support Group would be of relevance. **Costs?** No.	would be a long week looking out the window.' (Male participant 3, 70). COMMUNITY CONNECTIONS All the respondents described the importance of community connections – 'Along came Football Memories – right down my street, always loved football… I had lost my love of football when I was diagnosed; there was nothing in it for me. Football memories encouraged me to go back to football.' (Male participant 4, 63). 'Dementia Resource Centre – very, very normal, I'm in a situation where I am happy. It (the service) keeps me in touch with the real word. I wouldn't be able to go on without the service. I don't know what would happen to me. It's part of me now, part of my wife.' (Male participant 4, 63). UNDERSTANDING THE ILLNESS 'I didn't know what it was (when I was diagnosed), how it was going to effect me.... It upsets me, I speak to God sometimes… you must be doing this for a reason. I won't be any good to anyone. It get's me down a bit.' (Male participant 2, 72). 'W gave me all the books, read them for two weeks, started understanding it.... Now that I understand what it is I can accept it.' (Male participant 4, 63). PLANNING FOR THE FUTURE	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		In relation to planning for the future – whether it was future decision making or planning for future care, only one person with dementia discussed this. 'If things change…natural continuation of my care, more than happy at Morgan Street. I watched them at day care and its brilliant…that's really geed me up knowing that there will be care when I need it. Day care staff make a point of recognising you when you are there. I really want it to be at Morgan Street – the care.' (Male participant 4, 63). …'In relation to the Talking Points Outcome, this revealed that for the people with dementia using the service all were able to identify ways in which the service had an impact on their quality of life' (Authors, p7). • 'In the group there's different personalities, get close to each other and that's what keeps us going.' (Male participant 4) • 'It's alright going to meet folk and going to Craigie Bowling Club.' (Graeme) • 'Keeps me involved and I can't do that at home.' (Male participant 2) • 'Getting out and about meeting different people and getting transport. If I didn't have transport I couldn't go anywhere.' (Male participant 3) The author note on page 7, in terms of 'process', people were very keen to praise the support provided by	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		staff and this may have been emphasised, as the participants were aware that the researcher was the overall manager of the service. - 'Coming into a new situation and finding staff really respect you.' (Name not provided) - 'Encouraged to be positive. No-one has ever said poor Joe.' (Male participant 4) - 'I'm alright the way it is I like the company, if the staff wasn't good I wouldn't be long in telling you.' (Male participant 1) - 'They look after you really well.' (Male participant 2) 'All the staff are very helpful, I can ask them anything. All the staff in Morgan Street. In that way it's really helpful to me.' (Male participant 3)	

9. Cook G, Brown-Wilson C and Forte D (2006) The impact of sensory impairment on social interaction between residents in care homes. International Journal of Older People Nursing 1, 216–224

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Study aim The aim was to draw on older people's narratives to illuminate the experience of living in a care home and the impact that vision and hearing impairments	**Participants** Older people receiving social care **Sample characteristics** Sample age First study participants were aged between 52 and 95 years. Second study participants were aged 70–100 years.	**Narrative findings** The authors suggest that the cross-cutting analysis from both studies highlights the difficulties residents experience in interacting with others, in the home, as a consequence of sight or hearing impairment, and the potential impact this had on feelings of social iso-	**Overall validity rating** +

Research aims.	**PICO (population, intervention, comparison, outcomes).**	**Findings.**	**Overall validity rating.**
have on the individual's ability to engage in social interactions with other residents**.** **Methodology** **Qualitative study** The paper draws on two research studies, The first study, 'a hermeneutic inquiry examining the meaning ascribed to living in a care home' and the second study, 'a constructivist study, exploring relationships between residents, families and staff'. 'Both studies drew on older people's narrative accounts to explore their experiences of living in a care home. On independently interpreting the narratives, a similar theme emerged around the challenges to social interactions experienced by residents with sight and/ or hearing impairment. This resulted in a cross	**Sample size** Paper draws on two studies. The first study involved 53 interviews with people aged between 52 and 95 years, who had lived in four different care homes between 1.5 and 6 years. The second study involved 18 residents (aged 70 to 100 years) who lived in one of the care homes within this study. **Costs?** No.	lation. They argue this point is illustrated through narratives from two residents, one with sight impairment and the other with hearing loss. They also say that the narratives show the problems these people encountered and how resilient they were in adjusting to their sensory loss and maintaining social interactions. There are several findings within the main text that relate to how older people discuss their sensory impairments. Below are examples of where explicit reference is made to service use. Summarising across the accounts, in terms of barriers, the authors comment: That as staff in care homes are in a position to know people's backgrounds, this helps to facilitate introductions between residents which is positive for building friendships between residents (Authors, p221). The importance of this is exemplified in this account from a resident: 'There are two people I sit near and I can hear to talk with, everyone else is so far away. I would be lost without them. I can talk to [resident 1] because I can hear her. She keeps me up to date, I usually have to ask her what's for dinner. There can be somebody next door to her and I just can't hear them. I should feel lost if there wasn't the three of us. If [resident 1] and [resident 2] weren't here, I would be lost' (Resident, p220). That residents with marked sensory impairments may be without specific 'label' or diagnosis, making it difficult for staff to acknowledge a resident's problem (Authors, p222).	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
study analysis to further illuminate this theme' (p216). The first study involved 53 interviews with people aged between 52 and 95 years, who had lived in four different care homes between 1.5 and 6 years. The second study involved 18 residents (aged 70 to 100 years) who lived in one of the care homes within this study. Data in this home was collected through six semi-structured interviews with residents, 100 hours of participant observation and two resident focus group interviews. **Country** UK **Source of funding** Not reported.		That key to supporting older people with vision and hearing impairments is "ensuring that equipment is well fitted, positioned correctly and in good working order. However, nurses have been found not to have the awareness, knowledge or skills to achieve this (Authors, p222). Additionally, residents with sensory impairments spoke about the need for consistency in settings and the environment they were living in: 'I used to go down to the sitting room which is beautifully decorated with lovely armchairs and lovely furnishings and photographs. Really nice you couldn't get it more homely. They keep changing things around which makes things worse for me. Never mind' (Resident, p220–21).	

10. Cook G, Thompson J, Reed J (2015) Re-conceptualising the status of residents in a care home: older people wanting to 'live with care'. Ageing & Society 35, 1587–1613

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Study aim The aim of the study was to help older people to tell their stories of life in a care home. This paper examines the complex issues surrounding the residential status of care home residents in terms of basic human needs. The authors note that not many studies in care homes have extended engagement with residents to explore their views, and furthermore, a lot of existing research has focused on the move to a care home, rather than life within a care home. Hence this study is novel in that sense. **Methodology** Qualitative study 'This study was a biographical investigation that sought to explore	**Participants** People receiving social care Older people recruited from diverse types of care home including one 20-bed nursing home, a 40-bed dual registered home, a 78-bed dual-registered home, and a 40-bed nursing/residential and high-dependency elderly care home. **Sample characteristics** *Sex* Seven female and one male resident. *Sample age* Aged between 52 and 95 years. *Level of need* Older people recruited from diverse types of care home including one 20-bed nursing home, a 40-bed dual registered home, a 78-bed dual-registered home, and a 40-bed nursing/residential and high-dependency elderly care home. Had lived in these homes for one and a half to six years. **Sample size** Eight older people and each resident	**Framework areas** Respect, dignity and control Personalised support Active participation in lived experience of care Care and support for people's needs **Narrative findings** Much of the existing research has focused on the move to a care home, instead of living in a care home. This study does the latter, hence its uniqueness. Five themes emerged that collectively show that residents wanted their residential status to involve 'living with care' rather than 'existing in care'. The five themes were: 1. 'CARING FOR ONESELF/BEING CARED FOR' Acute and chronic illness, disability and increased frailty were major reasons that limited participants' ability to carry out one or more self-care or health-care need and precipitated a move to a care home. Most participants indicated that depending on others in the care home environment was challenging where staff had little knowledge of their preferences and dislikes. One female resident explained: 'They put things on me and I haven't seen them for months and months. I don't know where they get them from. One day you have a vest on and the next day you haven't. I had no vest on today. She was just going to put my blouse on and I said, 'Oh I have to have something on	**Overall score** ++

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
the meaning and meaningfulness that older people attribute to their experiences of living in a care home. The research design followed Gadamer's (1975,1976,1989) hermeneutic dialogical process, in which a dialogue is created between the researcher's and the participant's understandings of particular phenomena, with a view to attaining a greater appreciation of the participant's stance' (p1591). Multiple interview approach to explore the narratives in depth. **Country** UK **Source of funding** Not reported.	was interviewed up to eight times over a period of six months. **Costs?** No.	inside my blouse, you can see right through this' (p1595). Participants endeavoured to remain as independent as possible within the care context. A male resident said this improved his quality of his life: 'Oh I can control my own life … and that is a big thing. You know I wouldn't like to keep having to ask the staff to take me here or to do this for me or do that. When you can do it yourself it is much better. It makes it, it makes your life more pleasant' (p1596). 2. 'BEING IN CONTROL/LOSING CONTROL' The participants described situations and events where they were able to make decisions and act on them. However, there was also evidence that residents did not feel able to have a say about the day-to-day management of the care homes where organisational systems were staff-centred. A female resident reluctantly accepted the dining room seating arrangements: 'I sat at a good table once where they were very nice and friendly. We have single tables now. We used to have a long table where everyone sat down. Now we have tables of four all over and it depends on the table that you sit on . . . it is not as much fun as before' (p1598). 3. 'RELATING TO OTHERS/PUTTING UP WITH OTHERS' Communications with staff were largely classified as 'functional and relational'. Functional interaction, the most widespread, emerged from care practices and was concerned with identifying and dealing with residents' needs. Relational interaction involved sharing	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		personal or topical information that was of mutual interest and opportunities for residents to experience 'companionship and reciprocity within the routine of their daily lives' (Authors, p1600), but was compromised by high staff turnover and demanding staff workload. For example, another female resident described how this had a significant impact on her, making her feeling: 'Very upset. You never know who is going to walk through the door when you wake up in the morning and when they bring your breakfast in. You ask their name and you ask that half a dozen times during the day because you have forgotten and the next thing you know they have gone and they don't even say goodbye – they just disappear' (p1600). Participants with limited mobility had little choice regarding contact with other residents and were almost totally reliant on staff to facilitate access to public areas of the home. 4. 'ACTIVE CHOOSERS AND USERS OF SPACE/OCCUPYING SPACE' Separate rooms allowed participants to nurture private lives with family and friends. But small room size restricted their options in terms of furnishings and fittings. Furthermore, some appliances and services were unavailable to residents (e.g. private telephone lines and internet), which meant that some activities could not be kept discreet (e.g. telephone conversations using the care home's line). None of the participants had locks on their rooms, and staff often entered residents' rooms without asking; participants,	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		however, felt that this was standard practice and did not complain. 5. 'ENGAGING IN MEANINGFUL ACTIVITY/LACKING MEANINGFUL ACTIVITY' Participants described the 'sameness of it all', a female resident explained: 'I get up, helped to get ready, have breakfast and then I would be taken to the day lounge. Then lunch, then tea and then back to bed. That is how it is, every day!' (p1604). Most significance was placed on activities that provided a goal or purpose or created a sense of fulfilment or achievement, e.g. activities with family and friends. The role of activities co-ordinator and support of staff were seen as paramount in this respect. Limited resources affected the range of activities available, e.g. transport problems and staffing issues restricted excursions and outings with friends and family.	

11. **Cooper C, Dow B, Hay S et al. (2013) Care workers' abusive behavior to residents in care homes: a qualitative study of types of abuse, barriers, and facilitators to good care and development of an instrument for reporting of abuse anonymously. International psychogeriatrics / IPA 25, 733–41**

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Study aim Not stated but within background section says: "to ask care	**Participants** Carers/family members Staff working to provide social care to adults with dementia in residential care homes. Care worker 8 (22%);	Narrative findings Page 734: Discussions focused on barriers to delivering good quality dementia care. Care workers were encouraged to give examples from their practice of	**Overall validity rating** ++

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
home workers to report abuse anonymously". **Methodology** Qualitative study Qualitative focus groups with 36 care workers from four London care homes, asking about abuse they had witnessed or perpetrated. **Country** UK Older people's nursing and residential homes in inner and outer London. **Source of funding** Not reported	Care assistant 18 (50%); Registered mental nurse 2 (6%); Social worker 1 (3%); Senior worker or manager 7 (19%); Working full time 33 (91.7%); Hours worked per week 34.8 (2.8; 21–40). **Sample characteristics** Sex 26 (72%) Ethnicity Filipino 11 (31%); Black British 9 (25%); White 8 (22%); Chinese 2 (6%); Asian 1 (3%); Mixed or others 5 (14%). Sample age 44.5 (11.9; 23–67). **Sample size** Focus groups were facilitated by two to three researchers (SH, CC, and DL), lasted 60–90 minutes, and had 6–13 participants (Table 1: 36 participants in total from 4 focus groups). The four care facilities were as follows: a local authority residential care home for older people with dementia, a charity run residential care home providing personal and dementia care, a private nursing home for people requiring general and dementia nursing, and a private residential care home for older people specialising in dementia care.	situations when good quality care had not been delivered or when they had been concerned that abuse had occurred. Page 736: Reports of abusive behaviours witnessed could mostly be divided into three categories: (1) Situations which the care workers thought were due to insufficient resources or competing demands, such as residents waiting too long for personal care or being denied care they needed to ensure they were moved safely or were not emotionally neglected. (2) Instances when staff acted in potentially abusive ways, which they judged better for residents than alternatives; for example, care workers made threats in order to coerce residents to accept care, or restrained them, as they saw no alternative way of keeping them clean; and a resident at high risk of falls was required to walk as care workers were concerned that otherwise he would forget the skill. (3) Situations related to institutional practices; for example, residents not being given enough time to eat meals because of kitchen closing time. One caregiver described an act of deliberate physical abuse that took place in an earlier employment. Page 737: "Bureaucracy was frequently raised as a barrier to providing high-quality care.” "A lack of information about residents was also perceived as a cause of poor care.” "All the groups gave examples of how inadequate staffing levels or problems with equipment could result in negative outcomes for residents." Page 738: "All the groups discussed care workers feeling undervalued, ignored, underpaid, or blamed when things went wrong or not wanting to do the job and that this led to abusive practice." "…a greater likelihood of lower quality, including abusive care by staff that did not want to do the work.” "Care workers felt	

Research aims.	**PICO (population, intervention, comparison, outcomes).**	**Findings.**	**Overall validity rating.**
	Costs? No.	hurt by or angry toward residents who reacted badly to them and this may have made problems worse.” Page 739: "Care workers in all the groups described abusive situations occurring due to insufficient resources or competing demands, such as residents waiting for personal care, or being denied the attention they needed to have enough to eat, to be moved about safely, or to meet their emotional needs." Page 740: "There are legal, employment, and social barriers to care home workers reporting abuse they have witnessed or perpetrated, but they are the most likely to witness abuse."	

12. Fleming J, Brayne C and Cambridge City (2008) Inability to Get Up after Falling, Subsequent Time on Floor, and Summoning Help: Prospective Cohort Study in People over 90. BMJ (British Medical Journal) 337, 1279–1282

Research aims.	**PICO (population, intervention, comparison, outcomes).**	**Findings.**	**Overall validity rating.**
Study aim To describe the incidence and extent of lying on the floor for a long time after being unable to get up from a fall among people aged over 90; to explore their use of call alarm systems in these circumstances.	**Participants** Older people receiving home care 90 women and 20 men aged over 90(n=110), surviving participants of the Cambridge City over-75s Cohort, a population based sample. Participants’ usual place of residence (own homes or care homes), mostly in Cambridge. Older people receiving social care Participants’ usual place of residence (own homes or care homes), mostly in Cambridge.	**Narrative findings** Barriers to using alarms arose at several crucial stages: not seeing any advantage in having such a system, not developing the habit of wearing the pendant even if the system was installed, and, in the event of a fall, not activating the alarm— either as a conscious decision or as a failed attempt. These are detailed in box 1 on page 6: All DIRECT QUOTES FROM PAGE 6: 1. Examples of not wanting/having a call alarm: “My niece is only next door. I can bang on the wall if I need to call help.” Daughter’s comments: She refuses to have a call alarm because she thinks it would keep going off by mistake. She is worried enough about the string pull alarms in each room [sheltered housing scheme] and often won’t turn on	**Overall validity rating** ++

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Methodology Mixed methods Follow-up of participants in a prospective cohort study of ageing, using fall calendars, phone calls, and visits. Data were collected on the immediate consequence of falls among participants of a population-based study—the Cambridge City over-75s Cohort (CC75C). The methods have been described in detail elsewhere for the cohort overall (www.cc75c.group.cam.ac.uk), a longitudinal cohort study of older old people. This cohort initially recruited participants through general practices in the 1980s, when they were all aged 75 or over. Repeated surveys since baseline have gathered data on a range of variables including sociodemographics,	**Sample characteristics** Sex 90 women and 20 men aged over 90(n=110). **Sample age** Table 1, page 2: All participants (n=110): Mean (SD) 94.4 (2.4) Participants with ≥1 fall reported (n=66): 94.6 (2.6) Participants with no fall reported (n=44): 94.2 (1.9) Level of need Page 3: Participants were predominantly frail—most were unable to climb stairs, nearly a third were unable to walk outdoors, one in 10 were housebound, and about one in three were severely cognitively impaired. **Sample size** 90 women and 20 men aged over 90(n=110), surviving participants of the Cambridge City over-75s Cohort, a population based sample. **Costs?** No.	the kitchen or bathroom lights in case she pulls the wrong cord by mistake.” 2. Having a call alarm but not wearing it “I have got one but I don’t have to wear it yet, I just hang it on the back of the chair there.” “I wasn’t wearing my pendant. I don’t usually wear it . . . It was quite a struggle to get up. It took about half an hour. My sister pushed me across to the sofa bed and we used that to help get me up...I’ve been thinking after you asked last time, maybe I should wear it when my sister is out.” “I’d already taken it off ready for bed and put it on the bedside table then I couldn’t reach it.” [Lost balance getting undressed, was on the floor all night until next morning finally attracted the attention of someone delivering a newspaper by calling through the door bell intercom] 3. Examples of wearing but choosing not to use it: “I wanted to be able to get up by myself. It took me a long time to get up but I did it in the end. It makes me annoyed if I have to have help.” [Fell bending down to pick up a letter at the door] “I didn’t want to use the call alarm, although I was wearing it, for fear of being taken into hospital.” [Trying to stand up from the toilet, fell on her back] “I grabbed the portable arms round the loo when I lost balance but they tilted. I took quarter of an hour to shuffle from the bathroom through to the sitting-room so I could pull myself up on an armchair.” “Didn’t need to.” [He stood up from a stool after washing his feet in a bowl on the floor and fell backwards. Difficult getting up—pulling himself up by the sink he fell backwards again, but still didn’t use his call alarm] Difficulty in activating alarm “I couldn't have reached the alarm...like, well, I’ve got the frame but I can’t always reach it.” [Fell trying to get from bed to commode	

Research aims.	**PICO (population, intervention, comparison, outcomes).**	**Findings.**	**Overall validity rating.**
physical and mental health, function, and detailed cognitive assessment that included the mini-mental state examination. All those who took part in the 2002–3 survey (90 women and 20 men) were followed up in a prospective study of falls for one year or until death if sooner. Data recorded after each fall included whether the individual who fell had been able to get up without help, how long they were on the floor, any injuries, and whether they called for assistance. **Country** UK Participants' usual place of residence (own homes or care homes), mostly in Cambridge. Source of funding Government This study was sup-		while in hospital] "I tried to call Care Call but the pendant didn't work because there'd been a power cut the day before." [The trolley he was walking with tipped up and he went over too, got himself across floor to climb up onto armchair in about 10 minutes, then waited a couple of hours for his carer to come]. "I was wearing my alarm but I didn't think it would work out there in the street so I didn't even try it." [Lost balance at the gate, fell on pavement outside her flat] "Is at the kerb trying to get up but I couldn't. After what seemed like ages a car came by and a man wound down his window to ask if I was okay. He helped me up and back indoors." "It always seems a long time when you're waiting but I don't suppose it was really." [Found on floor by carer, confused. She had not set off the alarm, although she thought she had]	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
ported by an NHS executive research and development unit health services research fellowship. Pharmaceutical Supported by the BUPA Foundation.			

13. Fleming J, Glynn M, Griffin R et al. (2011) Person-centred support: choices for end of life care. London: Shaping Our Lives

Research aims.	PICO (population, intervention, comparison, outcomes)	Findings.	Overall validity rating.
Study aim The aim of this study was to collect the views of residents, their carers or relatives of older people living in five independent care homes and staff in those homes on the barriers to person centred support at the end of life and how these barriers might be overcome. This was part of a larger project called 'the Standards We Expect' aimed at guiding the development of systems and processes to support social care service users to determine how their rights/needs are met, through user involvement and negotiation among key stakeholders, and dialogue with a wider network.	**Participants** Older people receiving social care Professionals/practitioners Carers/family members Administrators, commissioners, managers **Sample characteristics** Sex SERVICE USERS: 6 were female and 2 were male. RELATIVES: 10 were female and 4 were male. Practitioners/Managers: 16 were female and 2 male. Ethnicity SERVICE USERS: All stated their ethnicity as White British. RELATIVES: All stated their ethnicity as White British.	**Findings** Study conducted over a period of a month in August and September 2007. BARRIERS Lack of EOLC discussions – Many residents said they had not talked about end of life decisions; only some said they had discussed EOLC with their relatives or care home staff; none had spoken to their GP. Only one resident had recorded decisions about their end of life. But it was uncertain if these extended beyond the subject of her funeral and will: No one had advanced care directives. Is planning for end of life care person-centred? Residents spoke about family deciding what would happen to them when	**Overall validity rating** +

Methodology Qualitative study stages involved: • Collecting statistics about the number of people who are admitted to hospital and what the outcome is. • Reviewing existing research on end of life care to identify key messages to inform research questions. • Collecting views of older people living in independent care homes, their relatives and carers and also staff on end of life care, barriers to person centred care. • Preparation of a report of the findings. • A seminar for all stakeholders to review the information and develop a plan of action involving carers and service users. **Country** UK **Source of funding** Voluntary/Charity Joseph Rowntree Foundation	PRACTITIONERS/MANAGERS: 11 stated their ethnicity to be White British. 4 described their ethnicity as Black African, 2 as Black Caribbean and 1 as Pakistani. **Sample age** SERVICE USERS: Average age was 82.6 years old. RELATIVES: Average age was 65 years old. PRACTITIONERS/MANAGERS: Average age was 46 years old. Level of need SERVICE USERS: The average time the service users had been living at their nursing or residential home was 2 years and 10 months. **Sample size** 33 people and a focus group of a further seven carers and relatives broken down as follows: 8 service users. 14 relatives 18 individual practitioners and managers. **Costs?** No.	the time had come, but that in some cases decisions were not written down. One resident said that no one had talked to her about her wishes as she approached the end of her life, but she did not mind this: "No, I don't want them to...I have got it on my mind all the time and it doesn't go away. I don't like being over-powered with it" (Resident, p15). Reluctance of staff to talk with residents about end of life - This was one of the most significant barriers to choice in EOLC. "It is very difficult when you don't know them, it is easier when people have been here a little while and you have got to know them a little bit better...if I am doing the general pre-assessment I will probably leave that question until a little bit later on in the assessment so at least you have got a little bit of a feel for how that person is feeling at the time" (Practitioner, p20). One resident had planned his end of life needs with his son and daughter-in-law and knew that they had been discussed with the care home staff who had 'not really' talked these through with him. Finding the right time to discuss end of life wishes – Staff generally felt that end of life discussions with residents and relatives were	

		not appropriate when the resident first moves in: “We do do the basic care plan within 48 hours of them coming in. But things like end of life care we have a specific page in the care plan for death and dying, and so we tend to get to know them a little bit better and speak to the relatives and try to formulate something they are happy with” (Practitioner, p21). The impact on families and carers of end of life planning – Families can experience immense stress and guilt, which sometimes led to disagreements between relatives and residents about end of life issues. Concern that relatives were making decisions on behalf of residents – Many relatives were making important end of life decisions for their loved one with minimal resident participation, for example in relation to completing paperwork: “If they (residents) are capable of signing, if not it would be the next of kin who would be responsible for it” (Practitioner, p23). One relative spoke of paperwork about end of life decisions being filled in by her family without discussion with the resident, despite nothing to indicate that the older person was incapable: “I don’t know whether they (staff) have dis-	

		cussed it with her but we ourselves have signed a form, a ‘no resuscitation.’ … Me and my sisters have spoken about it, we have not discussed it with my father, he is 87, and we decided we didn’t want resuscitation. But I don’t think it has been discussed with her (mother) because I don’t think she would understand. …We haven’t spoken to her because death to my mother is a bit of a no, no, she doesn’t want to know about it” (Relative, p23). Staff attitudes – One resident said she felt staff attitudes were a barrier to person centred care at the end of life: “Attitude, the attitude of some carers is wrong, they like to boss old people about and say we are in charge, they are not, they are doing a job” (Resident, p24) Funding and staffing levels – Some interviewees mentioned a lack of staffing and funding constraints which had a negative effect on good practice in care for people in end of life care. “We could always do with more resources, we could always do with someone additional to sit with people in the end of life stages, I don’t believe that anyone should be left on their own… that can be a problem” (Manager, p25). Agency staff –	

		Support from staff who were acquainted with residents, as the end of their lives neared, seemed to vary between homes. “When agency staff are on my mum has sometimes no teeth in, she is a poor eater any way and with no teeth… Since the changeover in January in a short time three hearing aids just disappeared and she is really fretful, she needs her hearing aid and when she hasn’t got it she is really disorientated she is really agitated. So when things happen like that it is really distressing and it happens more when agency staff are on” (Relative, p27). People who chose to die at a care home being admitted to hospital - This was a major barrier to choices in end-of-life care. Staff spoke of the need to have the correct end of life paperwork signed by all required parties, including GPs. Without these signatures, problems could arise where residents were admitted to hospital when they had previously expressed a wish not to be. DNAR from hospital: it was not always clear if a ‘DNAR’ from hospital applied in other circumstances. One traumatic incident occurred where a resident was resuscitated in front of her family, as a DNAR	

		form supplied for an earlier ambulance journey from hospital was no longer valid. A lack of prior discussion and planning can lead to difficult decisions as the end of life approaches: “...we had an instance that we had a lady who we had to ring 999 for, the lady was nearly 100. And when they all got here, ... they were just about to take her off to hospital, and her daughter said ‘No I don’t want her to. Is she going to get better? No, leave her here, I want her to die here where she is loved and cared for” (Practitioner, p30). Fear of blame – Several practitioners were worried that if they followed residents’ wishes about not being resuscitated or taken to hospital at the end of their lives, this could lead to criticism and blame for neglect for letting an older resident die naturally. Cultural differences at the end of life: There was an absence of residents from ethnic minority groups: “We haven’t had any experience here… Oh we have, at the time it was a bit of a panic, it was a Jewish gentleman that passed away and we had a bit of a panic trying to find a Rabbi… At the moment if anything happens then we would probably need to refer to the policy book, generally phone round for specific	

		advice or advice from the family hopefully" (Practitioner, p34).	

14. French S and Swain John (2006) Disabled people's experiences of housing adaptations. In: Clutton S, and Grisbrooke J eds, editors. An Introduction to Occupational Therapy in Housing. London: Whurr Publishers Ltd

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Study aim The section of the chapter entitled 'Disabled people's experiences of housing adaptations' is based on interviews with disabled people who have had considerable experiences with housing and considerable contact with occupational therapists in the recent past. Four interviews focus specifically on housing issues and were conducted for the specific purposes of this chapter; three others explore the relationship between occupational therapists and clients more generally. The authors aim to gather some "real world" experiences for	**Participants** People receiving social care **Sample characteristics** *Disability* People with physical disabilities **Sample size** Seven disabled people **Costs?** No.	**Framework areas** Respect, dignity and control Personalised support Care and support for people's needs **Narrative findings** BARRIERS 1. CHOICE AND CONTROL When communication breaks down, or there is a power imbalance, choice and control is challenged. The resistance to the power relationship with the OT is described in a female participant's experience and words such as 'battle': 'What I did find incredibly difficult to come to terms with was somebody coming into my home and saying, 'This needs to be done and this is how it's going to be done.' I had no say whatsoever to the point where…well one of the things is the front door which is completely flat because I'm in a wheelchair. I could cope with a small rise very easily and I demonstrated that I could manage. What happens now is that whenever you open the door the leaves blow in because it's so flat. I had quite a long argument, added to which the builder had difficulty finding such a flat front door' (p14). She continues to describe: 'The only battle that I won, and it was a major	**Overall score** +

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
the purpose of illustrating some of the qualities users value in occupational therapists and some of the problems that may occur in therapy from the user's viewpoint (Authors, p10). **Methodology** Qualitative study Seven targeted interviews with disabled people - four focus specifically on housing issues and three explore the relationship between occupational therapists and service users more generally. **Country** UK **Source of funding** Not reported.		argument that held up all the work for about three months, was that they wanted to lower all the work tops in the kitchen to my height and I kept pointing out that there were three other members of the family and I didn't want to have to do all the work! What we actually did was a carpenter friend of mine put rollout tops under the existing tops so I have something my height and they've got something at their height. It was as if I was living on my own and that the property was theirs' (p14). 2. BEING LISTENED TO Another female participant, describes significant problems in being listened to or believed. For example, she had problems closing the backdoor to her block of flats and the other tenants started to complain that the door was being left open. 'So I started to get notices pinned on the back door that said, "Please keep this door locked at all times, close the door". And if I put two wheels over my ramp they would slam the door even if I was going into my garden area and I've always had to have keys to get back in. An OT visited me… and I explained that I couldn't drive the wheelchair and shut the door and she said could they attach a hook thing on to my shoulder that would hook on the door and, if I was able to manoeuvre the chair properly, this hook would grab on to this other thing and the door would shut behind me. And I thought "Well I might get decapitated or something." I said, "I don't think that's going to work." It took many, many months for the OT system to put this right. I had to demonstrate that I couldn't actually shut the door to three different people…Then they said yes I could have my remote on that door' (p16).	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		3. OT CONSTRAINED BY SYSTEM A third female interviewee, felt that occupational therapists are constrained by the system. ‘I think the difficulties have been with the previous OT. She was all too aware of what she was allowed to recommend from a financial point of view and she was very aware of what the process was ... But instead of saying... “We aren’t going to get funding for a downstairs toilet until M is eight because that’s the way the system works”, if she’d said “Yes I really feel that M is entitled to a downstairs toilet, of course he should have a toilet, but I just cannot get it for him,” then I could have understood that. But she didn’t, she kept saying that until he’s eight he doesn’t need a toilet downstairs. And she’d turn up with commodes and all sorts of ridiculous equipment’ (p16). 4. POWER IMBALANCE The provision of designs and equipment and the type of relationship initiated are elements that are part of the development of a power relationship. For instance, another participant found her occupational therapist distant and rigid and was helped by a friend and her carer when OT equipment could not be used: ‘When I got home the social service OT came and she started as if it was day one with a big assessment when I’d had the whole thing done in hospital. I was ill and in a lot of pain, sick most of the time, couldn’t eat, and I couldn’t be doing with it. I thought, “Just go away, just go to the hospital and they’ll tell you everything you want to know.” She was neutral. She was just doing her job with her clipboard. I can’t remember her name - she was just a professional. She came back to say that there was a waiting list for this bath	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		thing so I'd have to have bed baths for three months from the carer. Finally this thing arrived, none of us knew it was coming, it came with a man in a van – a lovely, friendly man with this contraption – but it didn't fit. We got to "breaking rule time" then which meant "blow what they said." My friend and my carer got these two boards and they made a slide system to the bath. The OT didn't help one bit. When we told her the contraption wouldn't work she said "Well, that's that then, it will have to be bed baths." She never came again' (p17). FACILITATORS 1. CHOICE, CONTROL AND PARTNERSHIP Where user choice and control exists alongside a genuine working partnership with the occupational therapist, creative and satisfactory solutions can be found. A mother and son's examples portray this where occupational therapists understood and supported their wishes. The mother believes that the OT assigned to her son is constrained by finance, but, despite this, she supports the mother and not the system. 'She makes recommendations that are clearly based on what she believes to be right and she listens and she's prepared to alter according to family circumstances. An example of that would be when she originally looked at our old house for rails around the house, she made the recommendation, came back for comments, and took on board what I had to say, and made some alterations. She's also got off the fence and written to local authorities, complained and pleaded with them to alter curbs, pavements,	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		roads around the house. It is not part of her brief really but she is prepared to do that' (p17). The son describes: 'When I was being offered accommodation by the local authority and the housing association it was very useful to have the OT there who could say "Well no, that's not actually suitable for this person." That I found useful because I felt very pressured to just take somewhere to live whenever I was offered somewhere. I was in crisis and I was thinking "No this isn't right, this will not work" and I was really worried that I wouldn't be able to get out…I found that they reassured me and fought my corner, which was to say "Don't you worry, stop in that short-term accommodation as long as you need to, until it's right for you, don't feel pressured to take something that's 75% of the way towards something you are after if you physically can't cope with it"…So I think they give you psychological support as well because of their expertise when everyone else was saying, "Well it's a disabled flat so just get yourself in there"' (p18).	

15. Gajewska U and Trigg R (2016) Centres for people with intellectual disabilities: Attendees' perceptions of benefit. Journal of Applied Research in Intellectual Disabilities 29, 587–591

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim The study aims to explore the perceptions of people with intellectual disabilities of the	**Participants** People receiving social care - People with intellectual disabilities who attend a day and community learning centre.	**Framework areas** **Care and support for people's needs** The study investigated whether the day centre was supporting the participants by meeting certain identified needs:	**Overall score** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
benefits of attending day and community learning centres, and whether the stated goals of the centre studied by this piece of research, of providing social support, life skills and greater control by attendees over their lives, are being met. **Methodology** Qualitative study Unstructured individual interviews. **Country** UK – East Midlands. **Source of funding** Not reported.	**Sample characteristics** Sex – 4 male, 3 female. Sexual orientation – Not stated. Disability – All have intellectual disabilities, and are described as having 'a mild level of disability' (587). Ethnicity – Not stated. Sample age – 'approximate age ranged from 23 to 54 years' (p588). The report stated that participants' true ages were not used, to protect their anonymity. Level of need – Participants described as having a 'mild level of disability' (p588). Socioeconomic position – Not stated. **Sample size** Sample size – There were 7 participants in the research. **Costs?** No – Not stated.	– addressing people's isolation from their communities through enabling them to form relationships with other attendees, staff and volunteers – enabling them to socialise with people who have had similar life experiences to them, so reducing loneliness – helping attendees to become more independent and find employment by helping them to develop life skills and acquire qualifications. The study found that most participants had acquired new skills, leading to them having greater confidence in themselves and their abilities. Feeling proud of what they had achieved also made them feel more confident. Participants report having an improved self-image: "I'm a better person for it. I'm not a bad person" (p589). Participants also report feeling a sense of purpose: "I've got something to do with my life" (p589) instead of being 'bored' or 'wasting their life away' (p589). **Narrative findings** The report provides a list of the themes that it states emerged from the data provided by the interviews, comprising 4 themes (Skills, Social support, Control and Self-image) and 11 sub-themes. However the report does not supply the findings for all of these headings, and focuses exclusively on themes of 'internal control' and the three sub-themes, which come under the theme of 'Self-image'. The report finds that:	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		Internal control 'Some participants reported having better control over their emotions and behaviours after attending the centre. This was partially due to greater understanding of others and their perspectives' (p588–9). An example is provided of one participant who became less argumentative and more tolerant of others: *'People said that, even "J" said I've changed. "P" said when I first came here I was abrupt which means quick temper, something to do with temper isn't it? Yeah, angry. But I calmed down a hell of a lot'* (Participant, p589). Self-image: confidence The authors' state that 'most participants expressed greater confidence in themselves and their abilities, following the mastery of new skills' and became more confident socially through learning to deal with unfamiliar situations (Authors, p589): *'[Before attending the centre] I wouldn't have done the pack bags at Asda and it's talking to other people because it's the people who need the bags packing... I wouldn't have done that couple of years ago but I'd do it now'* (Participant, p589). Self-image: self-worth The authors comment that participants spoke about having increasing respect for themselves, which included recovery from maltreatment, and that being praised for their work helped achieve this recovery:	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		'Started liking myself... Pff, I never liked myself...Obviously [because of] the way that I've been brought up, the way I've been treated over the years. That's all changing and I'm a better person for it. I'm not a bad person' (Participant, p589). Self-image: purpose The authors describe centres providing participants with different opportunities, which gave them a sense of purpose such as enabling them to carry out activities to benefit other people: *'Yeah it made me more erm happy. I've got something to do with my life, like helping other people, raising money for other... erm things to do here and all that so it is–it's a good thing'* (Participant, p589).	

16. **Glendinning C, Clarke S, Hare P et al. (2008) Progress and problems in developing outcomes-focused social care services for older people in England. Health & Social Care in the Community 16, 54–63**

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Study aim This paper examines some of the practical challenges in the planning, commissioning, and delivery of outcomes-focused social care services and the ways in which they can	**Participants** Older people receiving social care. Professionals/practitioners managers and practitioners (postal survey element). **Sample size** Postal survey – From 222 adult social care managers and practitioners in	**Findings** The research, a postal survey and case studies in six localities, was conducted between June and December 2005. Note: Change outcomes relate to improvements in physical, mental or emotional functioning. Maintenance outcomes are those that prevent or delay deterioration in health, wellbeing or quality of life. Process outcomes refer to the experience of seeking, obtaining and using services.	**Overall validity rating** ++

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
be addressed by drawing on a recent study into the progress of social services departments in England and Wales in delivering outcomes-focused services for older people (Glendinning et al. 2006). The research, involved a postal survey and case studies in six localities in England and Wales. **Methodology** Mixed methods A postal survey (using quantitative and qualitative measures) and case studies in six localities. **Country** UK England and Wales **Source of funding** Government Department of Health, as part of their programme of social care research at the Social	England and Wales known to be interested in developing outcomes-focused services in all across England and Wales, 54 responses returned. Case study – across the six sites, 82 staff and 71 service users took part in interviews or discussions. **Costs?** No.	CASE STUDIES SERVICE COMMISSIONING – change outcomes All the case study sites had recently established intermediate care and re-ablement services. Staff working in re-ablement and rehabilitation services voiced concerns that, where significant change outcomes had been achieved, these were not always maintained in the provision of longer-term support: 'It gets so far, then it’s out of our hands and we can’t follow it through. The end result, we don’t know...’ (Re-ablement service manager, p59). SERVICE COMMISSIONING – maintenance outcomes Maintenance outcomes are critical in helping older people who need longer-term social care support. But, considerable evidence points to the rigid nature of the commissioning and delivery of home care services; which means that such services cannot always deliver a full range of desired maintenance outcomes (Knapp et al. 2001, Francis and Netten 2002, 2004, Ware et al. 2003). Managers in some sites said that the home care services they commissioned were aimed mainly at physical maintenance rather than wider social or quality of life outcomes. Service users agreed with this and said they would like to get out more but had no one to take them – this was not part of their home care service (p59). POSTAL SURVEY AND CASE STUDY – showed that ‘Outcomes’ can have different meanings for medical and social care professionals and debates about ‘medical’ vs. ‘social’ models had impeded the development of integrated outcomes-focused day services in one site. Very few examples were found of initiatives that respondents considered outcomes-focused	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Policy Research Unit, University of York. Voluntary/Charity Social Care Institute for Excellence.		that had been in place for more than 3 years. Moreover, even in the case study sites, selected because they reported having outcomes-focused services in place, users said while individual outcomes-focused services were undoubtedly highly effective, their spread was nevertheless sometimes fragmented. The outcomes valued by older people appeared most likely to be achieved in services with strong inter professional teams and devolved resources over which staff had extensive control. For example, in re-ablement services, day centres and residential care homes, staff had access to a range of skills and resources they could deploy flexibly in response to users' priorities and concerns. However, there appeared to be inconsistency between these examples of outcomes-focused practice and service users' wider lives. For example, day centres could provide excellent quality services, with strong emphasis on process outcomes, for users. However, support for users to maintain their own social activities outside the day centre was non-existent. Authors point to 'most striking disjunction' between short-term re-ablement services and longer-term home care services, where the latter often acknowledged to be rigid and not responsive to users' desired outcomes, suggesting that the views of managers which reported that implementing outcomes-focused services requires a whole systems vision and strategy are valid (p61).	

17. **Goodman C, Amador S, Elmore N et al. (2013) Preferences and priorities for ongoing and end-of-life care: a qualitative study of older people with dementia resident in care homes. International journal of nursing studies 50, 1639–47**

Research aims.	**PICO (population, intervention, comparison, outcomes).**	**Findings.**	**Overall validity rating.**
Study aim The aim of the study was to explore how older people with dementia discuss their priorities and preferences for end-of-life care, and how this might inform subsequent discussions with families and practitioners. Interviewees were asked about their life in the care home, their health, thoughts for the future, and aspirations about end of life. **Methodology** Qualitative study An exploratory, qualitative study that used guided conversations with 18 people with dementia, living in six care homes. **Country** UK	**Participants** People receiving social care. Six residential care home settings (that is, providing personal care only). **Sample characteristics** *Sex* 13 female and 5 male. *Disability* Older people with dementia. *Sample age* Median age 84.7 ranging from 68.7 years to 92 years. *Level of need* All but four residents had a formal diagnosis of dementia. Dementia related disability using the Disability Assessment for Dementia Scale (Gelinas et al. 1999) showed a wide spread of disability ranging from high levels of dysfunction (0%) to no disability (100%) (p1642). **Sample size** 18 people with dementia, living in six care homes.	**Framework areas** Personalised support Continuity of care and transitions (incl. access) Care and support for people's needs **Narrative findings** Findings suggest that end of life care planning could be enriched by more careful attention to, and recording of, the everyday accounts and observations of what older people with dementia in long-term care identify as important (Authors, p1646). For many residents, an awareness of their dementia affected their self-esteem, confidence about whether they believed their views were worth listening to, and if they could influence decision making about current and future care (Authors, p1642). Most residents were able to express their thoughts and feelings about current and end of life care in a care home but on their own terms, usually emphasising particular issues or stories, or how they had managed illness in the past. Three themes that had relevance for thinking and talking about the end of life were identified; dementia and decision-making, everyday relationships and the significance of purpose and place. 1. Dementia and decision-making	**Overall score** +

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Source of funding Government National Institute for Health Research (NIHR) under its Programme Grants for Applied Research scheme (RP-PG-0606-1005).		Having dementia and living in a care home meant the older people often accepted that staff, family members and visiting clinicians would make decisions on their behalf. One man assumed his age was a factor in staff deciding not to treat any future illnesses: 'And people of my age, they don't [admit to hospital]… they just let us kick the bucket, don't they? Do you know what I mean by 'kick the bucket'?' (Participant 1 , p1643). One woman saw the dementia as a restriction on going out alone, and did not think decision making on her behalf was reasonable: 'Well I'm not allowed to [go out alone] in case I forget where I am and I don't know my way back, but, I said ''can I just go and have a walk around the grounds'', ''no''. I'd obviously find my way back from out in the grounds wouldn't I, I would have thought. I said that this afternoon to one of the girls ''can I go and have a walk round'' she said ''oh no''' (Participant 2, p1643). Despite reluctance, older people's ability to express preferences was a consistent finding in most interviews, but not all were able or wished to be specific about future care. 2. The everyday relationships Older people's views about EOLC were shaped by their daily experience of care and quality of relationships with care staff. For example, one woman strongly expressed her dislike of being disturbed and the noise of other residents and what she saw as staff	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		manhandling her. This description highlighted how she wanted to be talked to, that could have been recorded and used to provide on-going and future care. The quality of the relationships that people expected they would experience was a continual theme. One resident expressed it as friendliness and responsiveness, and felt sure the staff would look after her. 'It's the friendliness that keeps you going, I mean if you are not well, they're in there in a shot. . .they really (resident emphasis) look after me, they'll call the doctor, well I've had two good years this time, I've been in a while, but I've, the last two years I've got really well'' (Participant 3 , p1643). The care home was a place where individuals felt supported and where they would want to stay. But many participants distinguished between the kindness of the staff and the more negative experiences of a disciplined approach to care, the loss of their homes and few opportunities for meaningful participation. 3. Significance of purpose and place Conversation was often described in the context of loss, e.g. home or family, and significantly how these losses had an impact on their purpose in life. The effect of dementia intensified that experience but it was multi-layered. Even when residents had come to terms with living in a care home and grateful for the support that they received from staff, thoughts about their own care needs and preferred place of care was dominated by these losses.	

18. Hamilton S, Tew J, Szymczynska P et al. (2016) Power, Choice and Control: How Do Personal Budgets Affect the Experiences of People with Mental Health Problems and Their Relationships with Social Workers and Other Practitioners? British Journal of Social Work, 719–736

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Study aim 'This paper explores how, within mental health services, people's engagement with personal budgets may have impacted on their sense of empowerment and their relationships with social workers and other mental health practitioners' (p721). **Methodology** Qualitative study This paper draws on in-depth qualitative interviews with 52 service users with mental health problems and 28 mental health practitioners that were conducted in 2012–13 as part of a national study exploring the implementation of personal	**Participants** People receiving social care Professionals/practitioners Social workers = 11; Community psychiatric nurses = 8; Occupational therapists = 9. **Sample characteristics** *Disability* 52 service users with following conditions: Schizophrenia and related psychotic disorders = 14; Bipolar disorder = 14; Depression = 9; Personality disorder = 4; Other = 2; Multiple diagnoses = 6; Missing = 3. *Sample age* Service user age range 21–71, mean age = 44. *Level of need* Status in relation to receiving personal budget: Using personal budget = 37; Seeking/arranging personal budget = 7; Ended personal budget= 8.	**Framework areas** Respect, dignity and control Personalised support Info and comms Active participation in lived experience of care **Narrative findings** A number of themes connected to experiences of power, choice and control in the process of accessing, arranging and using a personal budget emerged. ATTITUDES AND VALUES 'The attitudes and values of both personal budget holders and staff helped to construct the discursive space within which choice and control could be conceived and enacted. A key difference that emerged was whether a personal budget was seen as a right or as a privilege – or more nuanced positions in between – which reflected in part how the idea of a personal budget was introduced' (Authors, p726). Where service users were not clear about the reasons for getting the budget, they could feel disempowered, while on the other hand, clarity helped engender a better sense of entitlement. '…it feels less	**Overall score** ++

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
budgets (see Larsen et al. 2013). **Country** UK Three local authority areas that were selected purposively to achieve diversity in terms of geographical spread, urban–rural status and levels of take-up of personal budgets.	**Sample size** 52 service users with mental health problems and 28 mental health practitioners; Male service users = 20; Female service users = 32. **Costs?** No.	like you're going begging if you know where you stand' (Interviewee, p727). Where the personal budget holder did experience real control, this could also add feelings of burden and pressure: 'When it comes to the use of public money for your care, which is what we're talking about...I just think you have a bigger responsibility with it, as well as a freedom' (Interviewee, p726). However, most users expressed how grateful they were for receiving this with one result being that they felt they could or should not negotiate the amount received: 'I was just so grateful to get it really that it didn't cross my mind to negotiate for anything' (Interviewee, p726). PERCEPTIONS OF CAPACITY IMPACTING ON THE PROCESS AND DECISION-MAKING In local authorities where eligibility criteria are restricted only to individuals in highest (critical) need, some participants were offered personal budgets at a point when they were still very poorly and/or did not feel able to manage or monitor the budget without support: 'I was against it, as well, because they said 'you will get paid and you've got to set up a bank account', and I thought, with not being well, why is all that?' (Interviewee, p727). 'If I was on my own at home, and in control of it myself, I don't know what I'd do with it, to be honest…I have to have somebody control that side of me' (Interviewee, p727).	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		Where service users had no support, e.g. from a peer brokerage organisation, they had to resort to family and friends. The authors state that it could be paradoxical that individuals were given the potential for choice and control through a personal budget when in reality it was hard for them to fully get involved in the process, but that in due course benefits could be realised as described below: 'To be honest, I didn't want no control to start with when I first applied. I found it easier just to let them deal with it, but this time round they've given me the budget and I just pay it as I go' (Interviewee, p727). Where individuals perceived they lacked capacity, this could be intensified by overly bureaucratic local authority systems '…the problem was that it was really hard to do. I think you have to have a PhD to understand it' (Interviewee, p727). POWER RELATIONS AND ORIENTATIONS i. Control as a transfer of responsibilities Several budget holders talked about the active role they had taken to secure their budget, for example, through doing self-assessments, writing support plans and letter writing to key contacts, and in turn this providing them a sense of control and power. ii. Resistance to transfer of responsibilities Other service users were resistant and would rather let others manage the responsibility of a personal budget on their behalf, reflecting what the authors call	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		a ‘learned passivity’ (p729). I wasn’t really participating… because it’s sort of the [mental health practitioner]’s job to do things like that…I had all the control that I wanted, which was none at all (Interviewee, p729). Several service users said that they were not aware that they were even permitted to be involved in the process: ‘My opinion isn’t even asked for…I was sat, quiet, she was filling in the forms, and then she said “sign it”, and I didn’t get a chance to read it’ (Interviewee, p729). iii. Choice as a shared and supported activity Although some service users described experiences of feeling very independent in making decisions and taking control of their support, most described that choices were made through discussions and reflection involving others. Both service users and practitioners highlighted that making choices together was much easier when there was a sense of rapport between them and a sense of mutual trust had developed. Some service users described having to be ‘so assertive and very confident’ (interviewee, p730) when working with practitioners to secure their chosen use of a personal budget: ‘It was almost like I felt pressured to go with that she wanted because I don’t want my care to be affected with her if I don’t answer the way she wants me to’ (Interviewee, p730).	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		LOCAL AUTHORITY APPROVAL Most interviewees described the decision-making process with practitioners in relatively positive terms. This compared with a lack of direct communication and knowledge about local authority decision makers and a 'perceived obscurity' of how decisions were made and signed off: 'All communications [were] between my support worker and somebody, I don't know who. So very little was to do with me' (Interviewee, p731). While many service users were able, to some degree, to negotiate with practitioners, they did not have this facility at the panel meeting of managers where decisions about funding of personal budgets are often made in local authorities: 'There's not a lot you can do about it, is there, if someone tells you the money isn't there then that's the deal' (Interviewee, p731).	

19. Handley M, Goodman C, Froggatt K et al. (2014) Living and dying: Responsibility for end-of-life care in care homes without on-site nursing provision — A prospective study. Health & Social Care in the Community 22, 22–29

Research aims.	PICO (population, intervention, comparison, outcomes)	Findings.	Overall validity rating.
Study aim The aim of the study was to describe the expectations and experiences of end-of-life care of older	**Participants** Older people receiving social care A total of 121 residents took part in the study in interviews and by	**Findings** Page 25: "All staff interviewed recognised the importance of initiat-	**Overall validity rating** +

people resident in care homes, and how care home staff and the healthcare practitioners who visited the care home interpreted their role. **Methodology** Mixed methods A mixed-method design was used. Interviews with care home staff and healthcare professionals alongside a review of care home notes. Limitations are noted on page 28: This study is limited in studying six care homes and associated primary care services in areas that may not be representative. To be able to address such a sensitive topic, our sample of homes was selected from care homes regarded as providing good care with good working relationships with primary healthcare professionals. It did not engage with practice in homes where there were recognised problems with quality of care. **Country** UK East of England **Source of funding** Government	agreeing to the review of their notes from a total population of 257 residents. Ninety residents (74.4%) remained in the study for the full 12 months. Professionals/practitioners 19 NHS professionals (3 GPs who were attached to 3 of the 6 care homes, 11 district nurses: including 1 team leader and 1 clinical manager), and 5 palliative care specialist staff working in community homecare teams/hospices linked to the participating care homes, gave consent and were interviewed. In total, 30 care home workers (9 care assistants, 8 senior care workers, 2 activity co-ordinators, 4 deputy managers, 1 assistant manager and 6 care home managers) gave consent and were interviewed. **Sample characteristics** Sex Table 3, page 25. Resident characteristics at baseline (n = 121) Female residents 94 (77.7%); Male residents 27 (22.3%). **Sample age** Table 3, page 25. Resident characteristics at baseline (n = 121) Mean age 87.5 (range 61–102, SD 7.08) and of those who remained in the study: Median age	ing discussions on preferred priorities for care or preferences about end of life. They highlighted that understanding a resident’s wishes could mean avoiding unnecessary admissions to hospital or stopping invasive, distressing interventions." Page 26 highlights the confusion about which professional initiates conversations about dying and planning for dying with residents: "Care home staff, through daily contact and close relationships, recognised that there were opportunities to enter discussions on end-of-life wishes with residents, but either felt unable to do this or did not think it was possible to say who had responsibility to raise the subject. Many care home staff hoped that GPs and district nurses would take the lead, at the right moment, even though healthcare professionals were described as only visiting to address specific health events or to undertake interventions, such as wound care." Page 26: Another barrier was time. "Time restrictions, limited intermittent contact with residents and apparent wellness of residents during initial consultations were all factors that complicated and inhibited discussions on end-of-life care." "The care home notes review had demonstrated	

Department of Health. Other This paper outlines independent research commissioned by the National Institute for Health Research (NIHR) under its Research for Patient Benefit (RfPB) Programme (PB PG 0906 11387).	(mean age) 88 (87.3). Level of need Page 24: The most common health problem recorded in residents' notes was dementia (38%), although this was probably under-recorded. Just under half of the sample's care home record made mention of them having three or more comorbidities (e.g. diabetes, heart failure, arthritis) separate from a dementia diagnosis. **Sample size** Ninety residents (74.4%) remained in the study for the full 12 months. Additionally, 30 care home workers (9 care assistants, 8 senior care workers, 2 activity co-ordinators, 4 deputy managers, 1 assistant manager and 6 care home managers) and 19 NHS professionals (3 GPs who were attached to 3 of the 6 care homes, 11 district nurses: including 1 team leader and 1 clinical manager), and 5 palliative care specialist staff working in community homecare teams/hospices linked to the participating care homes, gave consent and were interviewed. **Costs?** No.	recognising that a resident was dying and in need of end-of-life care was not a straightforward process." Page 27 discusses how healthcare professionals (GPs and district nurses only get involved at specific times): "The pattern of primary healthcare involvement in end-of-life care mirrored how contact was maintained for everyday care and was linked to specific tasks. GPs, for example, visited for medication reviews and changes, while district nurses were more involved in arranging equipment and monitoring. They were less than explicit about how they supported unqualified staff or liaised with relatives." This continues onto page 28 where it is argued that: "The findings presented here indicated that healthcare professionals did value care home staff knowledge, but this did not translate into shared decision-making or where there were concerns about the capacity of the healthcare services to provide on-going support on how the two groups could work together."	

20. Hart E, Lymbery M, Gladman JR (2005) Away from Home: An Ethnographic Study of a Transitional Rehabiltation Scheme for Older People in the UK. Social Science & Medicine 60, 1241–1250

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Study aim To explore the perceptions of older people and care home managers about a transitional rehabilitation scheme in Nottinghamshire. This study aimed to explore issues surrounding this sort of intermediate care through an understanding of TR as a social process, including interpersonal, cultural and organisational dimensions. We were concerned to gather the views of people—especially those older people who used the service and rehabilitation assistants who staffed the units—who have been little heard in the research to date. **Methodology** Qualitative study	**Participants** Older people receiving home care Altogether 55 people were interviewed, including 17 older people. Professionals/practitioners Altogether 55 people were interviewed, including the service co-ordinator, 7 care home managers and 30 rehabilitation staff (6 OT, 1 physiotherapist, 6 CCO, 16 rehabilitation assistants, 1 social worker). **Sample characteristics** Sample age Over 65 years of age (for elderly people). **Sample size** Sample size Findings of an ethnographic study of an intermediate care scheme in six residential care homes that examined the perspectives of three key groups—older people, care home managers and rehabilitation staff. Altogether 55 people were interviewed, including 17 older people, the service co-ordinator, 7 care home managers and 30 rehabilitation staff (6 OT, 1	**Findings** Findings are structured around three emergent themes. The first is 'consensus versus mixed perspectives' which reflects the wide range of perceptions of staff and older people. The second is 'a new culture in the making' which refers to the emergence of a new culture (Batteau 2000) of rehabilitation for older people in social services. The third theme of 'rehabilitation or adaptation' refers to the way in which 'rehabilitation' was being interpreted as a process of becoming adapted to the daily life and routines of the TR units. The extracts in the paper do not explicitly outline barriers to adult social care. However, detailed below are some examples where elderly people and/or professionals speak about differences between the TR service and residential care than highlights some of the difficulties experienced with adult social care and what was difficult about the experiences of the TR scheme as reported by the elderly people. Theme 1: consensus versus mixed perspectives Some older people interviewed reported less satisfactory experiences of their time in hospital compared to hospital and or care home staff. For example, this person who saw TR as "an unwelcome deprivation of her rights and liberties": Participant: "I felt well I don't want to be sort of imprisoned or anything like that because I've done nothing wrong…and while I don't think there's any question of	**Overall validity rating** ++

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Ethnographic study. The 'core characteristics' of ethnography were: it was small in scale, focussing on TR as a social process in the settings in which the scheme was organised and delivered. The study was designed to trace the development of the scheme over 2 years, with fieldwork concentrated in two phases, 12 months apart. **Country** UK Nottinghamshire. **Source of funding** Government Trent NHS Executive, UK	physiotherapist, 6 CCO, 16 rehabilitation assistants, 1 social worker). In total 58 interviews were conducted, including 4 interviews with older people on their return home—one of whom was also interviewed while in TR—and a group interview with 3 occupational therapists and 4 community care officers. **Intervention** List interventions of interest An intermediate care scheme operating in six residential care homes within Nottinghamshire, UK. **Costs?** No.	them thinking they're keeping us from doing what we want to do I think er, you, you could feel a little bit like that occasionally because your life belongs to you doesn't it? And what you do is very important to you and your way of going on is very important to you." (p 1244) "Nevertheless, older people's experiences of the scheme—even those who did not want to be there—confirmed managers' and rehabilitation staff's beliefs that the scheme was 'personal' in contrast to the 'impersonal' nature of hospital care." (Authors: p1245). Theme 2: a new culture in the making From the point of view of the professionals, the interviews showed they preferred the work on the TR scheme to their regular work in residential care. For example: "Well the residential side youget into a routine and everything's more or less the same….On the rehab you've got that many people coming in it's different every week plus there's more input. You're more involved with what goes off with them at home and their personal life and everything. (Interview transcript RA18U4:1). Here you've got the chance to talk to them more because you're doing exercises with them or you're learning them to make tea or make a sandwich. Whereas downstairs (in the residential home) you're with them to wash them and dress them and bath them, take them to the dinner table, bring them back. But you're not sitting with them to talk to them are you? So you've got more personal up here. (Interview transcript—RA11U5:17)" (p1246).	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		The paper comments that "rehabilitation required a much more personalised approach, with a particular emphasis on relationship building." (Authors: page 1246). Theme 3: rehabilitation or adaptation? "The TR scheme was developed on the assumption that the OT would direct both what was done and how it was carried out. However, while the OT assessed people and prepared the individual goal plans it was generally the rehabilitation assistants who were responsible for putting them into practice and keeping them up to date. Thus, there was potential for the therapeutic goal plan to be translated into something subtly different—given that it was put into operation by people who were not professionally trained therapists." (Authors: p 1247). "Our data challenged the view that the scheme provided a ‘‘simulated home environment’’ (as one occupational therapist described it). “Our findings suggest that managers and rehabilitation staff perceived the units as being like home but also as training units. For example, rehabilitation assistants used a socially constructed notion of ‘home’, which was abstract and general. By contrast older people used a personally constructed notion of home which was specific and personal to them." (Authors: page 1247). "Alongside the ‘personal’ and ‘home like’ approach, therefore, and somewhat in opposition to it, emerged	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		the idea of 'training' older people in 'batches'. Amongst rehabilitation assistants in particular, the concept of 'training' sat uneasily alongside that of 'rehabilitation' in the sense of promoting independence." Design of the TR units was another important factor and barrier to its success: "We observed that in two of the units the corridors were very long; during one visit we observed two residents going for a walk around them and getting lost—indeed they passed us three times. In this one purpose built unit the 'training kitchen' was so far from the residents' day-room that it was an effort for them to get there, especially with a frame." (Authors: page 1247). Conclusions relevant to barriers: "We conclude that policy makers need to be cautious in the development of residential forms of intermediate care, for two linked reasons. First, it should not always be assumed that home is best for all older people. Secondly, it is by no means straightforward to simulate the conditions of home in an institutional environment—especially one that is purpose-built." (Authors: page 1249).	

21. Hatton C and Waters J (2011) The National Personal Budget Survey: June 2011. London: Think Local Act Personal

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Study aim The POET (Personal	**Participants** People receiving home care	**Framework areas**	**Overall score** -

Research aims.	**PICO (population, intervention, comparison, outcomes).**	**Findings.**	**Overall validity rating.**
Budgets Outcome Evaluation Tool) surveys for personal budget holders and for carers of personal budget holders have been developed over several years as a way for personal budget holders and carers to report their experiences of personal budgets. **Methodology** Survey BUT direct user views included - 417/1,114 personal budget holders who completed the POET survey wrote in a comment about their experience of personal budgets. **Country** UK	People receiving social care Carers/family members **Sample characteristics** *Sex* 61% women. *Ethnicity* 11% non-White ethnicity. *Sample age* Almost half of people responding to the survey were aged 65 years or more (43%). *Level of need* The social care needs of working age adults (aged 16–64 years) were largely split between learning disabilities (17%), mental health needs (8%) and physical disabilities (25%). **Sample size** In total, 1,114 personal budget holders completed the POET survey, including 832 returns from the 10 local authority demonstrator sites and returns from at least 76 other local authorities. 417 of these personal	Respect, dignity and control Info and comms **Narrative findings** 163 personal budget holders commented on the impact of their personal budget on a specific aspect of their day-to-day life. The following are direct quotes from direct users – from those who added additional comments to the survey. Page 25: "Having the personal budget has completely changed my life and of those around me. My husband who is 75 years was finding things increasingly difficult to support me, and my daughter who was recovering from breast cancer was worried about the way things were breaking down and was unable to help. I rang social services one day in tears to see if I there was a possibility of any help and within a few days I saw a social worker who told me about the budget and how he thought it would work for me. I have never looked back and the stress and worry has been taken from us. I have lovely carers who support us in every way. They help with personal care, help in the home, shopping take me to my voluntary work and meetings which I would have to give up without them as my husband couldn't take me and we have trips out which stops me from being confined to 4 walls. My life is happier and more fulfilling now and I don't know what would happen if the support was withdrawn. I have independence now and hopefully can help others along the way."	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
	budget holders also wrote in a comment about their experience of personal budgets. **Costs?** Cost information Page 15 reports the costs of personal budgets, e.g.: "The median weekly amount of personal budgets was lowest for older adults (£133 per week), compared to younger adults with mental health conditions (£160 per week), younger adults with physical disabilities (£188 per week) and particularly younger adults with learning disabilities (£221 per week)" (Authors, p15). "Older adults and younger adults with mental health conditions were more likely to have lower value personal budgets (£1–£200 per week), and less likely to have high value personal budgets (£501 or more per week) than younger adults with learning disabilities or physical disabilities" (Authors, p15). "There was substantial variation across councils in the weekly cost of personal budgets, with median weekly amounts varying from £90 per week to £213 per week" (Authors, p15).	Although the account above was positive, the authors contend that most of the comments were in fact negative, as exemplified by the following narrative: "[The] Adult learning disability team took 14 months to process a claim for direct payments. I then was told at the time I would not have to pay a contribution. 4 months late I was then told I had to pay half my carers allowance towards my care. I had also to back pay my contribution using up all my savings. It has been a disgrace. I am still unsure how to spend it, or on what except my carer. The whole process has taken 2 years and been so stressful." The authors comment that relationships with staff and the 'system' were also mainly negative, e.g.: "Social services staff come from a different planet and have great difficulty speaking understandable sensible plain English and being answerable to their clients." Page 20: The authors report that respondents commented on the process of setting up personal budgets as cumbersome. For example: "It was very difficult to set up originally. I need to use contingency fund but have no idea how? Once set up there is no info on how to change/alter/reassess it. Once set up you are discharged from social services and have no idea/back up to contact on who to contact. Money is held by [broker] who don't know much about it!!". The authors also report themes captured from users in table 2, page 24. It includes 89 reported positive views of 'personalised care'.	

22. Hearle D, Rees V, Prince J (2012) Balance of occupation in older adults: experiences in a residential care home. Quality in Ageing & Older Adults 13, 125–134

Research aims.	PICO (population, intervention, comparison, outcomes)	Findings.	Overall validity rating.
Study aim The aims of the study were to explore the balance of occupation of care home residents to fill a gap in the literature, and to develop a methodology that could be applied to a wider comparative study. **Methodology** Mixed methods Single case study design using multiple data collection methods - included systematic observation, field notes and interval time sampling, both qualitative and quantitative. **Country** UK **Source of funding** Not reported.	**Participants** Older people receiving social care Professionals/practitioners **Sample characteristics** Sex 30 females and three males. **Sample size** Sample size The single site study was based on a privately managed residential care home for the older adults in South Wales. At the time of the study there were 33 residents in the home, 30 females and three males. **Outcomes 2 (quant)** Views/experiences **Costs?** No.	**Findings** All residents using the public spaces in the home were included in the study. The manager reported that most residents experienced mild confusion. The overall ambience of the public spaces in the home was 'one of passivity'. Televisions were on in both lounges, but few residents appeared to be viewing. One resident commented ‘‘we leave it on because someone might be interested’’. Conversations were occasionally initiated but were brief and the residents always responded actively to care staff who were attending to requests for personal care such as toileting (p128). Multiple conditions were described with their effects on the residents' lives. ‘‘I used to knit, make all my children's clothes and loved to go out in the car . . . now I cannot move, I cannot see and my hearing is bad . . . I wait for someone to come and get me from my room’’ (p128). Despite positive comments on the care they received, ‘‘I am well looked after’’, residents had little scope to do	**Overall validity rating** -

		any activity of interest ‘‘there is nothing here, I am so bored’’ (p128). Much of their time was spent sitting silently or sleeping, with very limited interaction with other residents and negligible contact with staff or with visitors. Residents 'solicited help from care staff' to use the stair lift to return to their rooms or go to the dining room. The only activity initiated by the care staff was in relation to personal care with an emphasis on toileting (Authors p129).	

23. Hebblethwaite A, Hames A, Donkin M et al (2007) Investigating the experiences of people who have been homeless and are in contact with learning disability services. Learning Disability Review 12, 25–34

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim The aim is to report the experiences of those with learning disabilities that have been homeless, and ascertain their viewpoints of learning disability services in one region, North East of England. **Methodology** Qualitative study.	**Participants** People who have been homeless and are in contact with learning disability services. **Sample characteristics** *Sex* 12 male and 2 female. *Sexual orientation* Not reported.	**Framework areas** Continuity of care and transitions Care and support for people’s needs **Narrative findings** Services accessed by disabled interviewees covered the statutory, private and voluntary sector. When the interviews were conducted, 10 of the participants were homeless and 4 had been homeless but were since re-settled. The relevant findings are about outcomes such as: wellbeing and quality of life, engagement with services and care, and support from agencies.	**Overall score** -

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Semi-structured qualitative interviews were conducted with fourteen people with learning disabilities who had experienced homelessness. **Country** North East of England, UK **Source of funding** Not reported.	*Disability* Learning disability but not clear what level of support needs. *Ethnicity* White. No representative of BME. *Sample age* 21–61 years. *Level of need* Not reported. *Socioeconomic position* Previously homeless, generally living in temporary accommodation. **Sample size** 14 participants. **Costs?** No. Not reported.	Support within accommodation Of the ten participants who were in temporary accommodation, there were mixed experiences of support. General positive experiences: where staff supported their needs, contactable, reliable: “Helped me with a bit of shopping and cooking and that – helped me with money” (p30). Other support mentioned was where staff supported people emotionally, going to appointments, accessing appropriate benefits and organising health needs. Four of the participants had negative experiences due to staff not being there for them, listening to their complaints and issues experienced with other residents and feeling misunderstood. Comments to improve service were about having staff to support the individual handle difficult situations within the temporary accommodation, improving the active participation in determining house rules, and having someone to talk to. Accessing health services Participants spoke about accessing health services, such as doctor’s appointments, hospitals and community nurse. Five participants spoke about having mental health problems and another five having physical conditions. They had been supported through medi-	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		cation, helpful advice and, in one instance, feeling listened to. Key areas of access was proximity to medical support and two experienced changing doctors due to the change in temporary accommodation. One participant described having difficulty in registering with a doctor's because of being in temporary accommodation. Support received from other agencies, family and friends Participants spoke of statutory services assisting them find temporary accommodation, access mental health provisions and life skills such as budgeting, cooking, shopping and filling forms. Although, three participants felt that they needed more support and help with being accommodated via social services.	

24. Hillcoat-Nallétamby S (2014) The meaning of "independence" for older people in different residential settings. The Journals of Gerontology: Series B: Psychological Sciences and Social Sciences 69B, 419–430

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Study aim This article aims to address the knowledge gap in research about older people's own understandings of independence to further develop an interpretative framework of this	**Participants** People receiving social care **Sample characteristics** *Sex* Three quarters of the sample were women, broken down as follows: .Residential care – 24% male; 76% female .Extra care – 21% male, 79%	**Framework areas** Respect, dignity and control Active participation in lived experience of care Care and support for people's needs **Narrative findings** The interviews were analysed using an analytical framework based on a review of research about older	**Overall score** +

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
concept within the context of three different residential settings -the private home, extra-care, and residential-care settings. **Methodology** Qualitative study The article draws on qualitative data collected from in-depth interviews conducted as part of a larger study completed in Wales (Burholt et al. 2010) designed to address knowledge gaps about meeting the needs of frail, older people residing in supported living environments. Qualitative interviews planned to gather subjective experiences of aging and care received in community, care home and extra care settings by exploring core topics about healthcare provisions, support networks, social activities,	female .Community – 30% male; 70% female. *Sample age* Participants were aged 60–98. The mean age was 80.8 years. *Socioeconomic position* About half of sample had previously held professional or semi-professional positions. **Sample size** Population of 91 frail older people - 29 in extra-care housing, 29 in residential care homes, and 33 in the community. **Costs?** No.	people's understandings of independence in different residential settings. The framework consisted of 14 themes and subthemes representing different aspects of older people's understandings of independence. Findings show that older people's understandings of independence are diverse, with some common to all three settings, others specific to a setting. The following themes highlight the views and experiences of participants in relation to their use of social care. 1. Older People's Understandings of Independence Multiple settings Across all three settings, independence is manifested in a willingness to purposely accept help at hand with ADLs. One resident explains that this helps them to be more selective in deciding what they need to do to remain independent: 'The arrangements are better for me, like take shopping. I can do it independently… the energy that I used to waste with trying to shop and cook, it's taken from me now, I don't have to do that, I only have to think about breakfast or tea and that's easy' (Extra-care housing service user, age 79, p5). Access to personal financial resources to pay for help promotes a sense of independence by giving respondents more choice and control in how they organise their lives. Despite increasing frailty, an extra-care respondent continues to see herself as independent, her ability to organise and pay for much of her own care needs illustrating this: "I have got in touch with the All Care Domestic Services myself. Nursing services they are. I have privately got a	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
frailty and disability, with specific extra questions on reasons and choices for moving for participants in extra-care and residential settings. **Country** UK Wales **Source of funding** Government The work was supported by the Welsh Assembly Government, Social Care Research Award, Wales, United Kingdom (RFSC07-3–012).		helper who comes on a Thursday and she does my shopping at the Co-Op … so I'm still independent" (Extra-care housing service user, age 83, p6). One respondent living in the community says that despite some financial help for ironing, they are able to take on the costs of other care themselves, "I get home care. My ironing's paid for by Supporting People services and my other ordinary care I pay for me self. That is personal care to get me washed and dressed in the morning – it all helps me" (Community, age 65, p6). Although the need to purchase services is less likely in residential care settings, residents can still exercise choice by using their own financial resources; one resident, for example, opted to pay for a private dental care, even though this service is provided (p6). CROSS-SETTINGS a) Extra-care and community settings 'Having access to and using resources to receive services at home' promotes a sense of independence: 'If you need help with your housework we get domestic time as well so that everything is looked at and seen to […]. So the domestic time is included in the monthly payments and some might need a lot more than others and then you find somebody who is more independent.' (Extra-care housing service user, age 78). b) Residential care and community settings Respondents' independence was evident in terms of openly asserting independence by rejecting support	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		and affirming the ability to be self-sufficient. One resident comments, 'I basically look after me self. I can do everything myself. I'm not like some of the people here; I am capable of looking after myself'. (Residential, age 75). Similarly in the community, a respondent who is asked to explain why they have opted to receive help at home affirms: '(…) you see, dependency in my view becomes more and more inevitable to the extent that you allow other people to do things for you. You have somehow to be as independent of gratuitous outside help as you can possibly manage because if you don't use it you lose it.' (Community, age 76). Some residents in these settings sense they lack control in their lives or feel disempowered to change their situation and are unable to do things as before. In the residential setting, a respondent says that, if given the opportunity, she could do more for herself: 'Interviewer: So, you don't have the option of getting yourself washed and dressed? Respondent: Oh no, no. Interviewer: Do you think you could? Respondent: I'd have to have help, I think, especially to get dressed but I think I could wash myself, the way they do ... you know, I'd do it in bed. I'd like to be more independent. […] in the morning, if they gave me the water and thing and you know, I'd try and have a go anyway' (Residential care service user, age 86, p6). SINGLE SETTINGS Extra-care setting	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		In this setting residents' independence is strengthened because of reassurance that help is at hand if needed. For example, one respondent points out that having moved to Extra-care because of her husband's deteriorating health and wellbeing since arriving there, she is free to continue her own activities and to go out because she can rely on support staff: 'No we've got a better quality of life since we've been in here. I know now I can go out and I know there's help on hand if anything happens to him. Because I mean like a few weeks ago I wasn't here and he had a heart attack. Well all the staff was here, you know…' (Age 62, p7). Community setting Community respondents are reluctant to move from their home to an institutional setting, for anxiety about losing independence. These individuals also associated a sense of independence with having resources to adapt their home or to use devices and equipment to help them remain there. Following hospital discharge, one respondent could access the top floor of her house with a stair lift, 'Last year I fell upstairs. And then they took me into hospital, sent me home and from there I've had the care plan that I have now… I got a stair lift and now I manage' (Age 86, p8). Residential care settings Participants in residential settings were worried about losing independence by becoming reliant on others. Others talked of losing their independence in terms of experiencing acute boredom, 'It gets a bit boring to say the least. I'm 71 now. I've been retired six years, six or seven years. And I'm getting fed up with life.	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		There's not enough to do. You've got a brain and they switched it off when I was 65. They thought I didn't know how to use it. But I want to use it. I need to use it' (Age 71, p8).	

25. Hoole L and Morgan S (2011) 'It's only right that we get involved': service-user perspectives on involvement in learning disability services. British Journal of Learning Disabilities 39, 5–10

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim The aim was to conduct a focus group with service users with learning disabilities in order to ascertain "their experiences of services, what was helpful and unhelpful, whether they felt involved and listened to, and suggestions for improving involvement" (p6). **Methodology** Qualitative study. Focus group held with seven people with learning disabilities re-	**Participants** People receiving social care. Seven people with learning disabilities. **Sample characteristics** *Sex* 4 male and 3 female. *Sexual orientation* Not reported. *Disability* 'Participants had learning disabilities, could meaningfully participate in group discussions, and had good expressive and receptive communication skills' (p6). The authors note there are varied levels of verbal ability	**Framework areas** Continuity of care and transitions (including access) **Narrative findings** Services assessed by people with learning disabilities (n=7), considered their insights into the varying experiences, which have been analysed in three key themes: (1) Feelings of unfairness and inequality; (2) Experiences of inclusion and power; and (3) Future visions. These are relevant to question one. (1) Feelings of unfairness and inequality Issues were about feeling an imbalance of power and where participants had felt like they had been treated unfairly. As articulated, when one participant recalled a previous tenancy he lived in, 'staff completely ignore you and walk away. That is not very nice' (p7).	**Overall score** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
cruited from a self-advocacy group and day centre for people with learning disabilities. **Country** UK. Two South West London boroughs. **Source of funding** Not reported.	and learning disabilities among participants. *Ethnicity* Not reported. *Sample age* Not reported. *Level of need* Not reported. *Socioeconomic position* Not reported. **Sample size** 7 participants. **Costs?**	Participants reported that they felt reliant on staff to meet their needs but when they did not, they felt disappointed: 'Sometimes I've had to wait around that area, it's like waiting, I wait around for a bus sometimes, sometimes they do come. I just think to myself, "why have I got ready?" It's just one big slap in the face' (p7). Some participants spoke about feeling like they were not being treated or 'afforded the same rights' (p8). As commented by one person who stated: 'When you've got two of your friends…and you both want to move and live in a bungalow or out of a care home, I think staff shouldn't be allowed to say to one of them "no, you can't do that cos you need a bit more help". I think it shouldn't be allowed because whatever help anyone needs, they should be able to get it whether they're in a care home or an ordinary house down this road.' (Page 8). Over half of participants reported difficulties in feeling like they were not being listened to: 'It's very difficult to get across or to make everybody realise your feelings. Your feelings are not always met at all' (p8). (2) Experiences of inclusion and power Participants spoke of positive experiences where they felt empowered by services and professionals, which was generally due to 'accessible information and travel training' (p8). Explicit provision noted were: 'day	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		services, support workers, Occupational therapists, and psychologists': 'The council and OT got all my bungalow set up for me and it didn't cost me any money at all and anybody should have that right' (p8). While participants also referred to their personal and professional network that supported them which helped them to feel like their voice was being heard and that someone could represent them with their best interests: 'You can talk to your support workers or your friends or family. They will talk to us about any problems like the house, like [names of other residents] – they're always fighting cos they're not get on really well in the house' (p8). In some cases, participants appreciated self-advocacy forums and taking personal ownership over their own power: "I think that stuff that is easier now though, I think that's partly due again to the parliament and the work we did to get that to happen" (p8). A suggestion of recognition in the time given could be valued through financial accruement to the participants. (3) Future visions Participants explored potential empowering ways that they could be involved in making decisions: 'Well, I have got my annual review at [name of house], which is the home where I live in [name of town], which I share with three other people. One of	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		them is currently moving out on the 28th of this month and we're having a meeting, my annual review, this Tuesday and I'm going to press that the other two of us in future get involvement in the process when they select the next person to move in. Cos currently that doesn't happen and I feel that it's about time that it did… Certainly in the place that is Supported Living, like we are, it's only right that we get involved rather than get told who we're gonna have' (p8). Additionally, participants wanted to empower others and advocate for service users with different needs: 'My speciality job is – we've all got a Bill of Rights – and mine is for the hard to reach people. I mean people with severe physical and severe challenging needs because they each have the rights of yourselves and in the past they were just put in services or homes or whatever and they didn't get a say in the matter. Well, we're making it – we're making it our business that they get a choice as much as anyone else' (p8).	

26. IFF Research (2008) Employment aspects and workforce implications of direct payments: research report. London: IFF Research

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim Conducted on behalf of Skills for Care, this	**Participants** People receiving social care - People (employers) using direct payments	**Framework areas** Respect, dignity and control Personalised support	**Overall score** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
is the first ever large-scale study of recipients of direct payments in their role as employers. 'This research assessed the employment aspects and workforce implications of the Direct Payments scheme (Authors, p11). 'The research was also aimed at establishing a deeper understanding of the demographic composition and skills and qualifications that Direct Payment recipients and their employees are likely to need in order to ensure a close match between demand and supply' (Authors, p12). **Methodology** Qualitative study. This is a three-phase, large-scale quantitative research project encompassing the following: 1. Main employer survey – 526 face-to-face	and accessing the services of Personal Assistants. **Sample characteristics** Sex – 58% female, 42% male (p21). Disability – Physical disability / long-term illness = 242 Sensory impairment = 11 Learning disability = 42 Mental health problems = 9 Older person = 114 Carer = 108 Total = 526 Ethnicity – 88% of the (employer) sample were white. The authors note that 'because of the relatively low numbers of Asian, Black and Mixed ethnicity interviewees, it has been difficult to make meaningful comparisons between employers of different ethnicities. Only statistically significant differences between employers of different ethnicities are presented in the report (p21). Sample age – From the sample of 526, there was an even spread of employers of different ages. 114 were older people.	Active participation in lived experience of care Continuity of care and transitions (incl. access) Care and support for people's needs **Narrative findings** This narrative summary is based on reported findings from the first phase of this research. These findings focus on qualitative data from the main employer survey, carried out between February and November 2007. This was based on the findings of the Sheffield/New Types of Worker research and other key published research, and developed in consultation with the project steering group. The findings are presented under key themes. GENERAL SATISFACTION: The authors report that employer satisfaction with the PAs employed through DPs was very high - eight in 10 rated themselves as 'very satisfied'. Those employers who were receiving support administered by their Local Authority before receiving Direct Payments (48%) expressed dissatisfaction with these services, e.g. support worker's ability to carry out household tasks and their punctuality and general reliability (compared to only 8% of all employers dissatisfied with their current PAs (Authors, p28).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
interviews with Direct Payment employers in sixteen Local Authority areas. 2. Self-completion survey of Personal Assistants. 3. Telephone survey of Personal Assistants - 100 individuals who had completed the self-completion survey. The SUE review is based on the first phase focusing on qualitative data from the main employer survey, carried out between February and November 2007. **Country** UK	Level of need – 'The majority of employers participating in this survey (71%) have been receiving Direct Payments for over a year, with only 5% in receipt for less than six months' (Authors, p21). Socioeconomic position – No detail provided on SES. **Sample size** Sample size – 'A total of 526 Direct Payments employers were sampled from across 16 participating Local Authorities, representing 7% of the total population of 7,539 individuals in receipt of Direct Payments in these areas, and 1% of the total number of employers nationwide (54,151)'. (Authors: page 13). Employers were divided into six groups where older people comprised the largest proportion (29%), followed by carers (27%), and employers with a physical disability or long-term illness (27%). Employers with learning disabilities and those with sensory impairments or mental health issues made up (12%, 2% and 3% respectively).	ABUSE: Over one in ten employers who have accessed support through their Local Authority in the past have experienced psychological abuse from their support worker (13%), most commonly related to the support worker undermining or belittling them, excluding or ignoring them, or insulting them. Such abuse was reported much less by employers using DP to employ someone. RELIANCE ON FAMILY/FRIENDS: The most common benefit expressed by employers was a reduction on the reliance on family and friends by employers and existing carers (21%). Example comments included: *'It has stopped me having to rely on my mum and dad. I can ask my Personal Assistant to do things that I would not like asking my parents to do. I feel more independent and it's less worrying not having to rely on my parents'* (Participant, p42). *'It has made a huge difference to me and my wife as the people responsible for xxx. It means we can go out to the theatre or on holiday without relying on family and friends'* (Participant, p42). *'It has made a great difference. It has taken a lot of weight off my husband who is not well himself - he has a bad back. The tasks the Personal Assistants do, he does not know what to do'* (Participant, p42).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
	Intervention List interventions of interest. Direct payments. **Costs?** No.	INDEPENDENCE AND CONTROL: 14% described how receiving DP has led to them gaining or re-claiming their independence, and the same number (14%) stated that the scheme has allowed them to gain more control over their lives and to make their own decisions: *'It means you are more in control, even if it is a bit of a headache sometimes'* (Participant, p43). *'It has given me freedom. I can now get out and about when I want to rather than waiting around for someone to help'* (Participant, p43). *'Without Direct Payments, I would not be able to hold down a full-time job and live my life so independently. I am in control'* (Participant, p43). *'It means I am now free. It is a lot more flexible and it means I can chop and change what I want to do daily'* (Participant, p43). CONSISTENCY: One in seven employers (15%) said that the scheme had changed the way they are cared for as they can now employ the same PA on a consistent basis, with whom they can build a more personal and trusting relationship: *'It has given me the ability to choose the person who is looking after me. I am a very private person. Now rather than having different people in every day, I*	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		have a person who knows me and what I am capable of doing' (Participant, p43). *'It has allowed me to have continuity of care. This means that the Personal Assistant knows how to deal with them [the employer], she knows what food they can eat and she has got free run of the house and I trust her'* (Participant, p44). FINANICAL REMUNERATION FOR FAMILY/FRIEND: Two per cent reported specifically that Direct Payment has allowed them to employ a family member or other personal friend who would not previously have received any financial support for caring for them: *'It makes me happier that someone is now getting paid to do the jobs, like showering me. I think it is a job that someone should get paid to do. It has given me more control over my life'* (Participant, p44). IMPROVED STANDARD OF CARE: Twelve per cent of employers and their representatives feel that the introduction of Direct Payment has led to them getting a better standard of care: *'My carers are marvellous. More like a friend than doing a job, more like a friend or neighbour's attitude. My cleaner does extra jobs that were not done before. The Personal Assistants do certain tasks that they would not do in regular hours. I do not have to keep telling them what to do'* (Participant, p44).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		Consistency of support (15% of employers) and choice (13% of employers) and this had made a considerable change to the way care was provided: *'It has given me the ability to choose the person who is looking after me. I am a very private person. Now rather than having different people in everyday, I have a person who knows me*' (Participant, p43). BARRIERS: A number of barriers were reported: 1. Admin and paperwork pose a lot of problems. *'Being an employer and doing the PAYE and all the paperwork. It's very daunting'* (Participant, p45). *'The big thick instructional book frightened me...'* (Participant, p45). 2. One in ten employers with concerns reported specifically that they find dealing with Personal Assistant payroll and tax administration problematic. *'The only concern is that I was not writing down everything, e.g. everything that gets spent. They did not tell me you had to fill in forms and are audited every year. I was not told that you could pay for the Personal Assistant holiday carer. The paperwork is too much'* (Participant, p46). Three per cent of employers noted that they feel those issuing Direct Payments are disorganised, and	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		a further 3% reported that they feel they do not communicate well with employers: *'There is a lack of communication and understanding. There are problems with the collaboration between the DP and the ILF. Employing a number of PAs, this increases amount of paperwork and auditing. I sometimes feel there should be more support in this process'* (Participant, p46). *'There have been difficulties in hiring staff due to the numbers of hours allotted. i.e. 1 hour in the morning, 2 hours in the afternoon. Potential staff want more hours than I can give them to make it worth their while working*' (Participant, p47). *MONEY:* *'My only concern relates to the fact that I am not getting enough money to cover each month. I really need someone to come in every day, rather than no-one being here on Tuesday and Friday as happens at the moment'* (Participant, p47). *One fifth of employers cited poor transport links:* *'People need a car to drive here, as it is a very rural area...'* (Participant, p57).	

27. Institute of Public Care. Oxford Brookes University (2010) Oxfordshire County Council: support to the early intervention and prevention services for older people and vulnerable adults programme: report on study of care pathways. Bath: Oxford Brookes University

Research aims.	**PICO (population, intervention, comparison, outcomes).**	**Findings.**	**Overall validity rating.**
Study aim: The aim of the research was to identify the critical characteristics, circumstances and events that lead to a care home admission in order to provide appropriate services to prevent or delay such an admission. **Methodology** Mixed methods The project combined a quantitative and qualitative approach. 1. Secondary analysis of admissions records. The aim was to obtain data on a quarter of all admissions across the county over the year prior to the study. 2. Interviews with a sample of the 115 older people admitted to a care home in 2008-2009, their informal main carers where available, and care managers. A total of 21 interviews, including seven older people, eight carers	**Participants:** Older people receiving home care Older people admitted to a care home in 2008–2009 Professionals/practitioners Care managers. Carers/family members Informal main carers where available were also interviewed. **Sample characteristics** Ethnicity Majority were white-British – numbers not given but says in text "The great majority of people going into care were White British (97.5%) and nearly three-quarters (71%) were female. This is similar to the profile of older people in Oxfordshire, particularly those aged 85 and above, and identical in terms of gender to an earlier national study based on 1995–1996 data" (p2–3). **Sample age** The median age at placement was 85.0 years old with a range from 65 to 103. Level of need Page 3: A number of conditions were identified among those being admitted: Urinary incontinence 45%; Dementia 40%; Bowel incontinence 34%; Depression 25%; Visual impairment 21%; Stroke 19%; Diabetes	**<u>Narrative findings</u>** Page 17. Men appeared to be likely to be admitted to care at an earlier age than women: 54% of men were under 85 years old compared with 36% of women (see Figure 2). While women were a little more likely than men to have been living alone (66% compared to 60%) or with another family member (19% compared to 13%) prior to going into a care; men were more likely than women to have been living with their partner (27% compared with 15%) prior to admission to care. Men were also more likely than women to have been cared for by their partner prior to going into care (17% compared with 10%) but much less likely to have been cared for by a son or daughter (34% compared with 51%). Page 19: Differences between men and women in terms of service use may reflect in part the higher proportion of men who lived with and were cared for by their partner prior to admission (see Table 2). In terms of mobility, men appeared more mobile than women at admission to care: 20% of men were able to walk without difficulty compared with 13% of women, and only 4% were not able to walk at all compared with 17% of women.	**Overall validity rating** +

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
and eight care managers, were carried out. There were three cases where the carers of older people with dementia were interviewed. The completed interviews were transcribed and an analysis of the transcripts carried out using qualitative data analysis software. This was triangulated with the data from the file audit. Older people and their carers were asked about circumstances and experiences prior to entering a care home, including: the previous living arrangements of the older person; their health and need for care in the four to five years leading up to admission; the circumstances around the decision to go into care; and whether there were any services or support that they felt could have enabled	17%; COPD 6%; Learning disability 2%. **Sample size** A total of 21 interviews, including seven older people, eight carers and eight care managers, were carried out. There were three cases where the carers of older people with dementia were interviewed. **Costs?** No.		

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
them to continue living in their own home for longer. This phase of the project also included mapping timelines for the older people who were interviewed to visually demonstrate their pathway into care. **Country** UK Oxfordshire County Council **Source of funding** Government Oxfordshire City Council			

28. Irvine F, Yeung EYW, Partridge M et al. (2016) The impact of personalisation on people from Chinese backgrounds: qualitative accounts of social care experience. Health Soc Care Community, Advance online publication. doi: 10.1111/hsc.12374

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Study aim To examine the factors affecting the social care experiences of	**Participants** People receiving social care Chinese background with a physical impairment who had received social	**Framework areas**	**Overall score** +

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
physically disabled people from Chinese backgrounds in England. **Methodology** Qualitative study In-depth semi-structured interviews - in the language of choice of the participants (English, Cantonese or Mandarin) between July 2012 and February 2013. **Country** UK England **Source of funding** Other National Institute for Health Research (NIHR) School for Social Care Research (SSCR).	care from adult services in the previous 6 months. **Sample characteristics** *Sex* From Table 1, page 4: Twenty-six people were interviewed: 16 female. *Ethnicity* Chinese *Sample age* From Table 1, page 4: Twenty-six people were interviewed with a range of ages from 19 to 69 years as follows: Female participant 69/F; Male participant 68/M; Male participant 50/M; Female participant 34/F; Female participant 68/F; Female participant 60/F; Female participant 50/F; Male participant 19/M; Male participant 64/M; Female participant 51/F; Female participant 64/F; Female participant 64/F; Female participant 61/F; Male participant 62/M; Male participant 65/M; Female participant 35/F; Female participant 53/F; Female participant 53/F; Female participant 64/F; Male participant 40/M; Female participant 60/F Female participant 45/F; Male participant 68/M;	Personalised support Info and comms **Narrative findings** Information and communication: The narrative accounts focus on knowledge and information received on personal budgets. Most did not refer to personal budgets and when questioned directly about them claimed that they had little knowledge, e.g.: "(I've) never heard of personal budgets" (Female participant, 69/F, p5). Or "No one ever mentioned personal budgets to me, the Chinese community worker never told me about this" (Male participant, 50/M, p5). The authors comment that a small number of participants were aware of personal budgets but that participant accessibility to them was constrained because of difficulties navigating 'what was viewed as an overly complicated system' (Authors, p5). For example, one participant said: "I used personal budgets for a while, but it was too troublesome. Even my daughter was put off by it, although she can speak English. Nothing is perfect, we had to employ someone, and it took time to do it, organise the payroll, pay slips, their leave . . . There is a lot to learn. In the end, my daughter and I agreed not to use personal budgets" (Female participant, 34/F, p5). And another said: "It sounds very troublesome. I don't know many people. If I have to employ someone, I don't know where to find this person" (Male partici-	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
	Male participant 28/M; Female participant 56/F; Male participant 50/M. Narrative findings are based on a sub-sample of above. **Sample size** From Table 1, page 4: Twenty-six people were interviewed. **Costs?** No.	pant, 68/M, p5). The authors report that many participants were unable to utilise the resources provided by personal budgets or were not sure if they were even entitled to access them. The authors go on to comment that this lack of knowledge/information led participants to ask family and friends to meet their social care needs: "You know I had three operations. I cannot put the socks on myself. Sometimes I feel really miserable. I need to ask my husband to help me take my shoes off. It is very stressful for him. He is getting old and he needs help as well I am not sure if I am entitled to personal budget, direct payment" (Female participant , 36/F, p5). The authors report that the desire to maintain individuality meant participants avoided using available services because of issues of trust or pride. For example, one participant said: "If the government gave me money to hire someone to look after me, I will only hire my daughter . . . I had negative experiences with care workers in the past . . . I will only trust my daughter to look after me" (Female participant , 69/F, p5). Personalised support: Cultural values and linguistic Cultural values had pragmatic implications on the way social care services were received. For example, the authors cite the following example of the importance of food within Chinese culture: "We Chinese, you know what I eat is simple Chinese meals. Unless you can employ a westerner who can prepare Chinese food but that is impossible" (Male participant, 50/M, p5). And another said: "You know when you cannot	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		speak the language, you cannot communicate with others. It's very troublesome…even if the social worker comes to see us, it's no good if we cannot communicate with them" (Female participant, 50/F, p5). However, the authors report how personal budgets can be used to help mitigate such problems so that 'services that aligned with their cultural needs and preferences' (Authors, p6): "Personal budgets allow me to hire Chinese speaking domiciliary care… it helps me to get someone with the cooking, cleaning, shopping. Without the budget, I will not be able to do anything. I received the service as I expected and I am happy with it" (Female participant, 35/F, p6). The authors argue that their study shows that 'when people from Chinese backgrounds make use of personal budgets, they are able to exercise choice and access much needed culturally equivalent services that may not be available through conventional means' (Authors, p6), which is in line with previous findings on other marginalised groups.	

29. Jones K, Netten A, Francis J et al (2007) Using older home care user experiences in performance monitoring. Health and Social Care in the Community 15, 322–332

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim To test the degree to	**Participants** People receiving social care.	**Framework areas** Active participation in lived experience of care.	**Overall score** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
which the performance indicators actually reflected quality of service. The aims of the survey were to enhance comparability between participating authorities and to investigate: • Whether the items used as a basis for the performance indicators adequately reflected home care quality; • Whether the Satisfaction Best Value performance indicator used the most appropriate cut-off point; • The underlying constructs of home care quality and potential for developing measures of quality from the items. **Methodology** Cross-sectional study To avoid response bias that the majority of the questionnaires	**Sample characteristics** *Sex* 84% of respondents were 75 or over and about a quarter were men. *Ethnicity* Additional guidance was given on the assistance that should be offered to black and minority ethnic service users, such as questionnaire translation or help to complete the questionnaire if the service user had limited literacy skills in their own language (Department of Health 2002). The majority (99%) of respondents described themselves as white (British, Irish or any other white background). The largest single other group (150 respondents) described themselves as black. *Sample age* Older people. Age group 65–74, 3224 (16%) 75–84, 8731 (42%) 85 or over, 8703 (42%). *Level of need* Nationally 43% of respondents had help to complete the questionnaire. Information was collected about the	**Narrative findings** The majority of the questionnaires are to be self-completed although alternative methods, such as face-to-face interviews or telephone interviews, would be acceptable where necessary. The response rate for the 34 participating councils ranged from 36 to 83%. The average number of hours was lower in this sample, which suggests that it may be those at the very highest level of service receipt: those most dependent on services that are under-represented. Nationally 43% of respondents had help to complete the questionnaire. The results suggest that Satisfaction and Suitable times as performance indicators are both reflecting the overall experience of services users and service quality. Satisfaction, as the basis of a Best Value indicator, was highly associated with other indicators of user's experience and excluding it from the analysis resulted in less than 0.4% change in the proportion of variation explained. This suggested that these were appropriate questions on which to base indicators. Overall 37% of the variance was explained by the positive and negative carer quality factors, compared with only 16% in the initial factor analysis that combined carer characteristics into a single factor. Consistent with previous research (Collins and O'Cathain 2003), distinguishing between levels of satisfaction appeared to provide a valuable insight into service users' views on the standard of services received.	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
be self-completed although alternative methods, such as face-to-face interviews or telephone interviews, would be acceptable where necessary. Councils were advised to plan to send out a maximum of two reminder letters to these service users. A pairwise correlation matrix was analysed to overcome the problem of missing data. Reliability analysis using Cronbach's alpha was performed to measure the internal consistency of the factors. **Country** UK **Source of funding** Government Department of Health.	number of weekly home care hours received by respondents. The overall mean was 6.1 per week (SD = 6.8) and the median of 4.5 hours per week. This is lower than both the national average (mean = 8.1, SD = 2.4), and the average among home care service users in the participating authorities (mean = 7.8, SD = 1.8). **Sample size** 150 councils with social services responsibilities (CSSR), 34 of these that agreed to participate. Respondents came from 14 county councils, 8 metropolitan boroughs and 11 unitaries), but due to a separate exercise being undertaken in London, only one London borough participated. The 150 authorities in the national survey returned completed information on approximately 87 000 service users, nearly a quarter (21 350) of service users completed the extended version of the survey. The average response rate for the authorities in the extended UES was 65% and the median was 62%. **Costs?** No.	The results from the factor analyses suggest that using the extreme values for each survey item represented a better measure for each factor, supporting the rationale for using this response level in subsequent analyses. The findings have illustrated that two performance indicators designed to evaluate home care standards are indeed important dimensions underlying quality: Satisfaction and Suitable times. **Effect sizes** Do performance indicators reflect home care quality? Using factor analysis to identify a single factor, 29% of the overall variance in responses was explained with a Cronbach's alpha of 0.92 indicating a very high level of reliability. Two of the compulsory questions were highly correlated with the overall quality factor with factor loadings of 0.67 for Satisfaction and 0.57 for Suitable times. However, Contact with Social Services and Changes were excluded from the factor, suggesting these were not linked to the overall construct being measured. Carer characteristics (17% of variance explained, Cronbach's alpha = 0.90); • service quality (13% of variance explained, Cronbach's alpha = 0.84); • outcomes (10% of variance explained, Cronbach's alpha = 0.73).	

30. Katz J, Holland C, and Peace S et al. (2011) A Better Life: What older people with high support needs value. York: Joseph Rowntree Foundation.

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Study aim This study is part of Joseph Rowntree Foundation's 'A Better Life' (2009–13) programme. The primary aim of this project was to produce a robust framework of what older people with high support needs want and value. This would: • inform the work of the whole 'A Better Life' programme; • raise awareness among policy makers, practitioners, regulators, researchers, and older people and their carers; and • provide a base against which future project work can be considered (p9). **Methodology** Qualitative study	**Participants** People receiving home care People receiving social care Professionals/practitioners Volunteers and professionals working with people with high support needs in a variety of organisations Carers/family members Carers or supporters accompanied some of the interviewees **Sample characteristics** *Sex* Ten men and 16 women *Sexual orientation* Despite efforts, researchers said they were not able to speak to anyone who openly identified themselves as LGBT. *Disability* 'Most participants had mobility and/or sensory (deaf /visual) impairments. Nine participants had been diagnosed with dementia and others complained	**Framework areas** Respect, dignity and control Personalised support Info and comms Active participation in lived experience of care Care and support for people's needs **Narrative findings** From a literature review on what older people and/or those with high support needs have said they value, the researchers developed an evidence framework, including social, psychological and physical factors and things that act as barriers or facilitators, e.g. information and support. Conversations with study participants about what they valued were undertaken in order to test out the evidence framework. Generally, the participants agreed on the significance of the themes developed in the framework and were able to support these with their own examples or add new themes. Below are the ones specific to the guideline. GOOD RELATIONSHIPS WITH CARERS Paid care workers provide older people with high support needs with regular social contact and can reduce isolation. 'I'm going to need help in the mornings, and I'm glad of the help really, because I wouldn't see a	**Overall score** +

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Framework developed through a two-phase approach: 1. Evidence review of people's (with high support needs) views about what they value and aspire to, in order to identify the headings for an evidence framework. 2. Conversations with people with high support needs about what they want and value in order to validate the framework. The researchers also spoke to volunteers and professionals working with people with high support needs in a range of organisations. Most of these conversations were held on the phone. **Country** UK Scotland, Wales and different regions of England	of memory loss. Most participants had at least one additional serious health condition. These included muscular dystrophy, diabetes, heart disease, cancer, osteoporosis, incontinence. Two people had learning difficulties, one of whom was also blind. One younger person attended dialysis four times a week. Two people had been born with severe physical disabilities. Twenty-one participants were receiving formal care and many also received care from relatives or friends' (Authors, p56). *Ethnicity* Four BME participants. *Sample age* Ages ranged from 40 to 93. *Level of need* Some participants lived in care homes or supported accommodation; over half lived in their own homes in the community; and two were homeless people. All participants had complex health conditions including physical disabilities, learning difficulties and dementia. Some disabilities were congenital and others were acquired in adult or later life.	soul otherwise, and I'm woken up and they are wonderful really.' (Female participant, 85, living alone in her own home). One of P's carers is the link between P and another person she supports, having recognised that the two have common interests. P now enjoys sending and receiving cards and messages via the carer to the other person, who is blind. This example shows that good relationships with carers are not just about receiving good care, but are an end in themselves in that they can help promote positive social connections and friendships. But such relationships usually need time and consistency in order to mature (p24). PSYCHOLOGICAL WELL-BEING Self-determination Within this theme, the authors cover independence, autonomy, involvement in decision-making and control. For many, staying in control of key aspects of their lives was fundamental to their self-esteem and from a practical viewpoint, absolutely essential to avoid accidents and move around safely. I, who has dual sensory impairment, wanted the opportunity to show each new carer around her kitchen and familiarise them with her system. 'Being partially blind I have to know where everything is and I have my big plates there … my saucers there … she put the saucers on top of the big plates, course I went in there … whole lots went crash on the floor … now when they come I say to them … don't put anything on top of those big plates.' (Female participant, 85, who has dual sensory impairment).	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Source of funding Voluntary/Charity The Joseph Rowntree Foundation	**Sample size** 26 people with high support needs. **Costs?** No.	Where people were living in institutions and no longer had control over the day-to-day running of the household, some had simple requests for things to be made available to them. Another female participant wished that the nursing home staff would keep the food residents asked for in the kitchen: she particularly wanted fresh ham (p27). Page 35: BARRIERS AND ENABLERS The authors describe cross-cutting themes such as: information; financial resources; support; other people's time; transport and equipment; and technology and communication. Participants talked about these resources as the means to things they valued and that promoted their social, psychological or physical wellbeing. A lack of these resources created barriers to them achieving the things that matter to them. i. Information Access to information was random and mostly provided by health and social care professionals and family members. Information was generally substandard in quality and consistency and this has implications on access to care. A male participant (40), who is learning disabled, registered blind and has mobility difficulties, had missed out on a care package for 15 years because neither she nor her family had been made aware of her eligibility. A female participant had not been aware of extra care housing until a social worker's visit coincided with a visit from her son. 'The social services lady happen to come to see me when my son was visiting and she said, well have you thought of going into sheltered accommodation, I	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		said no, they wouldn't let me do that, she said they would … you're so independent, you're not safe, she said have you had a leaflet about [place] – she said If I were you, I'd go and look at it. I didn't know anything about them, no … I didn't know I could move into a place like this and it would just be like my own home, I thought if I moved I would be living with other people … like my auntie was in a nursing home, she went private … it cost her a fortune and all they did was sit in chairs in a room all day long, and I thought I hope they shoot me before I get to that stage, and that's what I thought it was, I never applied for anything like this.' (Female participant, 89, who has dual sensory impairment and uses a wheelchair). People with visual impairments were often dependent on others to read letters and documents to them. ii. Support. 'Where people need significant amounts of support, the quality of the care they receive and the relationships they have with carers are of particular importance in their own right: as we have seen, carers are the main source of social interaction for some of our participants. However, timely and effective support are also a means to an end, and can enable older people with high support needs to get out and about, and to participate in social activities' (Authors, p37). 'If I really wanted to go somewhere and I asked if they could sort it out, the staff, they would sort it out. (Male participant, aged 50, with tetraplegia). Conversely, where support is unpredictable, inflexible, and unresponsive or provided at the wrong time, it	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		can prevent people from doing things that are important to them and may even make life more difficult. 'Sometimes she's not here till about 10.00, maybe sometimes after 10.00 … she's got so many others to do, they need more done than what I do so I just have to accept it … I'd rather it was a bit earlier, but there's nothing that can be done about it, so I just have to get on with it and accept it and that's it' (Female participant, 85, who has mobility problems, p37). iii. Other people's time Often mentioned by many participants is the importance of carers having enough time to spend with them, not only to provide practical support, but also to listen to how they want tasks to be done. For those with severe communication difficulties, patience on the part of others while communicating with them was of paramount importance (p38). iv. Transport and mobility Where people had suitable mobility equipment and/or accessible transport in place, this clearly had an extremely positive impact on their quality of life: 'Tell you what's been a wonderful thing to me, has made a difference in my life, that wheelchair, it's given me a lease of life … [had it] five months … oh it's made a difference to my life.' (Female participant, 89, who has dual sensory impairment and severe osteoporosis.p 38). v. Technology and communication For those with hearing impairments, a lack of the right technology hampered communication. Two participants' problems with their hearing aids severely restricted their use of the phone or ability to hear when	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		in a group. For another participant, without a loop system, she had to have the television on so loud that she disturbed the neighbours. 'You see I have to have it on louder than I thought it was, 'cause I would hate to upset the neighbours … I have to explain that I'm deaf and blind... so hopefully [her support worker] is going to get me a loop system 'cause it's the only information I get on the news here …' (Female participant, 89, who has dual sensory impairment, p39).	

31. Komaromy C, Sidell M, Katz J (2000) The quality of terminal care in residential and nursing homes. International journal of palliative nursing 6, 192–200

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Study aim This study provides both an overview of death and dying in care homes and a more in-depth analysis of the care available to dying residents, their families and friends. **Methodology** Mixed-methods study The study involved three stages — a postal questionnaire (Stage 1), interviews	**Participants** Older people receiving social care **Sample size** For the survey - 10 035 residents (approximately 2% of the total resident home population in England). Interviews – structured and semi-structured elements with 100 heads of homes who were randomly sampled from the responses to the postal survey. Setting: Local authority, private and voluntary residential, voluntary nursing (with some NHS beds), and private and voluntary dual-registered homes were included in this study.	**Findings** Good quality care was influenced by internal and external factors. Staffing levels were a critical factor. Heads of homes noted that the workload varied according to the unpredictable nature of care work, where terminally ill resident placed huge demands on staff. Nursing home residents were more dependent and often had multiple and complex needs associated with extreme old age, required intense care and support. Increased demands when someone was dying included extra nursing care, spending as much time as possible with the resident, and providing support to visiting family and friends. At interview, 21% of the heads of homes in private, voluntary, and local authority homes said that poor staffing levels adversely	**Overall validity rating** -

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
with heads of 100 homes (Stage 2) and 12 case studies (Stage 3). **Country** UK - three distinct regions of England, the Northwest, the West Midlands and the Southeast. **Source of funding** Not reported		affected the quality of care that staff were able to provide to dying residents (p193). Heads of homes expressed that the problem was not only having enough staff to free someone to care for and sit with a terminally ill resident, but also that the demands of the work made it desirable for end of life care to be shared among several staff members (p194). The case studies illustrated the challenging nature of EOLC at night, where a lot of physical care, e.g. changing someone who was incontinent and alternating his/her position to relieve pressure, required two or more members of staff. This often meant that residents in other parts of the home were ignored. Two-thirds of heads of homes did not understand the principles or practice of palliative care. Of those interviewed who did, they could not see its relevance beyond caring for someone with cancer. The authors saw this as one of the most striking features of the research. The specific needs of dying residents were seen in terms of pain relief, the maintenance of dignity and being attended to, as end of life was imminent. The heads of homes felt that dignity was difficult to define, but those who did so most often associated loss of dignity with physical deterioration and decline. And many heads of homes assumed that older residents are resigned to death. The structure and location of homes also influenced the care dying residents received: The geographical location of a home hampered the ability of family and friends to visit especially if they had problems with mobility or were reliant on public transport. Many homes were converted from large old family homes and were not always set up to observe residents when they were ill or physically and mentally frail. Larger homes were often divided into	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		smaller units in an effort to create a homely atmosphere. Residents in some homes did not mix with people in other parts of the home, esp. when similar residents, such as the mentally confused and physically frail, were grouped together. This could increase the isolation of frail and dying residents within the home. Attending to residents, especially at night, inevitably meant that residents in other parts of the home were ignored and isolated. Not all of the residents were able to use the call system and residents who were dying were often those least able and consequently unable to call for help. One resident who was sharing a room with a dying person said that she had to call for help when her room-mate needed it (Resident, p197). A bedroom's size, layout and facilities greatly affected the ease with which care was given to someone who was ill, as well as the way in which relatives could be accommodated. GPs - 52% of heads of homes thought that the GP support was mixed. Five homes had 12 practices serving the home residents, and up to nine GPs from one practice may attend a dying resident. Keeping the same GP practice did not therefore always ensure continuity of care. A minority of the heads of homes thought that the support given by community nurses was limited. Continuity of care also identified in some homes.	

32. Mair M and McLeod B (2008) An evaluation and assessment of deferred payment agreements. Edinburgh: Scottish Government Social Research

Research aims.	PICO (population, intervention, comparison, outcomes)	Findings.	Overall validity rating.

Study aim The main aim of the research was to explore with care home residents and their relatives, their understanding of, attitudes towards, and experiences of DPAs, and identify potential for increasing uptake of DPAs. **Methodology** Qualitative study The research was based on 14 local authorities, and used qualitative methods to gather information from residents and their relatives, older people in the community and local authority officials. Fieldwork was carried out as follows: • One–to-one interviews with 4 individuals who have gone through the process of setting up a DPA, gathering views and experiences of the process • One-to-one interviews with 6 individuals who have no DPA in place, including a mix of individuals who have sold their property prior to moving into care, or who have had a Charging Order placed on their property as an alternative to a DPA, gathering views and experiences of the processes they had been through • Focus groups with 2 community-based groups of older people	**Participants** Older people receiving social care care home residents Professionals/practitioners Local authority officials Carers/family members Relatives of carers **Sample size** A sample of 14 local authorities was chosen to participate in the research. Figure 3, page 10 shows 7 'Routinely offer DPAs and have DPAs in place', 3 'Routinely offer DPAs and have no DPAs in place', 2 'Offer DPAs when the resident asks about them', 2 'Never offer DPAs'.	**Findings** The findings that follow are barriers to accessing care and deferred payment agreements (DPAs) as reported by residents of care homes or their relatives: Page 12: "Those who took part in the research revealed that the period leading up to their relative requiring a care home place, and the act of finding a suitable one, were both extremely stressful. Many of the relatives had had to cope with a period in which their relative's health had rapidly deteriorated and they had to arrange home care support for their relative, as well as experience a period where their relative had been hospitalised. Several of the participants described the process of choosing a care home for their relative as traumatic with many care homes being visited before they found a suitable one." "In all but 2 cases, those interviewed had no prior knowledge of the possibility of deferring payments for care home fees prior to their relative being assessed as needing a place and undergoing a financial assessment. Indeed, until the time of needing a place, few families had given any thought as to how they would finance it or the options available to them. Several	**Overall validity rating** +

gathering information relating to knowledge of DPAs and attitudes towards relevant issues relating to payment of care home fees • One-to-one interviews with 10 local authority representatives from social work finance. • 2 one-to-one interviews with front-line social work staff responsible for advising residents about funding options and arrangements, to gather information on practices and views in relation to DPAs and Charging Orders • Additional one-to-one interviews with a further four local authority representatives, which included staff from social work finance and legal services. **Country** UK Scotland **Source of funding** Government Scottish Executive		participants had been confused with the introduction in Scotland of free personal care for the elderly, wrongly assuming that this would mean that their relative would not have to contribute anything towards the cost of the care home place. Others thought that their relative would have to contribute, and that their house would have to be sold prior to them moving into the care home, or as soon as possible after this." "The 2 participants with prior knowledge of DPAs both knew about this option primarily because work colleagues had informed them." Page 13: "While a few of the residents we spoke to were very pleased with the information that they were given about the options that were available to them in terms of funding the care home place, around half were very dissatisfied. Most participants, therefore, said that it was of paramount importance that they should be provided with clear and comprehensive information about funding options." "The sources of dissatisfaction noted by participants included: • No information provided about alternatives available for deferring payments for care home fees. One participant heard of DPAs for the first	

		time during the process of the research. During the interview with her, she told us that the local authority had not mentioned any possibility of deferring care home payments either through a DPA or a Charging Order. • Obtuse language used in the literature provided by local authorities. Several of the participants indicated that the language used in letters and leaflets they had received from the local authority about the choices available to them was quite difficult to understand, and that frail older people may struggle to comprehend them. • Lack of knowledge of DPAs among frontline social work staff. One participant, who had been aware of DPAs prior to contacting the council, informed us that the social worker she contacted about deferring payments did not know what a DPA was, and was unable to provide any information to the resident and her family at that point. • Negative presentation used by local authority staff in their description of DPAs. Some participants felt that the description of the DPA they were given by the local authority was extremely negative. One participant stated that she felt that the officer she spoke to was trying to put her off applying for	

		one. She was advised that, “she would have a fight on her hands (to uptake a DPA) and would have to wait for months to see the agreement concluded”. Another participant stated that they had been informed that there would be “high” interest charged on payments, in addition to the other obligations involved in entering a DPA. In fact, no interest is charged until 56 days after the death of a resident and this advice suggests a lack of understanding of the detail of the procedure amongst front-line staff. However, in this case, the issue of interest being added to payments ended the participant’s desire to pursue the DPA. Furthermore, another participant stated that the local authority had been keen to point out the more onerous aspects of setting up a DPA, such as being responsible for insuring and maintaining the property for the length of the agreement, without at the same time describing any perceived benefits from entering into such an agreement." Page 16: "In terms of the understanding of DPAs among the representatives of residents who were interviewed, it was apparent that not all understood what a DPA was; in fact one participant had never heard the	

		phrase until the actual interview itself. Such variation in the level of understanding is perhaps unsurprising, given the lack of information about DPAs provided by local authorities, as highlighted in the previous section." "The confusion that undoubtedly exists amongst relatives of care home residents is not confined to the issue of DPAs. It was clear that many of the residents interviewed found various aspects of the funding arrangements and the process of placing a relative in a care home to be complex. One respondent said that she had not been aware that her father's property would be part of the equation when the local authority assessed his contribution to the care home cost; another thought that the introduction of free personal care had meant that her sister would not have to pay anything towards the cost at all." Page 26: 4 main barriers were identified in terms of what prevents care home residents and their families from applying for a DPA. 1. The research has found varying practices across local authorities in terms of offering and promoting DPAs and this is likely to have acted as a barrier to uptake. 2. Lack of infor-	

		mation being passed by local authorities to residents about the ability to enter into such an arrangement with the local authority in the first place. 3. One of the other main factors deterring care home residents and their families from entering a DPA is the upfront cost associated with setting up a DPA. These costs include lawyers' fees as well as charges (up to £500) levied by the local authority. 4. The level of bureaucracy surrounding the DPA process was quite off putting to older people thinking of entering residential care.	

33. Malley J, Towers A, Netten AP et al. (2012) An assessment of the construct validity of the ASCOT measure of social care-related quality of life with older people. Health and quality of life outcomes 10, 21

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim This paper aims to demonstrate the construct validity of the ASCOT attributes. **Methodology** A survey of older people receiving publicly	**Participants** People receiving home care Older people (aged over 65) using home care services who had indicated that they were happy to be approached to take part in further research. **Sample characteristics** Sex	**Framework areas** Respect, dignity and control Personalised support Info and comms Active participation in lived experience of care Continuity of care and transitions (incl. access) Care and support for people's needs	**Internal validity** ++ **Overall assessment of external validity** ++

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
funded home care services was conducted by face-to-face interview in several sites across England. Data were collected face-to-face through computer-aided personal interviews in people's homes during 2009 in ten geographically dispersed locations across England. The interviews gathered socio-demographic information and details about service receipt and informal support. **Country** UK England **Source of funding** Other This project was funded by the UK National Institute for Health Research (NIHR) Health Technology Assessment	Table 2: 68.1% female. Ethnicity Table 2: 98.3% white ethnicity. Sample age Older people (aged over 65). Table 2: Age (n = 301) 65 to 69 27 9.0%; 70 to 79 95 31.6%; 80 to 89 137 45.5%; 90 and above 42 14.0%. Socioeconomic position Table 2: Income (n = 182) £275 or less per week 122 40.5% £276–374; 40 13.3% £375–424; 13 4.3% £425–£574; 2 0.7% £575 per week or more 5 1.7%. **Sample size** In total, 566 contacts were attempted from a sample of 778, producing 301 (53%) complete interviews. **Costs?** No.	**Narrative findings** The authors report that their study shows evidence to support the construct validity of the ASCOT attributes. A number of key findings are reported in relation to the sample of older people included. However, the key findings of interest to RQ4 are those reporting on the validity of ASCOT as a measurement tool. With respect to this, the authors report that it is feasible to use ASCOT with older people. They found that "all 301 participants responded to every item in the instrument" (Authors, p12). Having said that, a significant minority of responses were proxy, which the authors report was at a higher rate than for other QoL measures/tools. The authors say that they think suggests the respondent lacking the capacity to answer survey questions – but to answering survey questions in general rather than the ASCOT questions specifically. The authors summarise from their analysis of the distribution of the ways the items were scored that they "seemed plausible" (Authors, p12). They argue "although the distributions were skewed towards good outcomes, if services are doing their job properly this type of distribution is to be expected" (Authors, p12). A key finding was that the items related to Food and drink and Accommodation were found to be highly skewed. The authors report that they tested the revised wording in a parallel piece of work (reference provided in the paper) and the new wording "achieved better distributions in a sample of equipment users" (p12) – note this is a different group of sample respondents to the one reported in this paper. See limitations below, the authors report that more work needs done on testing the reliability of the ASCOT measures for older people and they also suggest the	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Programme (project No. 06/96/01).		instrument should be validated on a sample of younger social care users.	

34. Mathie E, Goodman C, Crang C et al. (2012) An uncertain future: the unchanging views of care home residents about living and dying. Palliative medicine 26, 734–43

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim This research aimed to explore the views, experiences and expectations of end-of-life care among care home residents to understand if key events or living in a residential environment influenced their views. To the best of the authors' knowledge, this is the first English study to interview care home residents at different time intervals over a year and examine how their views and expectations are shaped by the experience of living in care homes.	**Participants** Older people receiving social care Administrators, commissioners, managers Nine care home managers were invited to participate in the study by letter, and those who expressed an interest were then visited by the researchers. **Sample characteristics** *Sex* Figures from the larger sample of 121 as follows: 94 (77.7%) females 27 (22.3%) males. After 31 dropouts final sample was 63. Final gender numbers not provided. *Sample age* 61–102 years *Level of need* Nearly half (46.2%) of the residents	**Framework areas** Respect, dignity and control Info and comms Continuity of care and transitions (incl. access) Care and support for people’s needs **Narrative findings** The research concluded that older people are able to talk about living and dying, over time, but experience, observation tells them that choice in EOLC may be restricted. There was a diversity of views on the amount of engagement with discussion about dying. A degree of acceptance of their situation in the care home seemed to have some bearing on residents’ ability to plan for the future. The findings challenge those that suggest that older people, as they become more unwell, want ‘more’ intervention not less (Winter L and Parker B. 2007). BARRIERS (page 737): Living in the present. Across the six care homes, just under half of the residents did not think they could plan for the future (theme 2 a: Future is uncertain, 2 b: Live day to day). For some of this group the future was by definition uncertain, and they were not convinced that advance planning would be helpful (theme 2 a). (Page 738): In all six care	**Overall validity score** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Methodology Mixed methods The study used a prospective design with a mixed method approach, and data were collected during 2008–2009. This paper reports on interviews with a sub-sample of care home residents across six care homes. The other parts to this study, not reported in this paper are: The aspect of care home culture was measured by a tool to establish the attitudes and belief systems of the care homes, and espoused approach to end-of-life care. Review of care notes four times over a year (the data for which are provided elsewhere) of all residents who had capacity to understand the aim of the study and consented to taking part. Separate interviews with nine care home managers who	had three or more co-morbidities recorded (median 2, mean 2.7). The three most common recorded diagnoses were dementia (38%), disorders of the circulatory system (excluding cerebrovascular accident) (38%) and musculoskeletal system (28%). Length of stay in care home: 18.5 months (median) 26.8 months (mean). **Sample size** Of the 257 older people who were resident in the care homes at the start of the study, 121 agreed to participate in the study (47.1%). Ninety residents (74.4%) completed the study and 31 dropped out of the study (23 died, five went to hospital (and did not return to the care home) and three went to other homes). Of these 121 residents, 63 from across the six care homes were interviewed up to three times over the period of the study. The residents were recruited from six care homes (identified through CQC directory) which provide personal care (washing, dressing, help with medicines but have no on-site nursing) in three disparate geographical areas and were purposively selected to include a range of providers (not for	homes, a minority of residents were sad and depressed about their lives in the care home (theme 3c. There is no future - depressed). For some, loss of purpose and the limited ability to make a contribution were recurrent themes in discussion about the future and how it felt pointless, including that care home staff may not have acknowledged the impact of these feelings. Three older people were clear they did wish to be admitted to hospital again after having negative experiences. It was not apparent as to how or if these views had been recorded in the home's care notes. (Page 739): The majority of residents, when asked if they would like to stay in the care home or go to hospital at the end of their life, said they would choose the former. Despite this, few residents had been asked to sign anything in this respect, and little evidence of their wishes was apparent in the care notes. If they became very ill they might have to be transferred to a nursing home or a hospital, and they felt they had no control or choice over this, and it would probably be up to a GP. Many residents felt they did not have choice. (Page 740): Very few residents said they had had a conversation with the care home staff about end of life, most saying they did not want to, even though some of the care homes were using care home-specific palliative care support tools, including advance care plans. The residents' felt that staff might not be that interested, that family members were the ones to talk to, or that there was nothing to talk about. Residents wanted to have someone to talk to about their past, their life in the care home, or just to be listened to. They described the staff as friendly, but felt staff were too busy to engage in the kind of	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
were invited to participate in the study by letter. **Country** UK **Source of funding** Other commercial source NIHR	profit, faith based, large chain), different in size and variable staff training on end-of-life care. **Costs?** No.	conversation that could follow on to talk about end-of life. FACLITATORS (page 737): LIVING IN THE PAST - Living in the past could also reflect the person's cognitive state at the time of the interview (theme 1 b: Living in the past), when discussing the future could be inappropriate if it was contradicting the person's sense of reality. Discussions about end of life care planning for those residents had to be tailored very differently. (p739): There was only one example of where decision-making and the development of a plan were done with a member of staff. At the first (research) interview the resident had been left with some forms to complete; by the second interview she had had a discussion with the manager: 'if I have a fall and I might be injured I don't mind going to hospital but I don't want to be kept in unless I've broken something and if they decide I'm dehydrated... rather come back here and be dehydrated, than in hospital. If I die I don't want to be resuscitated, if you know what I mean' (2nd interview). By interview three, she had written down her wishes. Page 740: The choices for end-of-life care are not always clear-cut for people living in a care home, especially where residents are not identified as being, or do not see themselves as being, at the 'end-of-life'. Many residents were not very worried about or aware of end of life care choices. Thirdly, the choices available are far more complex than a simple choice of either/or decisions (Authors).	

35. Miller E, Cooper S, Cook A et al. (2008) Outcomes important to people with intellectual disabilities. Journal of Policy and Practice in Intellectual Disabilities 5(3), 150–158

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim To ascertain the views and experiences of what outcomes service users with intellectual disabilities prioritise. **Methodology** Qualitative study - Data collection was qualitative with service users with intellectual disabilities (and a small proportion of carers supporting the service user) who are accessing various services. The relevant method of data collection is in the form of interviews. Note: The **initial phase (developing and piloting interview schedule)** of the research project sought to build upon earlier work conducted	**Participants** People receiving social care - Central England People First recruited 35 participants with intellectual disabilities from their local branches across England and Scotland and these were interviewed in the focus group. The research team interviewed 87 participants with intellectual disabilities and 12 of these interviewees were supported by their carers. It is important to note that "the project included service users and a small number of carers from three distinct service user groups: people with intellectual disabilities, users of services for older people, and users of mental health services" (p151). The research here focuses on the participants with intellectual disabilities; however, there is a reference to the other user groups. **Sample characteristics** *Sex* There is no information about the characteristics of the participants interviewed by the Central England People First (CEPF). The interviews	**Framework areas** Continuity of care and transition (incl. access) Care and support for people's needs **Narrative findings** The research team collected views and experiences from 87 individuals with intellectual disabilities, and in 12 instances, both paid and unpaid carers' views were collected as they supported the interviewee. The type of service and number of participants varied between the five study sites. The authors note that the contribution from CEPF focus groups is limited due to the nature of the questions about process outcomes rather than quality of life outcomes, and also because of the possibility that the CEPF is an advocacy organisation: *"... there members were more used to speaking out about experiences"* (Authors, p155). The relevant quality of life outcomes are reported here; these concern employment, social and community activities, safety, where you live, and wellbeing. ***Outcomes: Quality of Life*** These outcomes most reported were about activity and social contact.	**Overall score** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
by the Social Policy Research Unit at York University (SPRU)[1], and to develop and pilot an outcomes-focused interview schedule with service users. The research team involved researchers from the University of Glasgow working with service user researchers and researchers from the learning disabilities advocacy organisation Central England People First (CEPF). The **second stage**, (which is reported in this table) using the adapted interview schedule, was to identify whether partnerships were delivering outcomes to users. Interviews were conducted across five	conducted by the research team interviewed included 48 females and 39 male service users, 'so as not to exclude people with more profound intellectual disabilities altogether, we interviewed carers as proxies on 12 occasions' (p152). *Sexual orientation* Not reported. *Disability* Not reported. *Ethnicity* Not reported. *Sample age* Not reported. *Level of need* Not reported. *Socioeconomic position* Not reported.	<u>i. Having things to do</u> In a large proportion of interviews in each of the five study areas, employment was fundamental and it was reported that some participants would like to have a paid job. Additionally, some participants spoke about their volunteering as their main activity, highlighting the satisfaction in 'having the opportunities to learn life skills with a view to increased independence' (Authors, p153). <u>ii. Seeing people</u> In some rural areas, geographical location and transportation was cited as having an impact on social activities impacting on social isolation. A majority of service users mentioned the importance of regular contact with staff. One service user spoke about having an increased confidence as a result of support from the LD team in the urban south England setting. One woman living in an urban area in south England commented: *"My key worker will come here and talk, if I want to or the others…if they've got five minutes"* (Study participant, p154). Conversely, two issues were raised which was about the continuity of staff relationships with service users and staff shortages.	

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[1] Social Policy Research Unit at York University, identified three outcomes: maintenance (support to the quality of life), process (how services are delivered by staff), and change (making things better) (pg.151). (Nicholas, E., Qureshi, H. & Bamford, C. (2003). *Outcomes into practice*. York, UK: Social Policy Research Unit, University of York.).

Research aims	**PICO (population, intervention, comparison, outcomes)**	**Findings**	**Overall validity rating**
partnerships supporting people with learning disabilities. **Country** UK - Scotland **Source of funding** Not reported.	**Sample size** Total of 87. **Costs?** No. Not reported.	iii. Safety A majority of participants stated that social contact helped them feel safe, with several interviewees in service 3 commenting that contact with staff improved their feelings. One woman commented from rural Scotland: *"It's helped me to get over my stress… somebody to turn to when I go high. I've got a phone number down if I get any problems"* (Study participant, p154). iv. Where you live/living as you want Those in supported living reported a positive lifestyle especially having control over their lives. One paid carer (urban south of England) commented on the dramatic communication skill improvements an individual had gained now he was in supported accommodation: *"…he was moved around a few times to different places and it must be so unnerving… he was so unsettled and he was really frightened looking and wouldn't sleep at nights or anything like that and now he's been here for a couple of years he's got used to , he's more settled. I think it's the longest time he's stayed in a place"* (Carer, p155). ***Outcomes: How service users were treated in the service (p155)*** i. Valued and treated with respect	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		Some people with learning disabilities commented on the importance of services treating service users equally, ensuring professionals maintain their confidentiality and convey the right to access services: *"I think it's really good. Because, just because we've got learning disabilities doesn't mean that we should be you know taught differently, like a child or anything like that you know"* (Man, rural north England, Day Services, p155). <u>ii. Being listened to</u> Noted by many service users, being listened to is about one to one professional support and communication. Findings reported in an urban south of England day service, recorded that over half of participants commented that not being listened to can be a problem, which authors suggest is potentially due to resources and staff shortages. <u>iii. Choice</u> Choice was a valued outcome. In the focus group conducted by CEPF some participants felt they had "little control over their lives in residential care, and therefore placed high value on choice and having a say" (Focus group, p155). The research team reported that a large proportion of interviewees enjoyed having a variation in activities they can choose, but also the capacity to opt out if they just want to have a day off. Having choice over where they can live was also important.	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		A man from a day service in the south of England reported that their service had a forum called the 'Parliament': *"The Parliament – you decide what's good and what's not good and then you tell the different resource centres and all the places"* (Study participant, p156). iv. Reliability Reliability was not spoken about, nor did interviewees have many examples; however, generally positive experiences were noted. Where interviewees had negative experiences, this was due to professionals being late or not turning up, again potentially authors suggest this could be due to resources and staff shortages.	

36. Murphy J, Gray CM, Cox S (2007) The use of Talking Mats to improve communication and quality of care for people with dementia. Housing, and Care & Support 10, 21–27

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Study aim The central aim of this project was to examine the effectiveness of Talking Mats as a communication resource to enable people with dementia to express their views about their wellbeing.	**Participants** People receiving social care Although the study seems to imply that all participants were care home residents, for example by saying that care staff knew all of them individually, and by saying that it followed on from another similar study where seven people who had recently been	**Framework areas** Respect, dignity and control The researchers state that the participants were better able to communicate about their wellbeing by using Talking Mats than through structured or unstructured conversation, and thus could make care staff better informed about their support and care needs. Personalised support	**Overall score** -

Research aims.	**PICO (population, intervention, comparison, outcomes).**	**Findings.**	**Overall validity rating.**
There were two principal research questions: • Do Talking Mats help people with dementia communicate? • Are Talking Mats effective for all people with dementia, or do only those in the earlier stages of the illness benefit?' (p24). **Methodology** Qualitative study **Country** UK **Source of funding** Voluntary/Charity Joseph Rowntree Foundation	admitted to a care home participated, it is not actually stated explicitly. **Sample characteristics** *Sex* Not reported. *Sexual orientation* Not reported. *Disability* All participants in the study had dementia, although the severity varied. *Ethnicity* Not reported. *Sample age* Not reported. *Level of need* The level of need is not stated. However, it seems likely (although not stated explicitly) that the participants in the study were all care home residents, and so would have had more need of support than the general population. Additionally, all suffered from dementia, although to varying degrees, which would also be an indicator of a higher level of need for support. *Socioeconomic position*	The researchers state that the participants were better able to communicate about their wellbeing by using Talking Mats than through structured or unstructured conversation, and thus could make care staff better informed about their support and care needs. Info and comms The reviewers felt that the Talking Mats enabled the study participants to communicate better about their wellbeing than other methods it was compared to - structured and unstructured conversation. **Narrative findings** The study states its findings in three bullet points: • Talking Mats were shown to be more effective than both structured and unstructured conversation in allowing people with dementia to communicate their views about their wellbeing. • Talking Mats improved participant understanding, researcher understanding, participant engagement and the amount of time the participant remained on track. These improvements were particularly evident in people with moderate and late-stage dementia. In addition, Talking Mats reduced perseveration, increased the amount of time spent on tasks and improved the reliability of the information provided by the person with dementia. • Finally, although people appeared to become less able to place the Talking Mats symbols as their condition progressed, some people with late-stage dementia were still able to express nuanced views and to make use of the entire three-point visual scale' (p25).	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
	Not reported. **Sample size** 31 people with dementia participated in the study. **Intervention** *List interventions of interest* The intervention consisted of using Talking Mats as a way of enabling people with dementia to communicate. This was compared with communications with the same sample on four familiar topics, using two other techniques: unstructured (ordinary) conversation and structured conversation. All conversations were videotaped, and the completed Talking Mats photographed, and then the communications analysed and compared. 'Talking Mats consist of a textured mat on which picture symbols are placed as a conversation progresses. Three types of picture symbols are used to represent: • the topics to be discussed • the options relating specifically to each topic • the visual scale to allow people to indicate their general feeling about each option' (p23).	However, the report does not provide any details of how these conclusions were reached, save to state that the video recordings of the conversations were studied by two researchers and a final year psychology student in order to reach them. No examples are provided of how or why one form of communication was considered to be better than another, making it hard to know how much weight to give to the findings.	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
	Costs? No No data is reported about costs.		

37. Norah Fry Research Centre (2010) 'It's all about respect': people with learning difficulties and personal assistants. Bristol: Norah Fry Research Centre

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim The aim is to 'find out more about what makes good support for people with learning disabilities, particularly those who use direct payments or have one–one support through organisations or agencies' (p1). This is conducted through individual and group interviews with 19 people with learning disabilities, in some instances supported by their PA/Carer/Family member.	**Participants** People receiving social care - Interviews with service users: 19 Professionals/practitioners Carers/family members - Interviews with personal assistants who support the person with learning disabilities: 14. Interviews with parents or carers: 8. **Sample characteristics** *Sex* No information is reported about participants. *Sexual orientation* No information is reported about participants.	**Framework areas** Personalised support Active participation in lived experience of care Continuity of care and transitions (including access) **Narrative findings** Relevant findings are reported under a section dedicated to ascertaining the views of people with learning difficulties. These are reported under three categories on page 9. These were: a) independence and control; b) things people did with their Personal Assistant (PA); c) what people felt about their PA. Please note that the majority of interviews were conducted with their PA present. All participants felt that having a PA present had given them positive opportunities in life.	**Overall score** -

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Methodology Qualitative study – 'This stage of the project involved visits to 6 direct payment schemes to carry out group, individual and pair interviews with: 19 people with learning difficulties; 14 personal assistants or support workers; 9 managers of direct payment support schemes or provider organisations; and 8 parents or carers'. Service user interview data provided in tables. **Country** UK **Source of funding** Voluntary/charity - Norah Fry Research Centre and the Big Lottery	*Disability* All participants had a level of support needs and were eligible for social care support. There was a variation of learning difficulty and language ability ranging from differing levels of independence, to one participant with complex needs who was not independent or able to communicate. *Ethnicity* No information is reported about participants. *Sample age* No information is reported about participants. *Level of need* The participants' level of support ranged from one with one–one support for periods from 2 hours per week to 24 hours. *Socioeconomic position* Where participants live is reported in table 2 (p3): rented flat (7); family home (5); rented house (2); unknown (2); own house in shared ownership (1); temporary hostel (1); family placement (1).	a) Independence and control Questions explored if having 1:1 PA support helped to promote independence. The study found that independence means two different things. The first being about 'doing things on your own', which made people feel proud of themselves but it also concerned being able to cope with household tasks unaided, and being 'left alone' to get on with things. The following comments illustrate this theme: *"It's much better. I can get out a lot more, and do more for myself"* (Study participant, p9). *"Another thing I do, I do the ironing myself, I do my bedroom, I do my friend's washing and ironing. Last night I did four hours of ironing"* (Study participant, p9). *"When I go on holiday every year, and we don't have to have the staff with us"* (Study participant, p9). The other aspect of independence was about participants' relationship with their PA and having a more equal partnership. Participants expressed having choice over day-to-day activities, albeit there was a reported routine for domestic chores and personal care. The author summarises that 'moving towards greater control and independence has to be done as	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
	Sample size Total of 50 interviews, however 19 interviews were with service users. Other interviews were carried out with managers (9) of DP support schemes or provider organisations; personal assistants who support the person with learning disabilities (14); and with parents or carers (8). The purpose of the research question will not be reported here. **Costs?** No – Not relevant.	a joint effort, and we must remember that new skills and attitudes may need to be fostered both in people with learning difficulties and in the staff who support them' (Authors, p11). b) Things people did with their PA The general support a PA offered participants was about going out, shopping and money management. When asked what participants want support with, participants reported that the support received from his PA meant he brought food rather than vast CDs. Interestingly to the authors, emotional support was an area that PAs offered, as one man reports: 'We chat about how I feel about things, don't we? I tend to get stressed. I tend to get a little bit stressed – it can't be helped, can it?' (p12). Most participants commented that they just 'go out' with their PA, providing people with company and structure to their week. In one instance, the PA added a social aspect because they would go to the pub together, meeting up as friends to play pool with the PA's own friendship circle, adding to the participant reporting feeling included in his community. PAs were reported to negotiate aspects of their life and advocate on behalf of the participant. Instances	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		where this was necessary were described in the text as being involved with the police: 'in one case because of mistaken identity; in other cases because of becoming a victim of physical abuse' (p12). c) What people felt about their PA Notable themes around what qualities participants appreciate were about trust, mutual friendship and equality, and proactivity. i. Trust Participants commented on getting to know the person well because of the 1:1 support offered. ii. Mutual friendship and equality Participants discussed 'give and take', where the relationship was one of mutual friendship and equality. One participant stated he bought his PA a pint in the pub, another commented: 'It's about them understanding you, and you understanding them, isn't it?' (p13). iii. Proactivity Participants appreciated having a PA who would 'sort things out', but not necessary make decisions without consulting the person first. The response varied from people preferring their PA to stay in the background to wanting the PA to 'be quite forward in getting on	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		with things. Not too up front, but just trying to get things sorted for me' (p13).	

38. Patmore C, Qureshi H, Nicholas E (2000) Consulting older community care clients about their services. Research, and Policy and Planning 18(1)

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Study aim This study examined how Social Services Departments could routinely utilise information about the outcomes of social care for older people living in their own homes (Patmore et al. 1998). Views of different stakeholder groups were sought on two broad questions. What were important outcomes from social care? What were appropriate methods for gathering the views of older service users about outcomes achieved through their own services?	**Participants** People receiving social care Older people Professionals/practitioners Eight different sets of staff across Home Care, Day Care and Care Management, at a range of levels, were interviewed (not reported as part of this review). Carers/family members Three sets of family carers were interviewed (not reported as part of this review). **Sample characteristics** *Sex* Breakdown of male and female participants only provided for Asian men and women. As follows: Asian Older Men n=15; Asian Older Women n= 7. *Disability*	**Framework areas** Respect, dignity and control Info and comms **Narrative findings** Older people expressed a clear overall preference for individual interviews at home, which proved more appropriate than focus groups for people aged over 80. Written questionnaires were firmly criticised while views varied about individual telephone interviews. HOME INTERVIEWS All participants favoured individual home interviews because they could reach a wider range of people with health, mobility or vision problems than other methods could. Home interviews also allowed plenty of time and capacity for an older person to express their views and in their own words, which some participants felt might not be possible in group discussions and written questionnaires. People wanted to be interviewed by someone at management level with power to implement change based on their responses. Home interviews would also ensure that managers were directly confronted with the harsh	**Overall score** +

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Methodology Qualitative study 88 older users of Social Services community care were interviewed in groups, individually, or via telephone conference where senior service managers were favoured as interviewers. **Country** UK **Source of funding** Government Department of Health	Physical disabilities and dementia. *Ethnicity* Ethnic groups mentioned were Asian and Polish. *Level of need* Diverse group including older people receiving high and low levels of home care, housebound individuals, people who attend day care and people from minority ethnic groups, as well as people with physical disabilities and dementia. **Sample size** 88 older people. **Costs?** No.	realities of people's problems and living circumstances. Another recurrent theme was that senior managers had a 'moral obligation to witness first-hand the results of the services for which they were responsible' (Authors, page4). Preference for a service manager as interviewer was identified only among older people – not among their family carers, nor among Social Services clients aged under 65 in a parallel study (Bamford et al. 1998). Participants identified several desirable conditions including: plenty of notice to allow interviewees to prepare themselves; receiving an outline of the questions beforehand; the offer of a female interviewer for those women who desired this; and feedback on the outcome of interviews. (Study participants, page 4). Some older people suggested the following questions should always be asked in an interview, though without probing. •Are you managing? •Have you got enough money? •Have you got enough care or help in the home? •Can you get out of your house? •Can you make yourself a hot drink? •Do you get a diet that suits you? •Can you choose your own shopping? •Can you get a bath when you want to? •How satisfied are you with: your health? Your services? Your level of happiness? •Is there any type of help you want but which you're not getting? OTHER FORMS OF CONSULTATION I. Group discussions Group discussions received a modest degree of approval. The most positive comments about group consultations came from a focus group at a day unit for older people recovering from functional mental disorders though this has not been described in the paper.	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		The authors do note the nuances to these preferences. For example, Asian older people attending a community centre for day care felt group discussions would be helpful in eliciting their views of that care. But, they felt, individual interviews were more suitable for understanding their individual needs and the overall adequacy of their services. ii. Postal questionnaires These were generally criticised on the grounds that those with sight problems and lack of manual dexterity were disadvantaged. Furthermore, the closed question style of many questionnaires, their impersonality, the sheer number of questions and the ease with which answers could be ignored, were seen as drawbacks. iii. Individual telephone interviews There were mixed views on this medium. Some members of the telephone conference felt the phone allowed frankness. Common concerns, however, were around hearing difficulties and distance, in that a telephone conversation could not show practical problems at home. Some people seemed to have an intrinsic dislike of phones or to have manual difficulties in using them. Others did not like being phoned unprepared – a barrier avoidable through the advanced written notice used in this study. Opposition to telephone interviews was too widespread for them to be the sole method in a consultation. But they were favoured by enough people to suggest that they might be usefully offered as an option alongside other approaches. Our actual use of a telephone conference is discussed later.	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		iv. Personal diaries of service experiences A suggestion that this might be used and could be periodically borrowed for analysis for senior managers generated mixed views. Those who disliked the idea did so citing that many service users had problems with writing. Similarly, some older people liked the idea of managers making eyewitness assessments of the service, for example by visiting to watch home care staff in action. But more older people were against this or angry that their own home might be used to 'subject hard-working, well-liked home care staff to a distressing experience of scrutiny'. (Authors, page 6). CHOICE Generally the view was that different forms of consultation might suit different people, but choice was fundamental. People from minority ethnic groups broadly reflected the views of other participating groups, but also emphasised the importance of interviewing in the language of the interviewee's choice.	

39. Peace S, Katz J, Holland C et al. (2016) The needs and aspirations of older people with vision impairment: report for Thomas Pocklington Trust. Milton Keynes: Open University. Faculty of Health and Social Care

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim Primary aim:	**Participants** People receiving social care – 50 older participants	**Framework areas** Active participation in lived experience of care Care and support for people's needs	**Overall score** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
To facilitate older people with vision impairments living in community environments to express their preferences for where and with what kinds of support they would like to live. Objectives: To understand choices over lifestyle and living arrangements; To understand issues of personal identity; To consider how control and autonomy can be maintained or delegated; To address issues of risk-taking and responsibility (Authors, p13). **Methodology** Qualitative study **Country** UK – England	**Sample characteristics** Sex – Of the 50 older participants, 36 (72%) were female and 14 (28%) were male. Disability – 3 participants had been vision impaired since birth or a very young age – one of whom aged 54, was from a minority ethnic group. Ethnicity - 46 (of the 50 participants) self-defined their ethnicities as follows: White British [including White English] 32; Black British 2; Asian British 2; European 2; Black African 2; Asian 5 [excluding Asian British but including Asian (3), Indian (1) and East African Asian (1)]; Mixed race 1. Sample age - Age range was 69 to 99 years: average 79 years; median 80 years.	**Narrative findings** Key findings are presented within themes as follows. HOUSING NEEDS: Most participants lived alone, with the next largest group living with their spouse. Participants were asked if they had considered their future housing needs, and the possibility of living somewhere else. Other options such as moving to a bungalow, small flat, sheltered housing, extra care housing or residential care had either been rejected: *'I hope and pray that I never have to go into a home – I know a very nice home,… I've been in there for respite a couple of times when my family had booked holidays… but its £800 or £900 a week and I have no property to sell. I can't afford that. And there's no way the council are going to pay that sort of money. And that's the only place I'd really want to go, so I'm hoping I can manage*' (Participant, p24). HOME ADAPTATIONS: Many participants were comfortable with their current accommodation. The research examined whether they had made any alterations or adaptations to make it more suitable for the vision impairment. Three kinds of alterations or improvements were described as follows. 1. Changes that householders make occasionally to make their home more comfortable, more spacious or more modern, e.g. refitting of kitchens and bathrooms. Such improvements did not benefit vision impairment, but contributed to general wellbeing and feeling of homeliness and control.	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
	Level of need - Older people with vision impairment living in the community. Socioeconomic position - '12 participants described themselves as 'comfortably off' or 'comfortable or stated that their monthly income was equivalent at least to the mid quintile of UK pensioner incomes (i.e. 3rd level of five, from lowest to highest) based on the most recent Department of Work and Pensions calculation of mean pensioner incomes for couples and single pensioners (DWP, 2014). Nine participants fell within the second quintile, typically based on state and other small pensions and attendance allowance. Four of these participants had savings. Eleven participants fell within the lowest quintile, with their incomes typically comprising state pension and pension credit. They tended not to have any savings, and were primarily widowed or divorced women, but also included 2 men (one single, one married)' (Authors, p14). **Sample size** Sample size – 50 older participants.	2. Adaptations concerned with physical impairments or 'ageing' generally: Older participant: *'[Occupational Therapist] suggested putting a rail up there, she said if my wife was going to be discharged…She put a grab rail by the bath. There was a handle at the top of the stairs, on the landing there, so when you got towards the top you've got something to hold onto to pull you up. What else did they do? Oh they put a half step outside the front door'* (Participant, p26). 3. Adaptations undertaken specifically for vision problems – these included the installation of wet rooms and shower rooms, especially downstairs; and indoor and outdoor guide rails. Some participants mentioned kitchen improvements such as: *'Better lighting, colour contrasts, and installing window blinds to reduce dazzle*' (Authors, p26). *'Gaining advice about possible adaptions was hard to access and coupled with long waiting times for occupational therapy assessments or issues concerning funding. In a few cases, the local authority had funded adaptations, but more often they were self-funded or in some cases by a local sight loss charity. One participant described funding her own wet room after an OT decided she did not qualify for one. Another family converted an integral garage into a multi-purpose room so that the older person with vision and mobility*	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		problems would not have to go upstairs' (Authors, p27). ASSISTIVE TECHNOLOGY: The authors report that: '*Most interviewees were well versed about the latest types of aids and assistive technology available varying in sophistication and complexity. In many cases relatives or friends had scoured the internet looking for devices and priced them; sometimes participants had done this themselves or asked local vision organisations for advice. The most commonly used assistive devices were, in order of prevalence: various magnifiers (often several, in different rooms, and for image enhancement reader devices including Optelec); liquid level indicators; various labels and markers on domestic equipment; dedicated/ specialised lighting; talking clocks; talking watches and computers with special large character keyboards. Several also used personal alarms and one with poor hearing a vibrating pillow fire alarm'* (Authors, p27). The authors go on to say that: '*Beyond these commonly used technologies, there were others used by fewer people. One person used a braille clock and watch and made her own braille diaries. 'Talking' devices and services included talking books/news (one using Gujarati services); microwave ovens; and talking phones, keyboards, calculators and kitchen scales'* (Authors, p28).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		ACTIVITIES OF DAILY LIVING: The authors comment that: *'People described their activities of daily living (ADLs). How active they were related to their level of mobility, their vision, their feelings of wellbeing and how support was provided. Most participants were able to get in and out of chairs, wash themselves, put themselves to bed and go to the toilet. A small number (n=6) needed support to get in and out of bed and could not carry out basic washing or showering, or needed help at particular times*' (Authors, p30). For example, one participant says: *'At night wife has to help me to go to the toilet'* (Participant, p30). Regarding food preparation and eating, the husband of one prospective participant commented: *'She is keen to talk about technology that helps her, she has got talking kitchen scales, a talking measuring jug, a talking alarm clock and a talking calculator. She has also devices to tell her when her cup is full, and when a pan is boiling'* (Participant, p32). A VISION FRIENDLY ENVIRONMENT: The authors comment that: *'Whether accompanied or unaccompanied, going outdoors and walking in the wider community could be problematic and may require using a stick. Nine participants used ordinary walking sticks whilst eighteen*	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		used white sticks. The 'symbol cane' is used additionally to alert others to the loss of vision and users need to have training' (Authors, p34). For example, one participant said: *'The sight impairment team at the hospital put me in touch with the people who issue all this equipment. I asked for training for the long cane… and she explained to me how it works – I was taught how to use it and not to swish it around. I haven't resorted to using it yet, but I wanted to get an idea of what it was like whilst I'd still had some eyesight to judge what she was saying'* (Participant, p34). Another participant spoke about the barriers to pass the vetting system from the Guide dogs for the Blind: *'I tell you it's a real challenge for anybody who's got sight problems to actually get through their system… you have to come up to a certain level of competence, intelligence I guess, to actually manage a dog like this'* (Participant, p36). FORMAL SUPPORT: The authors comment that: *'Establishing how people initially found out about the formal support services they used was difficult as many participants could not remember. Relatively few recalled receiving home assessments from Occupational Therapists related to their vision loss at or after diagnosis. A few did remember visits by social workers / care managers. A minority had home carers visiting daily helping them with personal care which were arranged through social services or independently.*	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		Several paid for cleaning services and/or help in the garden, from weekly to twice a year, depending on their needs and priorities. Many respondents were connected to organisations that provided support for specific types of vision impairment such as The Macular Society, which focuses on a particular condition. The nature of this support varied, from advice to attending regular local support groups to hear talks from external speakers. For some respondents attending these meetings posed difficulties in terms of transport, with either practical or cost problems; but for many this was a lifeline and transport was organised through the members' (Authors, p41). The authors go on to comment that: *'Generic vision impairment organisations (such as the Blind Veterans UK, Action for Blind People, RNIB, and local sight-loss groups) provided similar support as well as additional help such as holidays, trips to local attractions and meals out'* (Authors, p41). The authors report that RNIB facilitated informal support among people with vision impairment, for example one participant enjoyed a mutual support network: '*Talk and Support' telephone connection: The RNIB connect six of us together on the phone every Thursday morning'* (Participant, p41). The authors discuss that: *'Where participants were not recruited through organisational networks they could feel very isolated as their*	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		contacts were limited to GPs and hospital clinics rather than support groups. These participants did not know how or who to challenge about changes in treatment for Macular degeneration. Other participants particularly from BAME groups were also unaware of the existence of organisations providing support for their specific sight impairment, although their pressure groups – as seen in Coventry and Liverpool - would invite people from national groups (e.g. RNIB and Action for Blind People) and manufacturers to give talks and demonstrate products' (Authors, p43).	

40. Pizzola L, Martos Z, Pfisterer K et al. (2013) Construct validation and test–retest reliability of a Mealtime Satisfaction Questionnaire for retirement home residents. Journal of Nutrition in Gerontology and Geriatrics 32(4), 343–359

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Study aim To 'investigate internal and test-retest reliability, and construct validity of a mealtime satisfaction questionnaire (MSQ) designed for residential care, more specifically retirement homes' (p343). **Methodology** **Cross-sectional study:** Survey with the	**Participants** People receiving social care 147 people in residential care. **Sample characteristics** *Sex* 76.4% female, 23.6% male. *Sexual orientation* Not reported. *Disability*	**Framework areas** Respect, dignity and control **Narrative findings** Narrative findings The study found that the mealtime satisfaction questionnaire (MSQ) has good internal reliability and test-retest reliability, and good construct validity when compared to the Philadelphia Geriatric Center Morale Scale (PGCMS). The study showed an association between mealtime satisfaction and quality of life at a particular time point. Based on this, the study authors further suggest that, to improve quality of life, satis-	**Overall score** -

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
purpose of determining tool reliability and validity. **Country** Not UK Canada. **Source of funding** Not reported	Not reported. *Ethnicity* Not reported. *Sample age* Median age=88 years. *Level of need* Not reported. *Socioeconomic position* Elementary education 19.4%, high school 38.1%, post secondary 42.5%. **Sample size** n=147 (fully completed surveys received). **Intervention** List interventions of interest Mealtime Satisfaction Questionnaire - questionnaire developed based on literature review and review of current mealtime satisfaction questionnaires. Items reviewed by an expert group. Pretesting was undertaken with a focus group of 6 retirement home residents. Final product is a 15-item questionnaire with responses on a four-point scale (Most of the time, sometimes, rarely and never).	faction with meal times should be measured and improved upon. However, this conclusion is not strictly supported by the findings of the study. No steps were taken within the study to improve mealtime satisfaction. It is therefore unclear whether improvement in mealtime satisfaction would indeed lead to improved quality of life. **Effect sizes** Response rate to the survey was 24%. The study examined the internal reliability and construct validity of the MSQ tool. Internal reliability was good (Cronbach alpha =0.83). Test re-test reliability was also good with intraclass correlation = 0.91 (95% CI 0.65 to 0.88). *Note: point estimate does not lie within reported 95% confidence interval. It is unclear why this is the case. Construct validity was measured using comparison with the Philadelphia Geriatric Center Morale Scale (PGCMS) - a scale used as a measure of wellbeing and quality of life in older adults. There was a moderate correlation between MSQ scores and PGCMS (r=0.356, p<0.01). Six individual items were positively correlated with the PGCMS (being offered disliked foods, appeal, taste, dining with tablemates, atmosphere and overall satisfaction). The overall association of these 6 items with PGCMS was r=0.444 (p<0.01).	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
	Costs?		

41. Popham C and Orrell M (2012) What matters for people with dementia in care homes? Aging & Mental Health 16, 181–188

Research aims.	PICO (population, intervention, comparison, outcomes)	Findings.	Overall validity rating.
Study aim The aim of this study was to determine to what extent the care home environment met the requirements of the residents with dementia, taking into account the views of managers, carers and staff about what they considered important and setting these findings in the context of a standard environmental assessment. **Methodology** Qualitative study Care homes managers were interviewed to seek their views on the most important factors in the environment when caring for people with dementia. Focus groups in each home, facilitated by the researcher (CP), were used to gather the views of residents with dementia, family carers and staff	**Participants** Older people receiving social care Care home residents with dementia. Professionals/practitioners Care homes managers were interviewed and care home staff were involved in the FGs. Carers/family members Family members. **Sample age** Residents aged 65 years or over. **Sample size** Five care homes within Greater London were recruited as a convenience sample through the researcher’s networks. Three were nursing homes, of which two had specialised dementia beds. One was a residential home with no specialised provision and one was	**Findings** Narrative findings Only those themes / statements that report on barriers are recorded here. Themes in relation to barriers – pages 183–187: 1. Activity and interaction – "Some residents said they were often bored, and family carers also felt residents were under stimulated. Many residents and family carers wanted more social interaction. Carers felt staff did not have time to sit and chat with residents and were often busy with other tasks. Managers recognised this need but felt staff constraints made it hard to find the time. Communication and language difficulties were noted in some homes where residents and staff might have different native languages and cultures. Staff sometimes expressed frustration that people would not	**Overall validity rating** +

as to what aspects of the environment they considered most important. **Country** UK Five care homes within Greater London were recruited as a convenience sample through the researcher's networks. **Source of funding** Not reported	a large care home providing residential, nursing and specialised dementia care. Size varied between 35 and 250 beds. All had access to a safe, enclosed garden.	speak English." 2. Freedom and safety – "Many residents felt they would have liked to be able to choose when they wanted to go outside or which room to sit in. In contrast, carers often felt that their relatives were not able to indicate their preferences, particularly as their dementia progressed. Residents expressed frustration at their lack of freedom to do as they wished, and even though all the care homes had safe secure gardens residents were disappointed that they could generally only use them when staff or visitors were able to accompany them." 3. Dignity and privacy – "Managers and staff mentioned the need to ensure privacy for residents while personal care took place but one resident noted 'sometimes the carers are rough." Page 185: "Whilst many residents participated in activities, many others did not and a number of carers expressed concerns that residents were not actively encouraged to join in." Page 186: "Whereas staff and managers saw health and safety as a top priority, residents identified their ability to make choices and have some control over their lives as more important and did not even mention health and safety."	

42. Rainbow Ripples and Butler R (2006) The Rainbow Ripples report: lesbian, gay and bisexual disabled people's experiences of service provision in Leeds. Leeds: Rainbow Ripples

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Study aim The authors describe the aims of this research as follows: .To gain an understanding of the needs and aspirations of LGB Disabled People in Leeds. .To assess current service provision from statutory, and voluntary agencies, and private businesses for LGB Disabled People in Leeds. .To gain an understanding of what constitutes good practice. .To inform service providers of LGB Disabled People's needs and how they can best meet them. .To create training materials on the issues raised for courses on health and social care. .To communicate the results of the research widely with all interested par-	**Participants** People receiving social care **Sample characteristics** *Sex* 8 were men and 12 were women *Sexual orientation* Of the 20 participants, six identified as 'Gay', 11 as 'Lesbian', and three as 'Bisexual'. *Disability* Physical impairment = 16; Blind, visual impairment = 1; Mental distress/user of mental health services (including 2 who added 'depression') = 5; Deaf/hearing impairment = 3; Learning difficulty = 2; Other impairments – listed as eczema, asthma, memory problems, Carpel Tunnel Syndrome and back problems = 4. *Ethnicity* 13 were White British. One Irish Traveller; One Black African; One White African; One White Australian; One White Welsh; One White Irish; One participant undeclared (p28).	**Framework areas** Respect, dignity and control Personalised support Info and comms Care and support for people's needs **Narrative findings** The authors summarise the unique experiences of lesbian, gay and bisexual disabled people as follows: '.There are few services which specifically consider LGB disabled people. · There are problems of homophobia in services particularly aimed at/developed for disabled people. · There are problems of disablism in services particularly aimed at/developed for LGB people. · There are interrelated misconceptions about disabled and LGB people which impact on service provision. · LGB disabled people sometimes have to deal with homophobia and disablism at the same time. The combination of the two can make their overall experience more than twice as bad as either experience on its own. · LGB disabled people have their own culture and have sometimes responded creatively to the discrimi-	**Overall score** ++

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
ties. .To raise the profile of LGB disabled people and the barriers they experience (Authors, p21). **Methodology** Qualitative study involving: i. in-depth interviews with Lesbian, Gay and Bisexual (LGB) disabled people, ii. interviews with key service providers, and iii. a questionnaire survey of a broad range of service providers. **Country** UK Leeds, England **Source of funding** Voluntary/Charity Comic Relief	*Sample age* Ages ranged from 27 to 58. **Sample size** 20 participants.	nation they face and gained personal strength, confidence and determination from their experiences' (Authors, p7). Views and experiences of LGB disabled people are discussed in the following areas: technical aids and equipment; personal assistance; and advocacy. TECHNICAL AIDS AND EQUIPMENT Page 127: i. Access to information on the availability of equipment A barrier to having what may be useful pieces of equipment is the lack of easy access to information on what is available. As one interviewee put it: 'There's a whole host of probably technical aids and equipment I could do with, but I don't know that they exist. And I probably haven't found them out. So like for undoing bottles, for taking things off...' page 127. Page 130: ii. Professionals – help or hindrance? Disabled people are usually reliant upon the expertise and advice of GPs, care home staff or other health and social care professionals, who hold power in controlling information and distributing technical aids and equipment. However, people mainly come into contact with such services at the onset of their impairment and not before. Page 131: iii. How are technical aids and equipment provided?	

Research aims.	**PICO (population, intervention, comparison, outcomes).**	**Findings.**	**Overall validity rating.**
		While self-referral is becoming more common, the need for medical assessment and health professional referral for technical aids highlights how powerful health professionals are in disabled people's lives. Many disabled people have no 'health' needs, implying that other routes should be available to access potentially helpful specialist equipment (Authors, p132). Everyday items (e.g. video recorders) can substitute for technical aids for some people, but other items may only be accessible through a small number of specialist suppliers. One interviewee recalled the homophobic behaviour of staff at an (anonymised organisation in Leeds): 'I remember asking them, the equipment officer, saying "What happens, if my alarm clocks broken, what do I do? You know, do I have to go and buy a new one, or do you replace it, or what happens." So, they knew I was gay, so they said, they just said "Get, get a man to come and wake you up. That'll be alright."... I mean I was, you know, obviously annoyed about that... Then I went through the interpreter... at the local communications support unit, so I went and said "Look I need this alarm clock now." You know, "Ring the equipment officer." You know, I explained. So the interpreter rang the equipment officer and said "Look we need an alarm clock now." And then the message came back via the interpreter saying "Oh don't worry about it, you can sleep with the interpreter and they can wake you up in the morning." So of course the interpreter is really put out by this.'	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		Page 134: iv. The cost and availability of technical aids and equipment Limited funds from a small pool of suppliers mean that the range of equipment and training in how to use it is often poor. 'Well I went, I did a Social Services assessment. Not long after I came to Leeds and I went yattering on then about doing computing...And they just wouldn't have it at all. They just won't allow Blind people, to err, to have computing equipment through their Social Services assessment. […] They don't see it as a priority. Well I'm sorry, but communi', communication is. As a political point it is a priority for blind people' (p135). Page 136: iv. The practicalities of using technical aids and equipment Technical aids and equipment have often been designed by non-disabled people with little input from disabled people. Service providers distribute unwanted and unhelpful equipment to disabled people, while direct requests for equipment by disabled people are rejected. One man who was born without one hand explains: 'I mean I had another artificial one [hand] which was a hook which worked on, it was a hook that was split […] into two that I could pick things up with and it was used by, there was a pulley system fastened to my right shoulder round to my left hand, so when I extended my left arm, these hooks would come open, and apart from looking like a bond villain, they weren't a great deal of use. […] And I had different hooks, I had a big hook, a small hook and a straight version and I had a fork that was a knife on	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		one side, a fork on the other, so (laughter) and you know the irony being, I don't use any of them really but they were the best they had for me' (p140). PERSONAL ASSISTANCE Five of the 20 LGB disabled interviewees indicated that they were receiving paid support from a personal assistant. One person commented on the homophobia and racism she had had to endure: 'At the moment I'm not getting out of the house at all because I'm not using the Independent Living Fund. I haven't re-employed anyone after a pretty disastrous experience with someone that just didn't suit at all. She was racist, she was homophobic, you name it' (p142). i. Types of assistance Personal assistance in the home with domestic and personal tasks was the most common support cited by interviewees. The assistance people felt they needed outside the home was often thought to go unrecognised by service providers. One man explained about the staff in the residential home in which he lived: 'What I get is pretty inflexible as to timing for a start. Also, errm, they claim that they're working towards independent living, but they don't provide the support that people need to go out and do things. They only provide personal support. I don't know what you might call nursing care or whatever really, even though they're not a nursing home.' 'This highlights a common frustration with the limited range of activities which professional, paid, personal	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		assistants would perform. For LGB disabled people, the ability to use personal assistance outside the home may be vital in terms of contact with the LGB community. LGB community activities tend to be organised on a citywide rather than a neighbourhood basis. Thus, a lack of willingness to provide these types of assistance may lead to a higher level of social isolation for LGB disabled people than for other disabled people, who may be able to access friendship networks more easily, through, for example the local pub or activities specifically for disabled people' (Authors, p143). ii. The nature of the assessment process Assessments for personal assistance and other needs did not take place regularly; therefore services could become out dated as people's need changed. Furthermore, what tasks individual personal assistants are willing to carry out may affect whether or not a person gets the assistance they desire and expect, or how flexible the service is. 'I need someone to be flexible. It depends what time I get my morphine. If I need to be out by 10am for a meeting I need it early, but they won't do an occasional early start' (p145). Page 145: iii. Direct Payments One woman described the low staff awareness of direct payments: 'I had a social worker who didn't know anything about direct payments. I told her what she needed to know. She hadn't had any appropriate training on it. And even though they say that they do these days, a lot of people that I know who have gone	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		on to direct payments, the social workers do not understand it at all. Errm. And it just takes an incredibly long time to get it sorted out.' Page 146: iv. LGB people's desires for improved personal assistance A person's sexual orientation, and gender were both identified as affecting the personal assistance received: 'There's also issues when I have had boyfriends there [at home]. Carers kind of. They're not very good at dealing with that whole situation really' (p148). 'I don't feel comfortable, errm, with ladies helping me with certain aspects of personal care at all really' (p148). ADVOCACY There was little awareness of the nature of advocacy services with people often turning to family and friends for advice and support. Poor advocacy services, and hence the limited control people can have over their own lives, were described by one man: 'Oh yes I have, and it's not been forthcoming. Particularly in the residential home that I've lived in, and particularly to do with sexuality issues on one particular occasion. Err, management have got a tendency to kind of gang up. The, the, they come in the meeting too strong, because I'm apparently, I'm this stroppy disabled person and, and they're scared of me in a way. They don't seem to realise that I also need support sometimes' (p153).	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		Advocates sometimes did not listen or made assumptions about the LGB disabled person: 'They didn't listen to me. They talked like I weren't there. You know. They just talked to each other' (p153). 'It just annoys me. They decide what's best for you, what you want. They assume I want to go to gay bars and stuff and I'm not into it' (p153).	

43. Redley M, Clare I, Luke L et al. (2010) Mental Capacity Act (England and Wales) 2005: The emergent Independent Mental Capacity Advocate (IMCA) service. British Journal of Social Work 40, 1812–1828

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Study aim 'The aim of the evaluation was to ascertain whether an IMCA service could protect the interests of adults who lack capacity and are without family or friends, and are faced with a potentially life-changing decision...and to identify and understand any practical difficulties that IMCAs might face following the introduction of the statutory	**Participants** Professionals/practitioners '(1) One IMCA caseworker from each advocacy provider organisation, again, just after the start of the pilot service and then shortly before the MCA came into force (fourteen interviews); (2) The person(s) in each advocacy provider organisation with responsibility for ensuring that local health and social care services were aware of the pilot IMCA service (eight interviews); (3) The decision-makers in health and social care who, having worked with an IMCA, made a substitute decision	**Framework areas** Info and comms Continuity of care and transitions (incl. access) **Narrative findings** 436 referrals were made to the pilot service, of which 249 referrals met all the criteria for eligibility. The main reason for rejecting the remaining 187 referrals was that the person referred was found to have family or friends who could be consulted. Data presented are from the 249 accepted referrals, involving 231 clients. QUANTITATIVE FINDINGS Decision-makers in health care were more likely than those in social care to have undertaken their own assessment of an adult's decision-making capacity.	**Overall validity score** +

Research aims.	**PICO (population, intervention, comparison, outcomes).**	**Findings.**	**Overall validity rating.**
service' (Authors, p1816). **Methodology** Mixed methods The quantitative data were collected by asking each participating advocacy organisation to complete a twenty-two item checklist describing each individual referred to the pilot IMCA and associated casework. Qualitative data were collected by a series of interviews with managers and practitioners about their experiences and perceptions of IMCA casework (Authors, p1818). **Country** UK **Source of funding** Government Department of Health	on behalf of an adult lacking decision making capacity (sixteen interviews); (4) Health care practitioners who had not worked with an IMCA but who had some knowledge of both the MCA and the impending statutory IMCA service (thirty-five interviews)' (Authors, p1818). Service (thirty-five interviews). Administrators, commissioners, managers '(1) each manager of an IMCA provider organisation, on two occasions: just after the pilot service was set up and, again, shortly before the MCA came into force (fourteen interviews)'. (Authors, page 1817). **Sample size** Not mentioned The exact numbers of professionals in the sample was not made explicit. However, their feedback is based on their interactions with 231 clients broken down as: .people with learning disabilities (40%) .people with dementia (33%). .a heterogeneous group consisting of adults with acquired brain injury, mental health problems, or a combination of these and other conditions (percentage not reported). .people whose capacity	Where social care decision-makers sought professional advice, this was almost always a psychologist or psychiatrist. 63% of the 231 clients had family or friends who could, in principle, have been consulted, but this was deemed by decision-makers not to be 'practical or appropriate' (Code of Practice, para. 10.77). Reasons included, 'conflicts of interest' (17%), suspicions that they had abused the person lacking capacity (11%), disagreements among different family members (3%) or disputes with the decision maker (3%) (Authors, p1820). Men and women referred for a change of address (CoA) prior to discharge from hospital were significantly older than those referred for other types of decisions. The majority (60%) of referrals for such decisions related to people with a diagnosis of dementia. The majority (60%) of referrals concerning a serious medical condition (SMT) were people with a diagnosis of a learning disability. 74% of the 231 clients used English or another spoken language, and nearly 17 per cent used another means of communication (sign language, pictures or non-standard vocalisations). Significantly, IMCAs reported that over half of the 109 clients whose referrals were completed at the end of the evaluation were able to communicate some indication of their wishes that could be passed on to a decision-maker (Authors, p1820). This enabled IMCAs to support these individuals directly in participating in decisions made on their behalf. QUALITATIVE FINDINGS i. Dealing with referrals	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
	was compromised solely by a physical illness (3%). **Intervention** List interventions of interest Pilot IMCA services offered in seven advocacy organisations that preceded the introduction of the new statutory form of advocacy. **Costs?** No	IMCAs spent just over nine hours on each referral. The mean duration of involvement was 68 days and this did not vary significantly according to the type of decision. IMCAs believed that their involvement should end only when a decision had been made and fully actioned. 'The Code of Practice requires decision-makers to keep IMCAs informed of developments (para. 10.14), and to make available in a report the information and issues that they believed to be important in respect of a particular decision (para. 10.20)' (Authors, p1821). ii. Time limited nature of IMCA role Few practical difficulties, e.g. interviewing clients privately or examining their records, were reported. However, what challenged IMCAs and their managers the most was that the 'decision-specific' and time limited (8 hours per client) nature of their role, which contrasted with other models of advocacy, stresses the significance of spending time to get to know a client before representing his or her wishes (Department of Health, 2005). iii. Change of accommodation decisions Decision-makers in both health and social care were positive about involving advocates in substitute decisions about CoA. Decision-makers in social care were impressed with the IMCAs' knowledge and saw it as an approach to improve their understanding of a client's needs, as an aid to communication between members of multi-agency teams, and as a reminder of the centrality of the client's interests when making a substitute decision. The seven healthcare decision-	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		makers who had worked with IMCAs in CoA decisions for in-patients shared similar views. iv. Serious medical treatment decisions Regarding decisions about an SMT, where healthcare decision-makers had not worked with an IMCA, the majority were not confident in involving anyone without medical training. This contrasted markedly in other situations where the same respondents were enthusiastic about the involvement of an IMCA in CoA decisions arising in the context of patients being discharged from hospital as decisions were not thought of as entirely medical. It was felt that IMCAs might be able to resolve many of the difficulties currently facing hospital discharge services, particularly poor communication between health and social care teams, and delays and problems securing funding for residential placements. The evaluation highlighted key differences between the different decisions. Health and social care decision-makers were generally very supportive of the need for, and potential benefits of, the involvement of advocates in CoA decisions. But concerning SMT decisions, healthcare decision-makers felt that advocacy was unnecessary, as clinicians believed that they were already able to establish and represent the views of patients lacking decision-making capacity, and furthermore a lack of medical training rendered their input as inappropriate.	

44. Riazi A, Bradshaw SA, Playford, editors (2012) Quality of life in the care home: a qualitative study of the perspectives of residents with multiple sclerosis. Disability and rehabilitation 34, 2095–102

Research aims.	**PICO (population, intervention, comparison, outcomes).**	**Findings.**	**Overall validity rating.**
Study aim The aim of this study was to explore how residents with MS perceive their QoL in the care home and to develop a conceptual model of QoL for care home residents with MS. **Methodology** Qualitative study Participants were interviewed individually in their care homes. **Country** UK Care homes were within a 100-mile radius of London, UK.	**Participants** Older people receiving social care **Sample characteristics** Sex Extracted from table 1 on page 2097: Gender Female 48% (interviewed) Disability Mobility indoors Wheelchair - 100% Ethnicity Extracted from table 1 on page 2097: Ethnicity White 95% (interviewed). Sample age Extracted from table 1 on page 2097: Age Mean (SD) 61.3 (9.87) Range 43–80 (interviewed) **Sample size** 21 interviewed, 16 not interviewed. Page 2096: Care homes offering nursing care and/or personal care, with both high and low proportion of MS residents were approached. Participants were recruited through their care home managers who identified potential participants, and forwarded the information about the study to participants who were interested in taking part in the study. Homes were	**Framework areas** Respect, dignity and control Active participation in lived experience of care Continuity of care and transitions (incl. access) **Narrative findings** Page 2098. Many participants spoke about the lack of control/choice: "The most important thing is for me to go home. This is not a home. In a month, I'll be in that wheelchair and I'll be gone". (Male, aged 58). However, for some they dealt with the lack of choice by accepting it and getting on with things: "I don't enjoy it, I don't like it, but you have to make the best out of . . . the best you can. I mean from my wife's point of view is, is that I think for her . . . it's not exactly for her it's, it's er I can have a quality of life if you like up there in one of those little rooms, listen to the radio or watch the TV, go to bed or whatever." (Male, aged 56). Others dealt with it by having a strong sense of 'self': "I think it's given me more confidence because one must stick up for oneself, and one could become institutionalised in here." (Male, aged 56). Some spoke of the benefits of living in a care home in relation to having on tap services: "When I was out living with my parents I think I had a physiotherapy treatment, physiotherapy once a fortnight, well what use is that there's just no use. So I mean here I have it 3 times a week, which is fantastic." (Female, aged 45). Page 2099 covers the theme of care environment and how this affects "Engagement in Activities", "Privacy", "Feeling safe" and "Personal care". For example, one person said: "I am thinking one huge advantage of this place, as it was purpose built so it's not, a really	**Overall score** ++

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
	within a 100-mile radius of London, UK. They differed in size, setting (urban/rural) and organization type (large vs. independent homes). Participants with a range of age, gender and disease duration were recruited using non-probabilistic purposive sampling. Participants were interviewed individually in their care homes. Informed consent was obtained from all participants. Participants who could not give consent and those who could not follow the interview questions did not take part. Thirty-seven individuals with MS were identified. Twenty-one residents from 10 care homes were interviewed. Recruitment stopped after 21 participants when data saturation was reached after 21 participants were interviewed. The authors state that this sample size is comparable with other studies using similar methodologies. Five of those who could not complete the interview had speech problems or could not communicate. Eleven could not follow the interview questions (p2097).	old building trying to convert it, but that cannot work every time I'm sure, erm, but having been purpose built so there's a lot of space erm, the rooms have you seen, the rooms? They're very good sizes . . . Yes the bedroom is excellent and the bathroom." (Female, aged 45). And some people mentioned improved relationships as a result of being the care home: "Well yes, I mean erm I'm glad in hindsight because the last thing I would want to do is er lumber them with me, I'm sure they would've erm been happy to look after me, but I don't think they would like to have to, er tend to me as carers here do, erm I think that's another aspect that they shouldn't see their father and in some situations I'd get into." (Male, aged 63). Page 2100: the authors point to positive attitudes as being key to doing well in care homes: "Attitude to residential living is also central to thriving in a care home." Another key conclusion was the value of support from other residents "Many residents with MS spoke of the importance of social support provided by other residents in the care home to their QoL, these included other residents with MS but also other residents of the same age and gender." (Key to this was being with people of similar characteristics to themselves.) Unlike previous research which showed a negative association between quality of life and moving to a care home, this study found the transition to care home life for MS residents did not necessarily lead to a 'loss of self'.	

45. Social Care Institute for Excellence (2009) Personalisation for Someone with a Learning Disability. SCIE TV Transcript. London: SCIE

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim No clearly stated aims in transcript. From introductory text (used as 'abstract'), the video aims to provide a case study showing how personalised, self-directed support is used by a woman with a learning disability called Angelman's Syndrome. **Methodology** Other – This is not a research study. There is no clearly stated methodology, however, the video features face-to-face qualitative interviews with family members, and scenarios from the life of a woman with a learning disability. **Country** UK	**Participants** People receiving social care Carers/family members – The video includes H's (female service user) dad, mum and sister. **Sample characteristics** *Sex* The video is focused on the experiences of one female who uses services and her family. *Level of need* Hhas a learning disability, epilepsy and is also partially sighted and has no speech. **Sample size** Not applicable – This is not a primary research study. The transcripts do not provide details of sampling. **Costs?**	**Framework areas** Respect, dignity and control – Female participant has no speech. Her mother describes how important it was to find out from people close to her what she would want from a personal budget. "We got a written account from everyone, which was quite a moving experience in itself, to get something written by each member of the family and people that were close to (daughter) as to what she would want from this personal budget" (p3, Mother of person with a learning disability). The family describe the significant impact that having a personal budget has had on their ability to enable their daughter to live the life she wants, with her family, at home. They also highlight the benefit this has on other family members. "We were at the point of our daughter going into residential care, not because we wanted it to happen but because it was the only way we were going to be able to function as a family. Being able to allow her to develop as a person, go out on her own and have her own life has given me my life back" (p4, Mother of person with a learning disability).	**Overall score** -

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Source of funding Voluntary/charity - SCIE is a charity, funded predominantly by government.		Personalise support – The focus of the video is on using a personal budget in a way that best meets the daughter's needs, specifically, this meant: - being able to pay her sister a wage as a carer to enable (daughter) to be supported by family members rather than external carers (which she didn't like) - investing in a yurt in the garden so that (daughter) has somewhere to go to socialise with her friends and her sister more independently, but still close to the house - paying for short breaks so (daughter) can build her independence but her family also get a break. Active participation in lived experience of care – The mother describes how inconsistency of support was a barrier to a positive experience, specifically, that her daughter did not like it when she was unable to be cared for by her family.	

46. Social Care Institute for Excellence (2010) Working With Lesbian, Gay, Bisexual and Transgendered People - People with learning disabilities: A gay man's story. SCIE TV Transcript. London: SCIE

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim No clearly stated aims in transcript. From introductory text (used	**Participants** People receiving social care – The video features a man with a learning	**Framework areas**	**Overall score** -

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
as 'abstract'), the video aims to provide an illustrative case study of how to support someone with a learning disability with their sexuality. **Methodology** Other – This is not a research study. There is no clearly stated methodology, however, the video features face-to-face, qualitative reports from someone with a learning disability. **Country** UK **Source of funding** Voluntary/charity – SCIE is a charity, predominantly funded by government.	disability who uses social care services. Administrators, commissioners, managers – The video features an academic from Bristol University, Nora Fry Research Centre. **Sample characteristics** *Sexual orientation* The video focuses on the needs of lesbian, gay, bisexual and transgendered people. *Level of need* Interviewee has a learning disability. **Sample size** Not applicable. **Costs?** **List interventions of interest** The video features a person describing their experiences of being supported by care workers.	Respect, dignity and control – R talks about how needs related to his sexuality were not addressed by care workers. "...I wanted to talk about having a relationship. And for every single time it was brought up, it always seems to be "Well we can talk about that a bit later on" but we never actually got to the point of talking about it..." (p2, person with a learning disability). Personalised support – R talks about taking control of his Person Centred Review by identifying who he wanted to invite, and being clear about the support he needed in relation to his sexuality. The academic in the video also described a study in which they found a lot of lesbian, gay, bisexual or trans people with learning disabilities who have the same needs and issues as LGBT people without learning disabilities and do not get the support they need. Barriers to getting the right support or living the life you want, were identified as: – workers and family members not wanting or not being able to talk about these issues with the person (and, related to this, homophobia, bullying and discrimination for the person) – concerns about risk and safety outweighing the focus on what the person wants:	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		"If you say to a support worker, 'I'm going to...hit a couple of gay nightclubs or a couple of gay pubs' the first thing they're going to start thinking of ‘are you safe? What's going to happen?...’ Sometimes they make it scarier, so people don't try things" (p3–4, gay man with a learning disability). Facilitators included: – clarity in national policy that people need to be given support in respect of sexuality and relationships – a need to challenge assumptions about who is and who isn't entitled to sex and relationships, and to challenge services to support people in the most personalised way.	

47. Social Care Institute for Excellence (2012) Challenging behaviour and learning disabilities – independent living. SCIE TV Transcript. London: SCIE

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim No clearly stated aims in transcript. From introductory text (used as 'abstract'), the video aims to describe how to provide personalised support to people	**Participants** People receiving social care – Two male service users with learning disabilities and behaviour that challenges. Professionals/practitioners – The transcript includes: – a member of care team of person with learning disabilities	**Framework areas** Respect, dignity and control – The transcript emphasises the importance of being able to communicate needs, and that behaviour that challenges can result for people with severe learning disabilities when this does not happen. "...if they can't say to us, back off a minute, give me a break, they might cast around for a way which works, a way that they can use which stops us doing what	**Overall score** -

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
with learning disabilities and behaviour that challenges. **Methodology** Other – This is not a research study. There is no clearly stated methodology. **Country** UK **Source of funding**	– a social worker supporting someone with learning disabilities – a team manager, learning disabilities support services. Carers/family members – The transcript includes the mother and brother of a person who has had behaviour that challenges, following brain damage at birth. Administrators, commissioners, managers – Professor of Learning Disability, Tizard Centre, University of Kent. **Sample characteristics** *Sex* Two male service users *Level of need* The transcript describes people with severe learning disabilities and behaviour that challenges. Male service user 1 – brain damage resulting from traumatic birth; behaviour that challenges.	we are doing, and that way might be hitting us, or screaming at us" (p1, Professor of Learning Disability). The mother of a person (Male service user 1) with behaviour that challenges talks about the positive impact made by using direct payments to recruit a specialist team to provide her son with personalised support. The team have a comprehensive plan, "a living document", that describes what he wants and what is important to him in his day-to-day life and experience. Examples are provided that show the importance and benefit of enabling people to have choice about all aspects of their life, and the benefits of this. Personalised support Info and comms – Male service user 1's mother identifies that services could have done more to help earlier in his life. Barriers to a positive experience were identified as: – lack of training for parents about how to support children with complex needs – challenging behaviour leading to exclusion from respite care so "families that have the most difficulty get	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
	Male service user 2 – profound learning disabilities, autism, behaviour that challenges. **Sample size** Not applicable —This is not a primary research study. The transcripts do not provide details of sampling. **Costs?** **List interventions of interest** The video made reference to personalised support, from trained workers, to enable people with learning disabilities to communicate their needs and preferences in residential care settings.	the least support" (p5, Mother of person with behaviour that challenges). The academic expert emphasises this, citing positive aspects of support as: – round-the-clock practical help for families – access to short breaks – access to specialist support from skilled, trained workers. Active participation in lived experience of care – The transcript describes how, with appropriate support in place, Male service user 1 can live in his own home, in the village he grew up in, near his family. The importance of this is emphasised by the academic expert who notes that, 'The best outcome for people whose behaviour presents a challenge is that they are able to live the kind of rich and varied life that we would want for anybody without needing to use their challenging behaviour' (p6, Professor of Learning Disability). The video highlights Male service user 2 who, with 24-hour support, is able to live independently. The team supporting him check in on him to make sure he is not socially isolated which could trigger "a very	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		quick sort of spiral to where he was before" (p8, Team Manager).	

48. Social Care Institute for Excellence (2014a) Challenging behaviour and learning disabilities – improving services. SCIE TV Transcript. London: SCIE

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim No clearly stated aims in transcript. From introductory text (used as 'abstract'), the video aims to describe how services can work to improve practice to reduce and prevent behaviour that challenges. **Methodology** Other – This is not a research study. There is no clearly stated methodology, however, the video features face-to-face, qualitative interviews with people with learning disabilities, those who support them,	**Participants** People receiving social care – The video features four people with learning disabilities using support services. Professionals/practitioners – The video features care workers in residential support services. Carers/family members – The video features the mother of a lady being supported in a learning disability residential service. Administrators/managers – The video features: - an area manager for residential support services from the National Autistic Society	**Framework areas** Respect, dignity and control – The video describes how challenging behaviour is a result of people having "vulnerabilities which are exacerbated by the way they are supported" (p1). When people are not able to communicate what they want or need, they can get frustrated and this can lead to challenging behaviour. The transcript notes that people's experience can be improved when they have choices in all areas of their life: The transcript emphasises the importance of interpreting behaviour that challenges as a manifestation of someone's discomfort, anxiety or other specific need and that good communication can address this. "...she can show her choice in all aspects of her life, whether it be an activity or whether it is something as small as choosing her breakfast cereal" (p4, Support worker, residential home).	**Overall score** -

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
those who manager services and an academic expert. **Country** UK **Source of funding** Voluntary/charity - SCIE is a charity, primarily funded by government.	- a service manager for residential support services from the National Autistic Society - a Professor of Learning Disability services from the Tizard Centre at the University of Kent. **Sample characteristics** *Sex* Two male and two female service users. *Level of need* The video includes four people with severe learning disabilities and behaviour that challenges, as follows: Female Participant 1 - profoundly deaf and severely autistic; significant communication needs. Female Participant 2- learning disability, behaviour that challenges and significant communication needs. Male Participant 3 – Asperger's Syndrome and behaviour that challenges.	Personalised support – The Area Manager of one service describes how a personalised approach means, "really understand[ing] the history behind the person" which, in turn, enables workers to empathise with them more, and understand what is driving their behaviour. There are a number of examples of how behaviour that can be seen as challenging, e.g. throwing cups, pushing staff, hitting other people, is actually a manifestation of people trying to communicate their needs. The workers describe how they can personalise the way they provide support to respond to people's needs e.g.: – enabling [female participant] to use sign language and symbols as a way of telling her support workers what she needs – monitoring then reviewing incidents of behaviour that challenges, or changes in someone's wellbeing, to identify the triggers and agree a plan of action – taking [female participant] to the day centre in a minibus on her own rather than with the other residents – making sure that [male participant's] day is planned in a structured way, in advance. Giving him a folder with this information in so he knows about what is happening, and about any changes to the plan, so things don't come as a surprise to him.	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
	Male Participant 4 – learning disability. **Sample size** Not applicable – This is not a research study. **Costs?**	– working with [male participant] to improve his motor skills so he can do things for himself, e.g. his laundry. Info and comms – The transcript emphasises the importance of interpreting behaviour that challenges as a manifestation of someone's discomfort, anxiety or other specific need and that good communication can address this. "If you put the communication in, and make sure that she knows exactly what she is doing at any given time in the day, she is a lot easier, she is a lot calmer...it reduces the anxiety straight away" (p4, Support worker, residential home). Active participation in lived experience of care – The transcript describes a range of ways in which people are enabled to feedback on their care and support directly. It also highlights the importance of training workers to understand what is a person's own "normal range of behaviours", so that when they notice something that does not fit within that, they know to be concerned and to communicate with the person and/or those that support them. "Communication is the key to how you manage consistency." (Manager, Residential Home).	

49. Social Care Institute for Excellence (2014b) Dignity in Care - Privacy. SCIE TV Transcript. London: SCIE

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim No clearly stated aims in transcript. From introductory text (used as 'abstract'), the video aims to describe how to ensure privacy is respected in all care settings. **Methodology** Other – This is not a research study. There is no clearly stated methodology, however, the video features face-to-face, qualitative accounts from people who use services and workers who provide support. **Country** UK **Source of funding**	**Participants** People receiving social care – The video includes people who use services. Professionals/practitioners – The video includes personal assistants. Administrators, commissioners, managers – The video includes service managers. **Sample characteristics** *Sex* The video features two males who use personal assistant support. **Sample size** Not applicable **List interventions of interest** The video made reference to support provided by personal assistants, and more generally to support provided in residential care settings.	**Framework areas** Respect, dignity and control – A key message is that "privacy is a fundamental aspect of maintaining dignity" (p1, narrator) and people have a right to this across a range of areas of their life: their home, their post, their relationships, using the bathroom, their personal information. Workers and managers emphasise that the default position, irrespective of where someone is supported, is to respect their privacy. This means, for example: – asking explicit permission before going into someone's room – asking someone what support they want – providing the minimum intrusion and maximum privacy with whatever support is provided, e.g. even if someone needs support to get onto the toilet, the worker can still give them privacy when they use the toilet – sharing information on a 'need-to-know' basis. A personal assistant describes how people open and check their own post, then asks for any support or actions to be undertaken as a result of what is in their post.	**Overall score** -

50. Stevens Alice K, Raphael H, Green Sue M (2015) A qualitative study of older people with minimal care needs experiences of their admission to a nursing home with Registered Nurse care. Quality in Ageing & Older Adults 16, 94–105

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim This study aimed to explore the experiences of older people with minimal care needs admission to carehomes with RN care in the UK. A key objective was to develop an understanding of why older people with minimal care needs chose to live in care homes with RN care. **Methodology** Qualitative study A qualitative inductive methodology using a grounded theory approach was employed in order to gain insight from the participants' perspectives. **Country** UK The study took place in	**Participants** Older people receiving social care. **Sample characteristics** *Sex* 12 residents (10 women and 2 men). *Sample age* 86 to 99 years **Sample size** In total, 12 residents (10 women and 2 men) participated in the study between August and December 2009. Five were admitted to a care home from hospital and 7 from their own home. **Costs?** No	**Framework areas** Respect, dignity and control Continuity of care and transitions (including access) **Narrative findings** The paper describes 'turning points' in terms of decision making to enter residential care. For some the trigger was being hospitalised or a sudden bout of ill health (p98). "The "turning point" for "choosing the path" was described as a result of a health event requiring hospitalisation or a more subtle realisation of the need for alternative arrangements" (authors). And one resident said, "Because I needed a lot more looking after, than they (family) could give me. Or that the uniformed people (carers) could give me (Mrs D)." And others spoke about the need to have others help them make this informed decision: "I wasn't in a fit state mentally or physically to start making those sort of arrangements even with help. So there just wasn't any question of it." (Mrs G) The paper goes on to describe how the need for beds in hospitals leads to families and patients being pressured into making quick decisions about what happens on discharge, e.g. where they should be discharged to. Page 99: the authors argue that "Prospective residents and their carers have been shown to benefit from good preparation in advance of the move" (authors) and that "The way in which the decision to enter residential care and the amount of involvement the participant had in that decision appeared to be important in the "settling in" to residential care. Participants who	**Overall score** ++

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
one geographical region in the south of the UK. **Source of funding** Not reported		reported making the decision to enter the care home appeared to have settled more quickly". (Authors). One participant stated: "I just liked it here. I like the staff here, I think they are wonderful, never find a better place (Mrs I)." The authors go on to argue that those without control and who have no say on the move are the ones who feel less settled. In the conclusions, the authors say that the transition journey was not the same for everyone and that the circumstances leading to the 'turning point' varied as did the level of control participants had on the choice of path appeared which in turn influenced how participants coped with "crossing the bridge" before "settling in" to the care home.	

51. Stewart F, Goddard C, Schiff R et al. (2011) Advanced care planning in care homes for older people: a qualitative study of the views of care staff and families. Age and Ageing 40, 330–335

Research aims.	PICO (population, intervention, comparison, outcomes)	Findings.	Overall validity rating.
Study aim The aim of the study was to explore the views of care home staff and families regarding ACP in homes providing nursing care or personal care only. **Methodology** Qualitative study	**Participants** Professionals/practitioners Nurses and care assistants. In care homes providing personal care only, where nurses not employed, a community nurse who visited the home was recruited to the study. Carers/family members 15 Residents' family and friends, 8 of whom were family and friends of residents with dementia.	**Findings** Dementia was seen as a key obstacle to residents taking part in ACP discussions. Staff and families identified residents who lacked cognitive capacity as a common barrier to ACP. 'Yeah if you ask mum where where she'd want to be she'd say with me…she doesn't know she's in a residential home, she thinks…she's in a waiting room	**Overall validity rating** ++

Country UK Study based in two London boroughs **Source of funding** Voluntary/Charity The study was funded by the Guy's and St Thomas' Charity.	Administrators, commissioners, managers Care home manager from each care home in the study. **Sample size** Care home managers = 33; Care assistants = 29; Nurses = 18; Community nurses 10; Residents' family and friends = 15, 8 of whom were family and friends of residents with dementia. **Costs?** No	from the hospital, waiting to go home…' (Family member of a resident). In these circumstances, family, friends and health professionals can make best interest decisions for the resident based on their knowledge of the resident. Nurses and managers suggested that families could sometime overrule residents' wishes where best interest decisions are in conflict with what the resident wants. Nurses and managers spoke of unexpected medical situations as barriers to meeting certain advance recommendations. 'Somebody may tell you, 'yes I'd be happy to die here'…but if, during an end of life phase they have some terrific bleed…there's no choice other than sending to hospital…' (Care manager of a nursing home). Some staff and family felt that resident reluctance to discuss ACP was probably because of residents' fear of thinking about death, 'Some of them, some of them as I say reluctant to respond…I think, maybe they're afraid…of dying…' (Nurse in a residential home). However, family members also thought it was due to residents not feeling at ease talking about these issues with care home staff. "Don't' think that's the job of the care home	

		staff…“Now you’re in the home we want to know where to send you when you die?” I mean, that would be a very creepy thing to do…” (Wife of a resident with dementia living in a residential home). Furthermore, some care assistants expressed hesitation about discussing end of life issues with residents, saying that it should be the responsibility of the resident’s family to engage in ACP discussions. Managers and nurses thought that some care home staff struggled with ACP because of their cultural beliefs: ”I know there’s other people (staff), some of them they have trouble discussing it…” (Nurse working in a nursing home). Staff also perceived that at times family members are reluctant to discuss their relatives’ preferences because of a reluctance to accept that their relative was nearing the end of life. Conflict between family and staff over ACP was identified by care managers and nurses. A common conflict concerned the nurses’ and managers’ awareness of the resident’s wish to die in the care home, but family insisting on a transfer to hospital. Staff felt that families were convinced that their relative would receive better care	

		in hospital. In contrast, staff believed the care home could provide a more comfortable setting for end of life care. "…Relatives…they've discussed with you and they've understood what's…the relative [wants]…but at the last minute they've changed their minds, and they think that the hospital will be the best place for their relative…" (Care Manager of nursing home).	

52. Stewart J and McVittie C (2011) Living with falls: House-bound older people's experiences of health and community care. European Journal of Ageing 8, 271–279

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim To examine the experiences of 8 house-bound, community-living older people of post falls. **Methodology** Qualitative study A qualitative research design, using an interpretative phenomenological analysis (IPA) approach.	**Participants** Older people receiving home care. **Sample characteristics** *Sex* Eight people, comprising 7 women and 1 man. *Disability* 8 participants – At the time the interviews took place, 7 participants used walking aids for mobility at all times, while 1 participant only used a walking aid when outdoors, and always accompanied by another person.	**Framework areas** Personalised support Info and comms Care and support for people's needs **Narrative findings** Analysis of the interviews resulted in four major themes: losing independence, losing confidence, losing social identity, and managing a changed self. The below captures quotes related to service use. Page 274: The authors give examples of participants no longer being able to manage by themselves: participants were no longer able to manage themselves. The following are typical examples: Female participant 1: "For instance my home help does all the shopping, but you dearly want sometime to do your own	**Overall score** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Country UK Scotland **Source of funding** Not reported	*Sample age* 8 respondents aged between 67 and 89 years (mean age 84 years). *Level of need* 8 participants – all had sustained a serious fall or falls requiring medical treatment, and subsequently received a multi-professional intervention programme specifically tailored to their physical and functional needs. **Sample size** Twenty letters were sent to potential participants, identified by their community physiotherapist, who had been discharged from the service within the previous 6 weeks. Eight people replied, comprising 7 women and 1 man, aged between 67 and 89 years (mean age 84 years). **Intervention** List interventions of interest All 8 participants had sustained a serious fall or falls requiring medical treatment, and subsequently received a multi-professional intervention programme specifically tailored to their physical and functional needs. Four participants sustained fractures as a	shopping, things you need yourself." Female participant 2 : “Now, I’m feeling I’m depending a lot on my daughter and it’s a lot on her shoulders because her husband died 2 years ago with cancer, and, and she’s had cancer, and I really feel she’s had an awful lot on her plate, and now to be landed with me." Page 275: Female participant 3, a 75-year-old woman with severe osteoporosis described encounters with home help workers, on whom she was totally reliant for meals and personal care. In describing these encounters, she made clear a lack of attention afforded to her as a person. Female participant 3: "You’re just a number—Say for instance, if you were able to make your coffee, you’d maybe have your sandwich and have your coffee later, well everything’s put in front of you. It’s like being in a home ‘There’s your meal, take it. Eat it or lump it’". Page 275: While the authors report some respondents (4/8) saying they were ignored or had not received information about their care or were not being listened to by health and social services, they go on to say not all reports were like this: "Not all interactions were negative, however, with involvement by health and social-care personnel often providing sources of comfort. The following quotations were in response to being asked whether they benefitted from the COPT involvement, and although only two of the participants felt they physically improved, the feeling of being worthwhile and no longer invisible was deemed of greatest benefit: Interviewer: “Has it been useful do you think, the physiotherapy programme?” Female participant 4: “I would say so.” Interviewer: “Can you tell me how?” Female participant 4: “Just the fact that someone was taking an interest in me.” Interviewer: “What was the best part of	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
	result of the fall requiring hospitalisation, and had returned to their own homes by the time the interviews took place. Each intervention was specific to the individual's physical and functional needs so details not provided in the paper. **Costs?** No	having S come out and, you know, having some rehabilitation?" Female participant 4: "The fact that someone was caring enough to do it." Page 276: The authors state that participants had found ways of coping with loss of identity (e.g. through having social services do more for them) by adopting an acceptance of their situation: "Part of this process of coming to terms involved attributing the possibility of future falls to circumstances beyond their control". And the authors also said: "participants regarded falls almost as risks of life that had to be accepted" and that "by making sense of their everyday experiences in ways that emphasised the positive aspects of these experiences, the participants were able to maintain personal identity and quality of life". Page 277: An important facilitator highlighted by the authors is care staff enabling individuals to see their own self-worth post falls. For example, they say that: "Although the rehabilitation programmes in the current study were not able to address the participants' loss of independence and confidence, for the majority of participants the benefit they felt they had received from the multidisciplinary programme was a re-affirmation of their worth, of having someone take an interest in them. This goes someway in overcoming the loss of social identity as a consequence of their dealings with other hospital and social-care staff." Page 278: The authors argue that future fall interventions must not only address physical consequences of a fall but also "be designed so as to ameliorate psychological difficulties, not add to them; delayed and impersonal delivery of even the most carefully designed service is unlikely to be experienced as satisfactory by those on the receiving	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		end". And that key to this is "promoting [older people's] ability to manage their sense of who they are will thereby allow older people to find continuing meaning in their everyday lives".	

53. Swain J (2005) Independent Evaluation: Developing User Involvement in Leonard Cheshire. Final Report. Newcastle: Northumbria University

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Study aim Aim of this evaluation is to conduct a review of and support the development of service user involvement at all levels and within all areas of Leonard Cheshire activity. Specific Objectives: 1. To explore the effectiveness of current strategies in promoting Leonard Cheshire's commitment to user involvement, including the Disabled People's Forum and SURE, from the viewpoints of the different stakeholders within the organisation. 2. To examine	**Participants** People receiving social care Professionals/practitioners **Sample characteristics** *Sex* No details provided. *Sample age* No details provided. *Level of need* No details provided. **Sample size** SERVICE USERS Individual interviews/group interviews/focus groups were conducted	**Framework areas** Respect, dignity and control Personalised support Info and comms Active participation in lived experience of care Continuity of care and transitions (including access) Care and support for people's needs **Narrative findings** Leonard Cheshire provides social care services including care-at-Home, residential homes and the employability scheme. This evaluation is focused on service user involvement within Leonard Cheshire, rather than the quality of service provision. The authors point out, however, that it is evident 'from the views expressed by service users that such a distinction is incompatible with their experiences. The better the quality of services they receive the more, from their viewpoint, opportunities and possibilities there are for service user involvement' (Authors, p40). The key themes expressed by service users from both stage	**Overall score** -

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
the possible barriers to the promotion of user involvement within Leonard Cheshire. 3. To consider options and make recommendations for future developments in user involvement in Leonard Cheshire. **Methodology** National, regional, local reports/ assessments/evaluations. **Country** UK **Source of funding** Not reported.	in residential homes, day services and care in community services. Group interviews/focus groups – 10. Each group was made up of approximately 6 service users. Individual interviews – 11. SURE meeting – approximately 25 participants. Total = 96 SERVICE PROVIDERS Director General; Regional Directors (2); Trustees (2); Director of Communications; Head of Quality and Standards; Head of Volunteering; Manager of DPF; Deputy Manager of DPF; SURE Facilitator; Volunteer Training Officer; Mentor (2); Forum Facilitator (2) Total = 17 **Costs?** No	one and stage two of the evaluation are described below: STAGE ONE – VIEWS OF SERVICE USERS LACK OF 'GROUND LEVEL' STAFF Most of the residents who were interviewed spoke about the fundamental problem of lack of 'ground level' staff and the impact on making choices in their daily lives right down to the most basic of needs: 'We have one bath a week, that's on a specific day' (Interviewee, p16). 'The toilet. That to me is basic. I was desperate and I rang the bell and at last they came. There are bells everywhere but the only time you don't have to wait is in the night. I just dread it every day...!' (Interviewee, p16). The link between user control and the level of support was evident in the following quotes: 'I don't feel all the time that I'm fully in control of what I do and don't do. For instance, I can't prepare myself a meal and I can't move my chair without the assistance of a carer. If I want to go anywhere quickly, go to the toilet or something like that, and don't get there in time, they say 'You should have asked' but if there's not enough staff about it's literally impossible to get there, you have to wait for someone to take you.' (Interviewee, page 16). 'The other night for what I wanted it was no good ringing because there was no night staff who could get into the dispensary. It wasn't worth ringing and I just laid in pain all night' (Interviewee, p16). Lack of personal contact with staff affected particpants' wellbeing, quality of life and their ability to make their views heard. 'Sorry to be negative but I find that if you go out you need a carer to come with you and there aren't always carers around that will come with you. They're always tied	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		up.' (Interviewee, page 16). 'By the time you've waited for them to come back you've forgotten what you wanted to say' (Interviewee, p17). Some residents felt less than human: 'You're more of a number than a person. You're a commodity. You're just a commodity, nothing else. I mean you're put to bed, you get fed, you get up in the morning and that's it. You can book up to go out but that depends on whether the driver's here or you can get a volunteer which we're very short of' (Interviewee, p17). '...some of these charitable organisations have in the past been run very much on a 'We know what's best for you' type of ethos and I think that Leonard Cheshire is struggling with this because obviously they have been looking after people with profound and severe impairments ...' (interviewee, p17). In these circumstances, empowerment and user involvement in the day-to-day decisions over their own lives can be seen as 'a problem'. 'One of the problems it (user involvement) causes is when residents become more empowered and aware of the opportunities of life they're likely to ask for more. In asking for more, it usually involves staff, and resources are already very scarce and limited, and centred mainly in providing basic daily care in washing, dressing, eating and they occupy an awful lot of time. Empowerment creates problems of staff support. And if the choice of empowerment involves travel then that's a further added burden. Not necessarily to pay the cost of travelling but to have the opportunity with limited transport or escort' (Interviewee, p17). Understaffing, can be used to justify the lack of choice over support staff. 'I do depend quite a lot on support and care from the domiciliary service which is quite good in the limited capacity that they have.	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		There is somebody they send to me that I don't want but what they say is "Well if you don't want her we haven't got anybody else"' (Interviewee, p18). 'Each one of us has a key worker but they have less and less time to spend on us. There's less and less 'one-to-one' going on' (Interviewee, p18). TRANSPORT Lack of transport and drivers was often mentioned and this has huge implications on their quality of life: 'The transport is very nice but we don't get out enough. There's a shortage of drivers' (Interviewee, p20). 'I had an OU thing that I wanted to go to. I arranged it three or four weeks in advance but two or three days beforehand the driver pulled out and I couldn't go' (Interviewee, p20). 'There's trips every week but they can only take three wheelchairs in the van' (Interviewee, p20). "I waited until half past twelve yesterday, just in time for lunch. I should have been here at ten. It was more or less just for the afternoon session" (User of day centre, p20) 'What I can't understand is that they're a big organisation, Leonard Cheshire, so why don't they fund it (transport). This is what I can't understand. Where is the money going? It's a big charity and we do a lot of fund raising here for Leonard Cheshire and we'd like to know where the money goes. We should be part of it, we should know where it goes' (Interviewee, p20). Lack of spontaneity and flexibility is also an issue: 'I go out quite a bit and I use transport if I can book it up far enough in advance. You can't be spontaneous' (Interviewee, page 21). AGENCY STAFF	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		The residents had negative opinions about agency staff, who they thought of as unskilled, unmotivated and not responsive to their needs. 'They're only in it for the money' (Interviewee, p23). 'They're not interested because they know they're not going to come back here again. It's just a day's work. They're just passing through' (Interviewee, p23). 'It's mostly at weekends that there's a shortfall of our own staff. Agency staff aren't so dedicated' (Interviewee, p23). Sometimes communication issues exacerbated problems: 'They only understand what they want. They don't listen. There was a chap feeding T. He's a resident, he eats, and he'll eat everything, but when he has a drink he has to have thickener in it because otherwise it goes straight to his lungs. And the bloke's feeding him, and giving him a drink, and T's coughing. He's choking because the drink's going straight to his lungs, and I said to him six times 'He wants thickener in it' and all he said was 'Stop coughing T'' (Interviewee, p24). STAFF ATTITUDES AND BEHAVIOUR Most residents thought the staff were doing their best under challenging circumstances. But, some residents described poor attitudes and behaviour, which in turn, affected how well the service users could control their own lives. Central to this seems to be the power that staff can have in the carer–cared for relationship: 'Yesterday I had a really bad day when I could hardly lift my hands up and he (another resident) was helping me. And they turned round and said, "Why aren't you doing that yourself?" and I said, "I cannot lift my hands up sometimes". I'd been using	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		the computer and my arms were really aching' (Interviewee, p24). Service users expressed fear about speaking out and making their views known: 'We can (make views known) through the Disabled People's Forum and we can through SURE. The only thing is you have to be very careful because if you say too much your name is mentioned and you are put down as a troublemaker...' (Interviewee, p24). 'My involvement with the Disabled People's Forum, we had meetings locally in our areas, whereby the chairman felt threatened inasmuch as he is disabled and in a residential care home and he was frightened like "If I write a letter stating these things I might be badly treated, I'll be singled out in the residential care home where I am and I don't know whether I can cope with that." You get labelled. It's the old thing: you're stirring it for others, you're causing trouble, all those issues' (Interviewee, p25). HEALTH AND SAFETY POLICY Residents said that the introduction of an excessively overprotective Health and Safety policy had an impact on the way people could control their lives and eroded their basic human rights throughout the organisation. 'When I came here with my husband we lived in the annexe and we didn't have to have any assessments. I'm now in a double room on my own and before I can use my microwave I've got to have an assessment on it, the same for boiling the kettle. What an insult! I did it in the community but I couldn't do it here until I'd had an assessment' (Interviewee, p26). 'You can't go out on your own unless you have an assessment. I find it insulting, very insulting! C said I've got another	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		one today. Then you get frustrated. People think we're imbeciles' (Interviewee, p26). ABILITY TO INFLUENCE THE MANAGEMENT HIERARCHY Most residents felt that the management of the organisation was distant and not interested in their needs: 'We'd like them to come down and speak to us but every time someone comes down they want the questions given to them beforehand, so they can rehearse their answers, or for whatever reason, before they come. They shouldn't do it like that. They won't just sit down with you. They're frightened of the response they're going to get' (Interviewee, p27). Service users had met Leonard Cheshire himself spoke positively about his personal approach. Some service users felt that the Leonard Cheshire Foundation had changed from 'a family' to a large-scale business organisation: 'Since Leonard Cheshire died you know they've changed a lot really. They like to do things their way now. Of course I knew Leonard Cheshire very well. If anything went wrong we could always go to him and he'd get it sorted out. He ran the whole organisation but now it's become more official. I don't think we have as much control as I think we should have. A lot of people now have never known Cheshire' (Interviewee, p28). FORUMS AND COMMITTEES Many people interviewed suggested that the power structures in the organisation's management made the user involvement committees and the Disabled People's Forum ineffective: 'I don't think these committees get anywhere. If they want any changes in	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		this organisation, they send us forms but they’ve made up their minds anyway so what’s the point?' (Interviewee, p31). TRAINING Training was often specifically mentioned: 'I’ve been involved in the setting up of NVQs for care staff and also NVQs for service users to be assessors. We get very good training from the DPF. There’s courses for committee skills, for DET training. If you can just forget for once the difficulties you are going to have, in getting support and transport. It is well worth it' (Interviewee, p32). MENTORING The effectiveness of mentoring depends on contextual factors, as expressed by one service user: 'It depends on your region and your relationship with the regional director and your relationship with each home. One home might be really supportive and everyone wants you to come back and another home may see you as a threat. I think for me it’s sometimes hard to get respect from staff especially care staff, sometimes I think they feel I’m interfering. They see me as a disabled person. (They are) unhelpful, not friendly, don’t listen, brush you off' (Interviewee, p34). RESIDENTS WITHOUT A VOICE There was significant worry that people with communication difficulties were not listened to throughout the organisation, between management and service users, and between regions: 'There are people here who can’t get their point of view across. They can’t talk' (Interviewee, p36). 'A lot of the more seriously	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		disabled people can't speak up for themselves' (Interviewee, p36). 'The reason I speak out is that I'm thinking about the people who can't speak, like H and W, and if things are really bad for us what the hell is it like for them?' (Interviewee, p37). LACK OF INFORMATION ABOUT MONEY Several of the residents were anxious about lack of information about how their fees were paid in the home. This gave rise to a feeling of lack of control in their lives: 'Where is the money going? It's a big charity and we do lots of fund raising here for LC and we'd like to know where the money goes. We should be part of it, we should know where it goes' (Interviewee, p38). 'The organisation is too top heavy. When I came here six and a half years ago, there were forty staff up at head office and now they have ninety. At the same time they reduce the staff here. They take the money away from where it's needed' (Interviewee, p38). SATISFACTION WITH LEONARD CHESHIRE SERVICES Some service users in expressing satisfaction showed little concern about user involvement. 'The thing I appreciate most here is the privacy. You are entirely private in your own room with en suite and it really is a treat' (Interviewee, p38). 'As far as I'm concerned, I mean I can't do anything for myself, I can't get out of bed, feed myself or do anything, I can't do anything to do with cleanliness, and I do find that they do it very well. They take care of you and do everything. And then we have lots of things to do, a lot of entertainment and we're taken out. It takes your mind	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		off how you are really. In that respect I find it's very good. I've only been here a year and a half, but I find that they have been very good to me'(Interviewee, p38). FINDINGS FROM STAGE TWO – CASE STUDIES Five case studies were conducted, which varied in scope and focus but the purpose was to document 'good practice', or changing practice, within Leonard Cheshire. Below are selected quotes from case studies where user views are evident. CASE STUDY 2 – Ponteland Independent Supported Living, Bradbury Court – The researcher carried out interviews with four residents. Service users saw Independent Supported Living as a very positive change in terms of services. The tenants experienced increased user involvement and more control. All tenants have individual social workers and care managers. i. How service users felt about independent supported living and how they handled change – A service user was asked how she felt about the changes in living situation: 'There wasn't enough time to take in what the changes were. They didn't give us the down side of it. They just talked about the positive side of it all the time.' When asked about the challenges, one service user said: 'We weren't told about how much responsibility would be put on our shoulders, on my own shoulders.' 'I am responsible for my own money which makes it feel more feel like you are in control of your own life more.' 'Now that I live in Independent	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		Living I get to keep all my benefits you see – so I get a lot more money. I can save my money up and go on holiday where before I couldn't afford it. The financial benefit is the main thing.' ii. PAs Personal Assistants (PAs) made a significant difference to tenants' lives: 'We have support to go out and do something normal and not go out with a great big group.' 'I feel I have got control of my life. I can plan what I want to do especially if I do it in advance. I thought of having a dinner party, but I wasn't very well for a while but next year I will be able to start doing that. They will help me to cook and they'll help me to plan a dinner party if I plan a little bit in advance. I sort of feel that I'm living in my own home, that my room's treated as my own home and I make my decisions about what I want to do' (Interviewee, p69). CASE STUDY 3 – DPF And The Learning Difficulties Service Edinburgh – Interview with service user who has moved to Independent Supported Living (purchasing LC care package) after moving out of a LC residential home: 'I found it very hard. I was looking for somewhere to live for 5 years but I couldn't find one because there were other units I could go to but they said I was too handicapped and one said I was not handicapped enough. So then I got me place at LC and been there ever since.' Asked about support: 'Yes, I have a support worker. She is called M and she is absolutely fantastic.' 'She stays. I am in sup-	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		ported accommodation, which means there are support workers already there. I am with seven other people.' 'Yes I have my own house. The support workers are there if we need them.' On the question of control, she said: 'Oh yes now I do. I have got my independence. It's great because now my mum doesn't have to worry about me and I don't have to worry about her (her mum has diabetes)' (p75).	

54. Swinkels A and Mitchell T (2009) Delayed transfer from hospital to community settings: the older person's perspective. Health & social care in the community 17, 45–53

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim This paper focuses on the perceptions of the effects of delayed transfer into the community, involvement in discharge planning and future community care needs of older people awaiting discharge from hospital. **Methodology** Qualitative study Study used a phenomenological approach to facilitate researcher's	**Participants** Older people receiving social care. **Sample characteristics** *Sex* 11 men and 12 women. *Sample age* Aged 65 years and over. *Level of need* A wide range of potential participants from different categories of delay (e.g. waiting for assessment, a care package or a placement in a residential or nursing home).	**Framework areas** Respect, dignity and control Continuity of care and transitions (including access) **Narrative findings** 1. Participants expressed annoyance, frustration, anxiety and low mood at their unfamiliar surroundings lack of personal privacy, and prolonged loss of autonomy in self-care and usual everyday routines. 'I didn't care whether I lived or died ... well, I hoped I died 'cos there was too much fussing about ... you get up at 6 o'clock in the morning here, and they started turning you about and giving you a wash ... you are mucked about all through the day and not left alone' (Participant, p48). 2. Participants placed great importance to being liked by staff and not being perceived as difficult or a nuisance. However, they sometimes expressed frustration and resentment at having to play this role. 'My	**Overall score** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
exploration and interpretation of participants' perceptions of delayed transfer from hospital. Phenomenology is concerned with the complex description that arises from people's detailed stories of their experiences. **Country** UK **Source of funding** Other commercial source funded by the Faculty of Health and Life Sciences, University of the West of England, Bristol, UK.	**Sample size** 23 Participants aged 65 years and over (mean age 82 ± 5.4 years) and with a mean delay of 32 days (± 26) were recruited from three hospitals based in two NHS Trusts in the South of England. **Costs?** No	daughter comes in and says, 'Don't say a word out of place.' I said, 'I don't'; she said, 'I do', but nobody is going to dictate to me from now on' (Participant, p48). 3. Low mood was reflected in a diverse range of emotions (e.g. sadness, hopelessness, apathy, grief) and situations; length of hospital stay, reliance on others, loss of personal autonomy, depersonalisation, death of a partner, irreversible change, boredom, routine and loss of productivity (Authors, p48). 4. Reduction in mobility caused anxiety and frustration, and participants were very aware of the possible harmful effects of lengthy hospitalisation on their health (Authors, p48). ***Involvement in planning for community discharge*** 1. For those participants waiting to go home, arranging domestic services (e.g. help with personal hygiene, washing clothes, shopping), waiting for equipment and lack of general health improvement were generally considered to be the main reasons for delay. Those awaiting a residential care placement talked about waiting for a place, which suited the needs of relatives, for example, the placement being convenient for family to visit (Participants, p49). Conversely, social services were perceived by other participants to have played a pivotal role in discharge, for example, by providing information or arranging equipment. Hospital staff: 'You are going home Monday? Won't that be great?' Patient: It will be absolutely wonderful. They delivered a bed and mattress. I couldn't afford it and they have been wonderful – social services and the OT and physiotherapist' (p49) 2. Participants felt that those responsible for their discharge were mainly from outside the hospital. Many	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		felt that nursing staff were too busy or did not have a key role. 'Nobody tells me (about leaving hospital). I asked them (nurses) but they don't even know themselves…' (Participant, p49). 3. There was an almost universal view that individuals could do nothing to influence their discharge from hospital. 'I am sure they have (taken my views into account), but I have not been in on those meetings or anything. You know it goes to the consultants and the physio, and so and so and so and so. All these people team together to make a decision presumably. I hope I am telling you right' (Participant, p49). 4. Transfer to residential or nursing care, in particular, was seen as a decision made by other people. Social services were seen to be influential and able to control the degree and speed of discharge arrangements. But some participants felt let down and distressed by what they felt were false assurances and delays in organising care and equipment (Participants, p49). 'They have said they can't do no more for me. They said you will be going home and next thing they say it is held up by social services. This keeps disappointing me' (Participant, p50). ***Community care needs*** – Often, when asked about future care needs, participants seemed either to misjudge the nature, amount and frequency of support needed to stay in their own homes or simply wished to carry on as before without any intervention from outside agencies (participants). Some patients were aware of the complexity of potential future arrangements after having used complex home care packages previously, but felt they had no say or role in the discharge process. 'They are going to provide me	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		with a person to do my shopping 1 day a week and put the dustbins down, as it is a little way down. Collect my prescriptions. I don't think there is anything else they have got to do. Oh, I think they did mention washing; they would do washing. They don't do domestic which they were trying to arrange, but how successfully I don't know' (Participant, p50).	

55. Teale EA and Young JB (2015) A Patient Reported Experience Measure (PREM) for use by older people in community services. Age and Ageing 44, 667–672

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Study aim The aim of the study is to describe the development of Patient Reported Experience Measures (PREMs) suitable for use in Intermediate Care (IC) services and to examine their feasibility, acceptability to users, and examine the extent to which the PREM items may be converted to a numerical score.	**Participants** People receiving social care A patient and public group (co-ordinated by the Patients' Association). Professionals/practitioners A panel of intermediate care experts, representation from the Picker Institute (a not-for-profit group that specialises in research methods for including healthcare users' views). **Sample size** Intervention number 131 bed-based and 143 home-based or re-ablement IC services in England. Bed-based, Number of services 131, target number of participants 6,550, PREMS returned 1,832, return	**Findings** Care and support for people's needs. **Narrative findings** Return rates for both the bed-based and home-based PREMs were low (28 and 13% respectively), though bed-based return rates were comparable with other national surveys (Friends and Family Test 36.9%), Higher return rates for the bed-based survey may reflect the different distribution methods of the questionnaires: PREMs for bed-based service users were distributed at discharge by hand; home-based service users received their questionnaires by post or by hand. Whether service users completing the PREM were representative of typical users of IC could not be assessed, a possible source of selection bias. The PREMs were acceptable to users, as reflected in the generally low rates of missing data. IC-PREMs might	+

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Methodology Survey the consensus group developed the questionnaire items. Tests for reliability were used using the Mokkan Scale to determine the Loevinger H coefficient. **Country** UK **Source of funding** Other No additional funding was sought for this analysis. The IC-PREMs were incorporated into the 2013 NAIC within the existing subscription model operating with individual commissioning groups.	rate 28%; Home-based, Number of services, 95, target number of participants 23,750, PREMS returned 2,983, return rate 12.6%; Reablement, Number of services, 48, target number of participants 12,000, PREMS returned 1,644, return rate 13.7%; Overall, Number of services, 274, target number of participants 42,300, PREMS returned 6,459, return rate 15.3%. Home-based and re-ablement services are considered together for the purposes of the Mokken analysis. Sample size 29 people in the consensus group, Two hundred and two providers of Intermediate Care services participated in the audit. Bed-based PREM: After removal of records with absent responses, there were 1,398 questionnaires available for Mokken analysis. Home-based PREM: After removal of incomplete records, 3,392 responses remained for analysis. **Intervention** List interventions of interest Development of a Patient Reported Experience Measures (PREMs) suitable for Intermediate care	have utility in identifying areas for service development, such as user involvement in treatment decisions, to improve the delivery of co-ordinated and integrated care. **Effect sizes** (The Loevinger Hi is a measure of unidimensionality: whether or not an item is measuring the underlying trait. 0.3–0.4 indicates a weak scale, 0.4–0.5 is moderate and >0.5, a strong scale.) Bed-based PREM The overall Loevinger H for this scale of 8 items is 0.44, indicating moderate scaling properties. The coefficient of reliability (ρ) is 0.76, indicating acceptable reliability. Home-based PREM: The reliability of the scale (ρ) is 0.81 (there were no significant violations of invariant item ordering), and the overall scale H was 0.41, indicating moderate scalability; Bed-based PREM, Staff have sufficient information 0.45; Involvement in goal setting 0.42; Questions answered 0.43; Confidence in staff 0.49; Involved in discharge decisions 0.45; Home circumstances considered 0.43; Information provided for family 0.41; Treated with dignity 0.47; Overall (H) 0.44. Home-based PREM Staff have sufficient information 0.37; Aware of goals 0.35; Involvement in goal setting 0.39; Aware of how to contact staff 0.34; Questions answered 0.39; Confidence in staff 0.46; Involved in decisions to discharge 0.52; Given enough notice about discharge 0.47; Information provided for family 0.42; Requirement for	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		additional equipment discussed 0.36; Discussion regarding further services after discharge 0.34; Treated with dignity and respect 0.46; Overall (H) 0.41.	

56. Think Local Act Personal (2009) A service user's personal budgets story. Video transcript. London: TLAP

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim Not research so no aim stated. Video evidence transcript from TLAP. **Methodology** Other Not research. Video evidence transcript from TLAP. Single case. **Country** UK **Source of funding** Not reported	**Participants** People receiving social care Single case of adult using social care service and using individual budget to employ personal assistant. **Sample characteristics** Sex – Female service user. **Sample size** Single case study. **Costs?** No	**Framework areas** Respect, dignity and control Personalised support Active participation in lived experience of care **Narrative findings** Video is about views/opinions of using direct care payments and using personal assistants, which meets the scope criteria. The service user describes the positives of using her personal budget to employ a personal assistant and the independence this gives her to make her own decisions and get involved in activities that would be restrictive otherwise. She says: 'I didn't want someone to be able to say to me "You can't do that" or "You can't do that". I wanted to be able to set a programme up so I could have what I needed when I needed it. My aims are to be able to access the community, meet my friends, be with family. Personal Budgets make it very easy for you to do that. I'm not able to go to see my family because they are, they live in houses that are totally inaccessible to me. What I can do is pay for a hotel room in London and then have my PA come along with me and she	**Overall score** - Poor on research methods and rigour but rich on direct user views. However, transcript is very short and no background section explaining context.

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		helps me while I'm in the hotel, I don't have to rely on a member of my family. I have in the past had to stay in nursing homes because I can't visit a hotel because the care hasn't been there for me. It's changed everything. I've been able to go places, do things, even the simple things like just going to the pictures has been a great change to my life and it's made getting up in the morning a positive thing rather than "Oh, not another day dragging on for another 12 hours".' She goes on to say: 'Getting to know what I had to do as an employer, it wasn't that difficult at all. You can have someone to help you do your wages, I chose to do my own and do my own accounting but people can have agencies or another agency to help them with their payments. Personal Budgets can help you to be independent, it can help you to live alone and live your life as an independent person. The freedom to choose, it's what's really brilliant about it, being able to choose when and where, who and why and it takes away the control from somebody else saying "You can't do that and you can't do this", so it's brilliant'.	

57. Think Local Act Personal (2010a) A service user's personal budget story. Video transcript. London: TLAP

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim Not research so no aims stated. Video evidence from TLAP.	**Participants** People receiving social care **Sample characteristics** Sex – Male	**Framework areas** Respect, dignity and control Personalised support **Narrative findings** A service user talks about having direct payments	**Overall score** - Poor on research methods and rigour but rich on direct user

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Methodology Other Not research so no aims stated. Video evidence from TLAP. Transcript of one case study. **Country** UK **Source of funding** Not reported.	Disability – Not stated exactly but transcript says he cannot walk. **Sample size** One case **Costs?** No	and describes having this kind of social support as being very positive. He says SDS (self-directed support): 'Has enabled me to employ a personal assistant OK. Because I only have one arm that normally works ok I can't open a letter, or a bottle and my PA comes first thing in the morning I employ her to arrive at 9ish in the morning, ok, and stay until lunchtime, that's it, that's 5 mornings a week, which is what I ask her to do and she'll work for that time, which is brilliant – so with my SDS (Self Directed Support). I buy that 'cause that's what I need'. He goes on to say: 'I've got another bedroom now, so in the future if it works out I could have a live in carer now. I would say first of all not to be frightened of what might seem a great bit step, but it's a step in the right direction, believe you me it is. Some people are going to be daunted by going to this whole thing of SDS (self-directed support), you know being this age, and disabled, and being this age and getting a mortgage right? Not easy – and start a little company going and employing one or two people – all that is fairly daunting for most people, but in fact there's help out there to help you there are people around to guide you through all that and I used them and it was easy, easy peasy'.	views. However, transcript is very short and no background section explaining context.

58. Think Local Act Personal (2010b) A Service user's personal budget story. Video transcript. London: TLAP

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim Not research so no	**Participants** People receiving social care	**Findings** Respect, dignity and control Personalised support	**Overall score** - Poor on research methods and rigour but

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
aim stated. Video evidence transcript from TLAP. **Methodology** Other Not research. Video evidence transcript from TLAP. Single case. **Country** UK **Source of funding** Not reported.	**Sample characteristics** Sex – Male service user. Disability – profoundly deaf **Sample size** Single case study. **Costs?** No	Active participation in lived experience of care **Narrative findings** This is a video of a service user who is profoundly deaf, describing how he lost confidence at the age of 16 when his eyesight started to deteriorate. He then started using his personal budget to help with his care. The service user says he previously 'had no confidence, my confidence was really, really low and I didn't have a lot of help or support'. He goes on to say: 'Now I have an individual budget and things are on the up for me, and things are really exciting – I've got PAs who help me and my life is much better'. He says: 'When I went to school it was a hearing school kind of in a mainstream school, there wasn't a lot of signing, just basic sign language I had when I was younger. Then I moved to high school, and there were around 30 to 40 deaf students there and they were using BSL, which I didn't really know about but I started to learn it and absorb it. When I became 16, and my eyesight started to deteriorate I was trying to communicate in sign language I was missing a lot of information – and a communicator came, he came and grabbed me wrists while he was signing. It's called hands on sign language and I understood from then on what I needed, I needed to change my BSL sign language to hands on sign language. So I'd like to have my hair cut today because I'm getting ready for tonight I'm going out in Manchester tonight with a lot of deaf friends, it's my girlfriend's birthday tonight, and we're going to have a bit of a party in Manchester with all my friends tonight. I don't really feel deaf-blind myself – I feel just like a normal deaf person I feel	rich on direct user views. However, transcript is very short and no background section explaining context.

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		very positive and with the hands sign language and the way I communicate and the way I'm guided, I'm quite happy with that…First of all, I had a direct payment, and with the direct payment everything was the same every week, you know, same hours same time, very restricting, you can't do that on a different day'.The service user describes how his PA told him how he could use an individual budget to help him. He says: 'My PA explained to me I'd need an individual budget and I'd need a reassessment which I had. I get to choose, the times, any time and also the people who work with me the personal assistants that gave me a lot of confidence I went out so much more'. The service user goes on to demonstrate how having a PA has enabled him to undertake activities he wouldn't have been able to partake in previously: 'Regularly I go and watch football, with my PAs, also helps me to go clothes shopping, he'll explain to me if I'm looking at some clothing, what it is what it looks like, the deaf club is what I enjoy the most. I meet all my friends there and we have a social life altogether and it's a really good time for me. I can go out and do anything in my time, when I want to do it. I have a job as a lecturer for a company called Hear First, they're a training company who run training courses for social workers. I talk to them about my life and I explain to them about individual budgets and direct payments and give them lecture to raise awareness for them to give them some idea how it affects deaf blind people, the feedbacks been really really good. They say they've enjoyed it a lot, and gives me confidence'.	

59. Think Local Act Personal (2012a) Making it Real. Video transcript. London: TLAP

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim Not research so no aim stated. Video evidence transcript from TLAP. **Methodology** Other Not research. Video evidence transcript from TLAP. Single case. **Country** UK **Source of funding** Not reported.	**Participants** People receiving social care Single case of adult using social care service and using individual budget to employ personal assistant. **Sample characteristics** Sex – Male service user. Disability – Has HIV related illnesses. **Sample size** Single case study. **Costs?** No	**Framework areas** Respect, dignity and control Personalised support **Narrative findings** Video is about views/opinions of using individual budgets and using personal assistants, which meets the scope criteria. A service user paints a positive picture of how having control over his budget, he can meet his personal needs well and remove the stigma that might have occurred had he not been in control over whom to employ. His description of his care suggests consistency of having the same person care for him is also an advantage to him. He says: 'When you use an individual budget and you have real control, you design it, you own it, you feel responsible for it. You want people to come on board that have the same values and aspirations. I've chosen to employ a gay man as a PA because I don't have to explain anything around my sexuality, I don't feel embarrassed to talk about my HIV. I don't feel uncomfortable if I decided to have a relationship, I don't need to feel anything at all other than that I feel supported. I feel that my care is a really positive thing for myself and I feel very happy with it because I'm in control, I'm able to decide what type of care I need and it can vary. I'm actually able to employ different people to do different things or employ the same person to do the same thing and I'm able to use one person to work in many different areas of my life. I share my PA with another disabled person, the turnover isn't so high so my PAs been with me for a year. We want to keep somebody that really works hard and is able to work in that social model of disability rather	**Overall score** - Poor on research methods and rigour but rich on direct user views. However, transcript is very short and no background section explaining context.

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		than us being products. For me to be pro-active and for to be the person I want to be in society, I may need a little bit of support but I feel that having that support and for me to own that support and for me to direct that support is really positive progress'.	

60. Think Local Act Personal (2012b) Making it Real – A woman with Alzheimer's. Video transcript. London: TLAP

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim Not research so no aim stated. Video evidence transcript from TLAP. **Methodology** Other Not research. Video evidence transcript from TLAP. Single case. **Country** UK **Source of funding** Not reported.	**Participants** People receiving social care Single case of adult using social care service and using individual budget to employ personal assistant. **Sample characteristics** Sex – female service user. Level of need – has Alzheimer's. **Sample size** Single case study. **Costs?** No	**Framework areas** Respect, dignity and control Personalised support **Narrative findings** Video is about views/opinions of using individual budgets and using personal assistants, which meets the scope criteria. A service user describes the positives of having a personal assistant and the independence this gives her to make her own decisions and get involved in activities that would be restrictive otherwise. She says: 'I've got Alzheimer's and I would never like to be on my own – you know, I love company, I like to have conversation and you know, people that are nice to me. I've got a carer, G and she's very good, she's fantastic, very reliable and she looks after me very well and very caring, which I like. I've known G many years but very capable person she is. She helps me indoors and we go out. I go to Age concern, places like that. We go to bowling, I love bowling - it's great fun. And I've got a sheet, you know, what we can do daily. I can make my own decisions and how I feel,	**Overall score** - Poor on research methods and rigour but rich on direct user views. However, transcript is very short and no background section explaining context.

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		then I explain that. Monday I have another carer M - just one day and then G comes and after that my children come so it's all slotted in. I'm very lucky to have such good people around me'.	

61. Towers AM, Smith N, Palmer S et al. (2016) The acceptability and feasibility of using the Adult Social Care Outcomes Toolkit (ASCOT) to inform practice in care homes. BMC Health Serv Res 16, 523

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Study aim Page 3: "The aims of this study were to: 1. Design a feedback-intervention based on the evidence collected using the CH3 toolkit (observational notes and interviews) and pilot it in a small sample of care homes in England. 2. Examine the acceptability of this feedback to care home staff and explore whether there were any reported changes in staff practice and/or measurable changes in residents' SCRQoL after the feedback had	**Participants** People receiving social care Two nursing homes owned by a national care home provider and two residential homes run by a small independent provider took part (all homes accepted people living with dementia and varied in size between 29 and 64 beds). **Sample characteristics** Sex 85% female Sample age Residents ranged in age from 73 to 97 years old with a mean age of 86 years. Level of need Given in table 4, page 8:	**Framework areas** Respect, dignity and control Personalised support Info and comms Active participation in lived experience of care Continuity of care and transitions (including access) Care and support for people's needs **Narrative findings** Key findings: 1. While the health and social care needs of the residents in the research declined over the time period being observed in the research, their QoL measures remained the same. The authors conclude from this that, "homes maintained residents' quality of life but did not improve it" (Authors, p12). 2. No differences in the SCRQoL between the residential care home with nursing needs and the one without were found after controlling for the differences in residents' needs and characteristics related to setting.	**Overall validity score** +

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
been delivered. 3. Examine and report new inter-rater reliability analysis on the CH3 approach." **Methodology** Mixed-methods Survey analysis of the current SCRQoL, as measured by ASCOT. Focus group discussions (with staff initially and then residents and their families) to provide feedback on changes in practice. **Country** UK England. **Source of funding** Other – This study was funded by the School for Social Care Research.	No needs 10 (50%); Some needs 8 (40%); High needs 2 (10%). **Sample size** Given in table 4: 20 residents, all with dementia and varying levels of need (No needs 10 (50%); Some needs 8 (40%); High needs 2 (10%)). **Intervention** List interventions of interest Comparison of SCRQoL over time: By subtracting expected SCRQoL from current SCRQoL, authors calculated "the SCRQoL gain", which shows "the total benefit of the intervention or service". Design a feedback-intervention based on the evidence collected using the CH3 toolkit (observational notes and interviews) and pilot it in a small sample of care homes in England. **Costs?** No	3. Staff and managers offered a generally positive view of the data collection process and feedback intervention. The authors comment that, "Staff and managers agreed with the feedback they were given and felt it accurately reflected the areas of quality of life they do well at (personal cleanliness and comfort, accommodation cleanliness and comfort, safety and dignity) but also identified areas they struggle to make time for (choice over food, control over daily life, social participation and occupation)" (Authors, p9 and 10). 4. The authors report that the feedback provided by them led to changes in practice. For example, one care home manager comments: "I completely changed the whole setup of the working day. So I looked at smaller groups of residents, because the staff were coming back to me and saying, 'We haven't got time to complete all of our tasks with so many residents.'.... They now have more time to spend with the residents in terms of social care; the little things, painting nails, and so on and so forth, and the lipstick and it's all very, very important. So that took the onus off of a task-orientated workload" (Care Home Manager Nursing National Chain, p10).	

62. Trappes-Lomax T and Hawton A (2012) The user voice: older people's experiences of reablement and rehabilitation. Journal of Integrated Care 20, 181–194

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Study aim This paper aims to report verbatim the voices of older people describing their experiences of rehabilitation services in community hospitals and local authority short-term residential units followed by "usual care" services at home – in other words, what service users thought worked well or could work better about rehabilitative care. The purpose of this study is to feed directly into the implementation of the DH Section 256 "reablement guidance". **Methodology** Qualitative study. Semi-structured face-to-face interviews in 2002–2003, with 42 participants (mean age	**Participants** People receiving social care reablement and rehabilitation. **Sample characteristics** *Sex* Those attending the 16-bed L/A unit = females 12; males 6. Those attending a small L/A unit = females 5; males 2. Those who went straight home from hospital = females 15; males 2. *Disability* Conditions included falls or fractures, strokes, medical/post-operative (e.g. aneurism, diabetic coma), other (e.g. major RTA, not coping, collapse, and incontinence). *Sample age* Mean age 81.4 years *Level of need* From the sample of 42,18 had spent up to six weeks in a 16-bedded rehabilitation unit attached to a L/A residential home. Seven had spent up to	**Framework areas** Continuity of care and transitions (incl. access) Care and support for people's needs **Narrative findings** Four main themes emerged: 1. THE COMPLEXITY OF REHABILITATIVE NEED The data showed that individuals need a range of interventions and techniques at different stages of recovery. Patients in hospital faced severe physical impairments, cognitive problems and emotional vulnerability. Those attending an L/A rehab unit had been discharged from a community hospital and had already regained some self-care skills and/or mobility while there. i. Goals Most goals in the community hospitals were about personal care skills and mobility: 'To manoeuvre from the chair to the toilet was . . . quite difficult. It doesn't seem so now of course, but it was then' (Participant 1, p186). 'We have a very difficult staircase (at home). I used to practise walking up and down' (Participant 2, p186). This compared to the L/A rehab units, where the main aim was on regaining independence and confidence. 'I was determined I wasn't going to stop like it (bedbound) . . . I was such a nuisance to everybody' (Participant 3, p186). Goals were very practical: 'Do my own shopping and washing . . . be able to use	**Overall score** ++

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
81.4 years) using interpretative phenomenological analysis (IPA). **Country** UK **Source of funding** Government This study was funded by the (then) Centre for Evidence-based Social Services, supported by the NHS Executive and Social Services Directors across the South West.	six weeks in one of 7 stand-alone L/A units, which had 3 or 4 beds each. In total, 17 people had gone straight home and received "usual" community services. All had originally been assessed as likely to benefit from six weeks in a rehabilitation unit (achievable goals, motivation and the potential to regain independence). **Sample size** 42 participants. **Costs?** No	my legs again, that was the main thing' (Participant 4, p186). ii. Supporting autonomy and self-care Hospital routines tended to emphasise dependence: 'Everything was done for you', 'When it was time for me to come home, they were still trying to do everything for me . . . And that really got my goat' (Participant 5, p186). In the rehab units, people welcomed the chance of 'doing it for yourself". 'They wanted us to do as much as we could . . . you could go in the kitchen and get your own tea' (Participant 6, p186). '(After hospital) you need . . . somewhere like that to give you confidence and think . . . I can do that at home' (Participant 7, p186). iii. Participants ideas for how needs could be better met When asked how the care process could be improved, mobility was a priority for most people in hospital, with almost everyone wanting more physiotherapy. However, other responses were more complex and participants differentiated between physical and psychological progress: • They talked about more purposeful and practical daily activities in the residential units: 'If I'd been taught a skill – that would have interested me a lot' (Participant 8, p186). • In both clinical and non-clinical settings, participants said they would have liked more chance to talk to someone who understood what they were going through: 'Deep down inside me I know life will never be normal again' (Participant 9, p186). But they said that staff rarely	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		had time to talk, as they were usually 'busy doing other things' (Participant 10, p186). • More emphasis was needed on enabling a sense of being in control. The need 'to do it for yourself' was often emphasised. 'You shouldn't take it for granted that people couldn't do anything. You presume they can do and when you find that they can't do it, then you take over' (Participant 6, p401–08). 2. THE EFFECT OF THE DIFFERENT SETTINGS Although hospitals and rehabilitation units varied in their effect on individual recovery, needs changed rapidly in both these settings as individuals recovered, highlighting the need for regular re-assessment and a diverse range of activities, irrespective of the setting. i. Positives Individuals valued the community hospitals for their small size, being local and having a friendly atmosphere. 'It was near home' (Participant 1, p187). 'There wasn't the rush that there had been in the (acute) hospital . . . all so free and easy really' (Participant 2, p187). Participants said they often made most progress in regaining basic skills, mobility and confidence in the community hospital. The smaller 3 to 4 bedded rehab units, on the other hand, seemed better able to promote mutual support and re-adjustment to 'ordinary' living. 'You made your own pot of coffee. You didn't think you could manage it but you did . . . you felt you'd achieved something at last. Yes, that was the start of the rehabilitation' (Participant 3,	

Research aims.	**PICO (population, intervention, comparison, outcomes).**	**Findings.**	**Overall validity rating.**
		p187). The strongpoint of the larger 16-bed unit valued by individuals was its on-site, multi-disciplinary team. 'Making me do things I'd never done before! You really felt something was happening at last' (Participant 4, p187). ii. Negatives The main disapproval of the community hospitals was the lack of things to do. When asked about a typical day, most people reported long stretches when they 'just sat beside the bed for countless hours and nothing was happening' (Participant 3, p187). They also said that clinical settings could hinder autonomy: 'You do get very dependent in hospital . . . someone tells you when it's time to do things and what to do and where to go' (Participant 4, p187). 3. THE DUAL ROLE OF THE STAFF Study participants described both 'hands-on' and 'hands-off' approaches. i. Motivation techniques In the community hospitals these could be quite subtle: 'You don't realise the back-up that was there all the time. You think you're doing it all, but you're not' (Participant 1, p187), or more direct. 'When you're not feeling well, you can't be bothered . . . you've got to be pushed a little bit. Otherwise you just sit back and think, "Oh I don't care". Although you know in your mind it's the wrong thing to do, your willpower won't do it' (Participant 2, p187). In the rehab units, however, even if unwilling when they arrived, most people soon recognised that the process of recovery involved	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		'doing it for yourself'. 'They'd say, come on, you're going to start doing some work . . . and they would show you how to do it' (Participant 3, p187). 'They liked you to try. If you tried, they are very pleased when they see you doing things' (Participant 4, p187). ii. Involvement in the rehabilitation process In hospital participants sometimes found it difficult to understand the reason for particular activities. 'It seemed ridiculous to me to be holding my hand out. I'd got past all those stages' (Participant 5, p187). In the rehab units recovery was promoted through collaboration. 'Tis up to me whether I can do it . . . or whether I take in what they say . . . Tis a partnership, yes, yes. If one don't want what the other one (wants) . . . it's no good. But if I think they're good, then it works together' (Participant 6, p187). iii. Uncertainty about the role/commitment of the staff In the community hospitals, there seemed to be 'some confusion about whether the staff were hands-on carers, hands-off enablers or just plain over-stretched' (Authors, p188). 'If you could manage on your own…they didn't bother much' (Participant 7, p187). 4. LIFE BACK AT HOME This theme relates to participants' experiences of transition from residential to community-based care. i. Readiness for discharge For patients going home straight from a community hospital, there was evidence of good preparation: 'I	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		had this punishing training on the stairs and knew I could actually do it once a day, so I did want to come back' (Participant 1, p188). But there were also examples of apparently unplanned discharges: 'Nobody seemed to know what I was going to do – me less than anybody' (Participant 2, p188). 'A woman brought me home – she just dropped me in and that was that' (Participant 3, p188). Discharge from the rehab units seemed to be well organised, with users valuing the pre-discharge home visits: 'I had to pass my test before they'd let me out'! (Participant 4, p188). ii. Lack of continuity/sudden cut-offs Several people said a one-off phone call or nurse visit would have helped when they first went home from hospital. 'Part of the fright of coming home was that you were completely on your own (when) you'd had a doctor every day and nursing staff all the time' (Participant 5, p188). There were similar reports of sudden cut-offs by the rehab units. For those living alone this could be very difficult. 'I closed my door and I thought "well, this is it – come on girl, you have got to do it yourself' – no one to push you now" ' (Participant 6, p188). iii. Community care support at home • Continuing problems: nearly everyone described continuing pain or physical limitations. • Lack of rehabilitative input: almost no one had received any therapy once they returned home, either from hospital or from a rehabilitation unit.	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		• Lack of "enabling" support: "standard" community services at home mainly involved physical assistive devices, but there seemed to be very low levels of self-care support either from the statutory or voluntary sectors. 'I got no help whatsoever, only a list of telephone numbers and "you don't meet our criteria" – it makes you a bit resentful' (Participant 7, p189). • Inconsistency of support: one or two people reported high levels of personal care, but with some misgivings. 'You never know when they're coming, you never know who's coming . . .' (Participant 8, p189). • Dependence on informal care: family and friends made up for the poor level of formal support received by participants.	

63. Turnpenny A, Caiels J, Whelton B et al. (2016) Developing an easy read version of the adult social care outcomes toolkit (ASCOT). Journal of Applied Research in Intellectual Disabilities, Advance online publication. doi: 10.1111/jar.12294

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Study aim 'The aim of this study was to develop and test a new version of the ASCOT Easy Read questionnaire (ASCOT-ER), building on an initial (untested) version. Specifically, the aim was to create	**Participants** People receiving home care People receiving social care **Sample characteristics** Sex Table 1: Focus groups: 13 female. Cognitive interviews: 9 female.	**Framework areas** Respect, dignity and control Personalised support Info and comms Active participation in lived experience of care Continuity of care and transitions (including access) Care and support for people's needs	**Overall validity score** +

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
an instrument that is easy to understand and minimizes task difficulty for respondents with intellectual disabilities".(Authors: p3). **Methodology** Mixed methods The study combined survey development and pre-testing methods with approaches to create accessible information for people with intellectual disabilities. A working group assisted researchers in identifying appropriate question formats, pictures and wording. **Country** UK South-east England.	Ethnicity Table 1: White British 27 (FGs) 18 (interviews). Sample age Table 1: Age range 20–39 years 16 (FGs) 13 (interviews); 40–59 years 4 (FGs) 5 (interviews); 60 years or over 4 (FGs) 3 (interviews); Prefer not to say 8 (FGs) 1 (interviews). **Sample size** Total participants: Focus group (32); cognitive interviews (22).	**Narrative findings** Findings are reported in relation to understanding and interpreting the questions within the ASCOT-ER: 1. The authors report the question item for the Food and Drink section was understood by focus group participants and cognitive interview respondents (p6). They say that: "Responses reflected different experiences, and attention was paid to the variety and balance of the food and drink that people were consuming, as intended by the domain description" (Authors, p6). 2. For the domain Personal cleanliness and comfort (Being presentable) the authors reported the items were less well understood. For example, the word 'presentable' was highlighted as being potentially difficult, and nearly all respondents commented that they had never heard it before. 3. For the domain Accommodation cleanliness and comfort the authors say that the question was understood without any difficulty by focus group and cognitive interview participants. Respondents living in different contexts (e.g. some were in shared accommodation) were able to reflect well on those contexts to respond to the question. 4. The domain Personal safety raised important issues. The authors report that discussions with the working group revealed that this was cognitively too challenging because most respondents reported feeling very different at home and in the community. For	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		example, one participant explained that he felt safe in his home but was more anxious when outside because of being the victim of a previous assault. These considerations led the research team to split the original question into two questions: one relating to safety inside the home and the other to how safe people feel when they are outside in their neighbourhood and local community. The authors report that all respondents consistently understood the two new questions. 5. For the domain Social participation and involvement the authors report focus group participants describing the question as easy to understand, and say all participants were familiar and happy with the term ‘social life’. They also report that the cognitive interview participants “appeared to understand the question and responded adequately reflecting on their experiences of seeing and keeping in touch with people important to them” (Authors, p7). 6. For the domain Occupation, which asks respondents to consider all activities in their daily lives using a series of bullet points, the question was considered very long and consequently the authors reported that “some respondents needed to read (hear) it more than once to process it fully”. Nevertheless, they argue that “participants did not need any further explanation nor did they highlight any difficult words” (Authors, p8). 7. The authors report that the domain Control over daily life alongside Dignity presented particular challenges during the development of ASCOT-ER. For	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		example, the authors say that during the focus groups a number of participants – particularly those with Autism – held the view that the question was not specific enough and therefore difficult to answer. They go on to say that other participants with intellectual disabilities found the term ‘control’ confusing. In response to comments from respondents the wording was changed to be about choice rather than control. The authors report that all but one respondent appeared to understand the revised wording. 8. For the domain Dignity, the authors report that an early version tested in focus groups included the term ‘respect’ (the question was: ‘dignity means being treated nicely and with respect’) and that participants highlighted this term as problematic. The revisions to the tool led to the word ‘respect’ being removed and dignity being reworded as ‘being treated nicely and kindly’. Respondents also raised concerns about the concept of ‘paid staff’. The authors say: “A further concern was that people with intellectual disabilities who use social services often come into contact with more than one paid staff member, who might have a different attitude or approach towards supporting people. Therefore, answering this question potentially requires a high level of generalisation that might be difficult for some respondents; cognitive testing paid particular attention to exploring this.” 9. Finally, a key consideration for the authors was how well people with intellectual disabilities would respond to tools with sets of response categories and if	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		they could reliably assign themselves to an answer. The authors found that when it came to specific response options, longer descriptors were more useful than those consisting of one or two words, like those commonly used in Likert-type scales. The use of happy and sad faces were reported as being helpful because people were already familiar with these images but some participants commented that they were 'childish' and a lack of neutral response and face – the ASCOT measure uses a four-point scale – was reported as problematic. 10. The authors report substantial changes being made to the original ASCOT-ER questionnaire. They argue that involving people with intellectual disabilities and autism in the questionnaire revisions helped by "identifying and including images that are both acceptable and relevant to the majority of participants" (Authors, p10). The authors conclude (p11) that the findings suggest that while most people with intellectual disabilities and autism should be able to use and engage with the ASCOT-ER, the ASCOT-ER would benefit from further systematic testing, particularly around validity and reliability.	

64. Valdeep G, Husain F, Vowden K (2014) Satisfaction with social care services among Black and Minority ethnic populations: exploring satisfaction with adult social care services amongst Pakistani, Bangladeshi and white British people. London: National Centre for Social Research

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Study aim The aim of this project was to provide explanations for the reasons behind these lower levels of satisfaction, focusing on two particular ethnic groups: Pakistani and Bangladeshi. White British people were also included as a comparison group. **Methodology** Qualitative study In-depth interviews and focus groups designed to explore whether lower satisfaction was related to how social care is delivered to or received by BME groups. **Country** UK Participants lived across three areas of England: London, Birmingham or Leeds.	**Participants** People receiving social care The sample was selected to ensure representation of both men and women and different ages (18 to 59 years or 60 years and over). Participants who were either in the process of applying for social care at the time of interview or had been in receipt of care in the previous 12 months. The sample included participants who were in receipt of personal budgets. Administrators, commissioners, managers Social care providers, e.g. Local Authority senior managers within adult social care, Home Care providers. **Sample characteristics** *Sex* Service users: 26 male; 35 female. *Ethnicity* Service users: Bangladeshi (19); Pakistani (23); White British (19). *Sample age* Service users: 18–59 (28); 60+ (33)	**Framework areas** Care and support for people's needs **Narrative findings** Pages 40–9: In the section titled "Service users' views of what local authorities offered them", some users spoke about social care providing social contact/companionship for them, for example: 'There are people [professional care workers] that really take care of me here and may Allah bless them and the biggest problem is the loneliness, it is killing me' (Female service user, Pakistani origin, London, p43). Those who were socially isolated were also reliant on their care worker for regular social interaction: 'I mean that's probably the highlight of your day' (Service user, Male, white British, Leeds, p52). Page 50 – In the section titled: "Receiving care", the authors describe users expecting care workers to be both professional and personable. For example, one service user said: 'I think it's important that, there [are] three attributes. One is punctuality, two is the rapport and three is getting the work done properly. She's [my care worker] got all three. If you haven't got all three, then it might be a problem' (Service user, male, white British, London, p50). The authors comment (p50–1) that there are challenges in reaching a good balance between service user expectations and delivery: "Some service users and relatives had unrealistic expectations of care workers duties, for example, an expectation that care workers could do tasks outside the agreed care plan. Secondly, care workers had pressurised workloads,	**Overall score** +

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Source of funding Other National Institute for Health Research, School for Social Care Research.	**Sample size** 61 service users; 24 social care providers. **Costs?** No	resulting in having to rush or struggle to complete all tasks in the given time." For example, on service user described her dissatisfaction at having her care worker refuse to do things outside of her care plan: ‘I have had carers who sort of said, 'It's not my job', and flounced out leaving me without bread and milk at the weekends’ (Service user, female, white British, London, p52). The authors go on to comment that service users expressed dissatisfaction over the late running of care workers and that unexpected lateness in particular caused anxiety for service users and was frustrating for relatives who relied on staff for assistance and respite. For example, one service user said: ‘You're looking at your watch and one o'clock comes and they're not here and two o'clock comes and they're not here and you start then to get anxious. Are they gonna come, aren't they gonna come?’ (Service user, male, white British, Leeds, p56). Service users were asked about 'matching' (e.g. a care worker with the same ethnicity as the service user). This was considered to be a lesser priority: ’They are here to do a job. When we go to hospitals we can't expect staff to be Muslims or from the same background as us’ (Male service user, Pakistani origin, Leeds, p63). The authors comment, "family members expressed more concern about ethnic matching than service users" (p71). The authors report that there was a general dissatisfaction with meal on wheels services, with the main issue being poor quality foods being provided at a	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		high cost. For example, one service user said: ‘They're charging £4.10 pence for a dinner in which there's a tiny pudding which you wouldn't feed to a dog, to be honest, but now, because [the] Council has removed their subsidy, they're going to go up to £5.71’ (Service user, male, white British, Birmingham, p66). Page 68: The authors conclude that: “Service users taking part in this study clearly suggested that the interplay of culture and religion influenced their level of satisfaction with social care. This was mainly expressed with reference to the attitudes and beliefs of older service users." Page 69: The authors conclude that "Dissatisfaction was experienced when local authorities and care workers did not consider the needs and contribution of other family members when providing care." Page 70: The authors conclude that personal budgets received through direct payments, "were a potential source of satisfaction for Bangladeshi and Pakistani service users and their families since they allowed care to stay within the family or the community". However, they note that they could also be a source of dissatisfaction because of the difficulties of managing them. Page 70: The authors conclude that language was a barrier for many service users and their families in terms of accessing care, which they say necessitated good levels of English in order to get the right services arranged.	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		Page 73: The authors comment that culturally appropriate care was relevant for those participating in activities outside the home, for example at day services. For example, service users expressed more satisfaction if activities such as exercise classes were segregated by gender. Pages 74–8, author recommendations included: 1. Having frontline local authority staff with relevant language skills; Navigating the social care system could be made easier for people by having a policy of user friendly language across all areas of the system – from websites to assessments. 2. Promoting direct payments and personal budgets, in particular, was suggested as a way to engage BME groups with social support services. 3. Local Authorities should provide 'Cultural awareness training'. 4. "Local authorities should have a policy of not using family members as interpreters within assessments and meetings with social workers; to avoid misinformation, and breaching confidentiality of service users." (Authors). 5. "Service users and families may benefit from training (provided by local authorities) to provide information on the role of care and support worker and care plans, and information on issues such as how to make a complaint." (Authors).	

65. Ward L and Banks L (2017) Older people's experiences of sight loss in care homes. Brighton: Social Science and Policy Research Centre

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim The research aims were: To contribute to improved standards of care and practice in residential care for older people living with sight loss. To generate understanding of living in care homes from the lived experiences of older people with sight loss. To gather the views of older people with sight loss, family members, friends and care home staff on good practice in residential care. To produce understanding about good standards of care and practice for older people with sight loss living in care homes and to make recommendations for an agenda for action (p2).	**Participants** People receiving social care. **Sample characteristics** Sex – 13 women, 8 men Sample age – between 63 and 98, **Sample size** Sample size – 21 care home residents, 10 care home staff 9 relatives of care home residents.	**Framework areas** Personalised support – Many spoke about the transition of moving into the care home and the adjustments of living in a communal environment with less personal space. The extent to which residents were supported with orientation and the physical environment varied (p4). Active participation in lived experience of care Care and support for people's needs – Complexity of needs within care homes. In addition to visual impairment residents were experiencing other health conditions including hearing loss, memory loss and confusion, and mobility difficulties. They clearly had emotional needs and some experienced poor mental health and depression (p4). **Narrative findings** The authors report several key themes including facilitators and barriers to good care, as follows: Facilitators: • Awareness of sight loss among staff, particularly agency staff. Awareness was also appreciated from other residents. • Adequate staffing levels and staff time to provide emotional and social support. Residents talked about wanting more time to just talk with	**Overall score** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Methodology Qualitative study. **Country** UK		staff and highlighted the importance of having company. - There was a need for support with becoming familiar with the care home for new residents for negotiating the care home environment. - The importance of volunteers to help engage in activities and go out but difficulty in accessing volunteers. - The importance of friendships, company and conversation but social interactions can require facilitation by staff. *'They're very, very good to me, they're very helpful. I mean they tell me every, you know, even to sitting down, turning round and sitting down and making sure that I'm, I don't fall, you know, they've been very good. … I mean like the nurses and the staff here, they, well, they, they're like friends, they're very good to me and I don't think they've been able to have done so much, because they have been good, they have been good, and been very patient, so they put themselves out, they're very, they're very good.'* (Participant, page 30). *'You can only say nothing but praise of them, they were unfailingly kind and polite and nice and helpful but they're pushed lately, I mean they're rushing around like I don't know what. They're all nice, I mean you know, the carers, they are all nice, I mean they don't sit down for half an hour to chat but I chat. They chat and then they go, excuse me, I must get on,*	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		which is fair enough but they are good.' (Participant, page 30). - A reliance on family and friends to provide difficulties where help from family and friends is not available. - The sense of loss related to sight loss and loss of activity, depression and lack of emotional support. Relationships with others are crucial in counteracting feelings of isolation. *'I like company, I'm not much good in my own company and here, I've been here two and a half years and the first year was really quite dreadful because there was very few people, not many people here and fewer still who've properly got their wits about them. I don't mean to sound awful but I mean there was no one to talk to, properly talk, you know. So it was miserable, miserable, miserable.'* (Participant, page 31). - The added financial costs related to sight loss, for example, transport and equipment. Difficulties with accessing or finding out about equipment, which might help to address the issues of living with sight loss. Barriers - Insufficient support from outside, especially lack of input from rehabilitation workers and lack of perceived support associated with registration.	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		'…well it's difficult to say anything about my sight without grumbling and I don't, I'm not a grumbler, I sort of accept things as they are' (Participant, p25). • More knowledge is needed of aids and adaptions, and technology that could help residents maintain their interests or develop new ones. '*Well it's all on one level, isn't it? If I go out that door and turn left, I'm in the, in where they serve the food up, you see, and if I go further in, it's a lounge, like, a sun lounge, windows all the way round and, you know, and televisions and record players and God knows what else. I've got no difficulty at all. If I went outside, I'd like to hold onto somebody or something that's firm'* (Participant, p38). *'There is an awful lot of things that I cannot do. I do try, I go down to the craft and I have a go but that I find very frustrating because I was so good at anything with my hands and now I can only feel and I don't know if I've done it right, you know, but I do have a go'* (Participant, p43). '*You feel, when you've had an active life you feel terribly frustrated that you can't see to do things, you can't use your brain'* (Participant, p43).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		'*So you don't really join in with activities?*' (Interviewer) '*One or two but not many because I can't do it properly and it upsets me*' (Participant, p43). • Better connections are needed with local external organisations such as sight loss societies and rehabilitation services. '*They say would you like a volunteer and you say yes and you forget all about it and then about eighteen months later! But it's a question of finding someone they think you'll, you know, match with and I've got an extremely good volunteer who comes, well when I ask her to, to sort of do a few odd jobs for me here and then, weather permitting, go out and have coffee or something'* (Participant, p34).	

66. Westwood S (2016) 'We see it as being heterosexualised, being put into a care home': gender, sexuality and housing/care preferences among older LGB individuals in the UK. Health & Social Care in the Community 24, e155–e163

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim The study aims to find out what choices older lesbian, gay and bisexual (LGB) individuals would like to make about sheltered hous-	**Participants** People receiving social care – Ten of the 60 participants were living in sheltered accommodation. The remainder lived in independent accommodation, but were within an age range where they may have been considering the	**Findings** Personalised support – The study highlighted the range of wishes expressed among participants about the sort of retirement accommodation they would prefer, e.g. exclusively LGB or LGB-friendly (i.e. non-exclusive). This highlighted the need for personal preferences of LGB people moving to supported older people's housing to be explored.	**Overall score** -

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
ing and residential/nursing care provision for themselves, given that some choices are not currently open to them, e.g. there was no specialist LGB provision, unlike some other developed countries where there is a growing number of specialist retirement facilities. The study seeks to analyse 'their concerns about mainstream sheltered accommodation and residential care, in terms of lack of visibility, risky visibility, unequal openness and compulsory co-occupation. It considers their differing sheltered housing/care preferences and the significance of gender for those preferences. The legal and social policy implications are considered' (p156). **Methodology**	sort of supported accommodation they might prefer as they grew older. **Sample characteristics** Sex – 36 women, 24 men. Sexual orientation – 'Of the women, 29 identified as lesbian, one as gay, two as bisexual and four (all in civil partnerships but previously in heterosexual relationships) were uncertain and/or unwilling to assign a label to their sexualities' (p156). Such detailed information is not provided about how the men identified their sexual orientation, although due to the nature of the research it must be assumed that all were gay or bisexual. Disability – Not stated. Ethnicity – All but one of the participants were white British. The ethnicity of the one is not stated. Sample age – 58–92 for women, 58–76 for men. The mean age for both was 64.	Care and support for people's needs – The study explores how LGB older people would prefer to have their needs met within supported accommodation, with specific regard to their LGB identity. **Narrative findings** Participants felt that older age housing/care spaces were intrinsically heterosexual: *'We see it as being heterosexualised, being put into a care home'* (Female participant, aged 60, p157). A male member of his local day centre committee for older people, would refrain from using this service: *'So although I'm actually supporting this heterosexual day centre, because of the need for it, I'm also trying to find alternatives for gay people . . . Because I can't see me fitting into somewhere like that . . . it's all geared to heterosexual people…Everything that happens, what they talk about, and their past, things that don't relate to me as a gay man . . . Everything's heterosexist, really. They can't relate to your needs . . . You don't have 'Gay Times' on the table, but you'll have something for heterosexuals on the table'* (Male participant, aged 65, living in sheltered accommodation, p157). Concern was voiced about both care standards and 'dominant heteronormativity' ('a lot of straight people singing Second World War songs'): *'I don't want to be sitting in a urine-smelling older person's home with a lot of straight people singing Second World War songs. I'd rather be sitting with people*	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Qualitative study – Semi-structured interviews. **Country** UK **Source of funding** Other – It is reported that the study was carried out for a PhD in law. Funding would therefore have come from whatever source the PhD was being funded by, which is not stated.	Level of need – As 50 of the 60 participants were still living in independent accommodation, it must be assumed that they currently had a lower level of support than that required for entering residential or sheltered accommodation. However, little information is provided about the participants' level of need. Socioeconomic position – 'The majority were well-educated and relatively affluent' (p156). **Sample size** Sample size – 60 **Costs?** No	*that I can relate to, watching gay cabaret, or getting some of the LGBT film festival films coming in, you know, that sort of thing'* (Female participant , aged 60, p157). Concern about abuse was raised: *'Because of our sexuality there's more to be abusive about potentially and because we're still considered less than, then the idea of stealing from us, or you know being abusive in some other way, is even more attractive. Well who cares about the fag, who cares about the dyke, they don't need the money, so in that sense we're more vulnerable'* (Female participant, aged 66, p157). Of even greater concern among participants was everyday homophobia. A female participant spoke about a friend living in sheltered accommodation, who is not open about her sexuality: *'…she lives her life privately. But she has to get involved in this sheltered unit, because there are coffee mornings and things like that and, you know, she doesn't want to be unfriendly. She wants to feel part of that community. She also happens to be Black. And she's had to listen to things, when people have been reading the newspaper, listen, when there's some gay issue or something, to things like 'Oh, if my daughter was like that I'd kill her'. No what does she do with that? If she challenges that she outs herself and then puts herself in a very vulnerable place'* (Female participant, aged 69, p158).	

Research aims	**PICO (population, intervention, comparison, outcomes)**	**Findings**	**Overall validity rating**
		And this issue carried over to perceptions of care staff attitude: *'What if they [care staff] took a dislike to me? I don't think many people here would understand it or accept it somehow'* (Female participant aged 92, living in sheltered accommodation, p158). LGB individuals 'continue to live in fear and hide their identities' in care spaces as echoed in the following quote: *'Be nice if you could have your partner's photo up, or have a place where you can be private together, or even, in a public place, hold hands without it being nudge-nudge, wink-wink'* (Female participant , aged 69, living in sheltered accommodation, p158). In terms of care preferences, the majority of participants said that there should be a choice of provision, for example: *'I would like to see a choice of care homes'* (Female participant aged 63, p159); *'I think people should have choice . . . and there should be homes for gays and lesbians definitely'* (Male participant aged 66, p159). Participants who preferred mainstream provision stressed the importance of integration, and wanting to avoid segregation and ghettoisation:	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		'I think care homes ought to be integrated otherwise you're going to get segregation' (Female participant, aged 69, p160). *'I don't want the LGBT community to be ghettoised. When I want extra care, I wouldn't want to be with just gay men. I've always seen myself as part of the wider community and want to remain there. As a gay man'* (Male participant, aged 70, living in sheltered accommodation, p160). The study concludes that there are a 'wide diversity of care concerns and preferences among older LGB people' (p161). A range of preferences were expressed, for living in accommodation that would be women only, lesbian only, men only, gay men only, LG/LGB/LGBT exclusively, or integrated provision. Ageing and sexuality were concerns for all, with gender considerations also being more significant for female participants.	

67. Williams V and Robinson C (2000) 'Tick this, tick that': The views of people with learning disabilities on their assessments. Journal of Learning Disabilities 4(4), 293–305

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim To gather the views of people with learning disabilities and analyse	**Participants** People receiving social care – Adults social care.	**Framework areas** Respect, dignity and control Continuity of care and transitions	**Overall score** -

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
the range of assessments and planning, such as service reviews otherwise known as individual programme plans (IPPs), or community care assessments. **Methodology** Qualitative study – This study contains three points of data collection, however, note this is hard to interpret because unclearly written. Point 1 titled 'Individual planning': The research team met with 46 people with learning disabilities who have individual programme plans (IPPs) and are in receipt of a day service. 25 people were then interviewed following an IPP, rather than a community care assessment because the researchers	**Sample characteristics** *Sex* Not reported. *Disability* Learning disabilities. Thirty-four participants were able to communicate, whereas 11 participants did not respond verbally or through a 'recognised system' (page 296). Other phases not reported. *Ethnicity* Not reported. *Sample age* Phase 2 – ages 14 to 47. Other phases not reported. *Level of need* Not specific. *Socioeconomic position* Not reported **Sample size** Point 1: Unclear, 25 interviews conducted.	**Narrative findings** Findings are reported under the following headings: i. Understanding the assessment process; ii. Understanding the IPPs; iii. Speaking Up for one's own needs; iv. Records of assessments; v. One year on; and vi. What the assessment process can achieve. **Key findings** Neither community care assessments as they stand, nor IPPs, are universally successful in their aim of putting the individual in control. In addition, the outcomes of community care assessments are not delivered in a reliable or prompt manner. People with learning disabilities reported that their assessments were often difficult to interpret, disempowering and inaccessible. Furthermore, fewer than half of the services discussed at the assessment were provided one year later. However, carrying out a separate assessment of the carer's needs was generally empowering, both to the carer and to the cared-for person. Findings are reported under the following headings: i. Understanding the assessment process; ii. Understanding the IPPs; iii. Speaking Up for one's own needs; iv. Records of assessments; v. One year on; and vi. What the assessment process can achieve.	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
wanted to investigate 'how this process contributed to their own choices and empowerment' (p295). Point 2 titled 'method': 51 families were approached who had a person with learning disabilities over the age of 11. This was then reduced to 45 interviews being carried out because one refused and five were under the age of 11. Point 3 titled 'method' and 'one year on' in findings: The research team then approached the original 45 interviewed for a follow-up approximately a year later to find out the outcomes after their assessment, but 6 responded and were interviewed.	Point 2: 45 interviews conducted. Point 3: 6 interviews. It is important to note that the authors only reported brief characteristics for point 2 which are: age range between 14 and 47; and 34 participants were able to communicate, whereas 11 participants did not respond verbally or through a 'recognised system' (p296). There is no further information about participants' characteristics. **Costs?** No	i. Understanding the assessment process There was a lack of understanding the assessment process shown by people with learning disabilities. Of the 19 participants who were asked about their community assessments, 4 people mentioned particular services or issues that their care manager had tried to solve and saw these issues as the purpose of the assessment For 1 person, this was about moving out from the family home into a supported living situation: *'It's to go to another house . . . it's part of his job to find a place'* (Study participant, p297). ii. Understanding the IPPs (Service review) Twenty-five people were interviewed about their IPP – which is normally focused on the individual's programme of activities. Many people with learning disabilities found the IPP system easier to understand, with 6 people expressing understanding of the forward planning function of their IPP, relating to their programme in the day centre: *'It's to do with my work.'* *'[It's] to see what's happening.'* *'They're about my programme. The IPP is usually concerned with the individual's programme of activities.'*	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Country UK **Source of funding** Government – NHS Executive South and West.		Some comments suggested that individuals were not 'in control' of the process, but that others were controlling them, with the IPP often used as a means of monitoring their behaviour: *'It's to see how I'm getting on and not upsetting people' (p298).* Only one person understood that it had a general function to help them plan for the future. iii. <u>Speaking Up for one's own needs</u> The authors report that people with learning disabilities are not 'used to being listened to, and perhaps lack skills and confidence'. One person recalls: *'I try to say something, and then I forget what I'm going to say'* (Study participant, p299). Twelve people reported to having private meetings with their social worker or key worker, and 10 reported feeling happy they were listened to. One participant recalled their key worker helping them to look for paid employment: *'She was helping me to speak up.'* At least 6 of 25 participants had not been present for their IPP, which supported previous research conducted by Carnaby (1997) who 'raised concerns about the real involvement of people who do not communicate verbally' (Author citation, p299). ***Community care assessment***	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		Of the 19 community care assessments conducted, 6 had a private meeting whereas 3 participants reported that they had not been spoken to. One participant commented about the meeting with their care manager: *'He didn't sit down with me like you're doing… he sat at the table with my mum.'* Parents can easily dominate these situations, and the way in which the meeting is set up can be very influential. The carer may assume that they have to speak for the person, and the whole process can become focused on the carer's views of what the individual needs (Authors, p299). iv. Records of assessments Community care Authors report that assessments are not always meaningful to people with learning disabilities. One participant described their community care assessment: *'It's just a pile of paper with lots of squares – tick this, tick that'* (p301). One individual who showed the researcher the record of his IPP said he could read. However, he was rather perplexed by the phrase:	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		‘Needs to participate more, verbally.’ Because of a lack of access to the printed record of assessment, many people depend on their carer to read the record to them. This makes it very hard for any kind of confidentiality to be maintained, IPP The IPP was reported to be more personal, and one participants’ plan was personalised and accessible, containing unique ‘strengths and needs, activities and goals… illustrated by means of photos that he had chosen and talked through with his keyworker’ (Authors, p301). Successful features of the IPP are reported to include: accessible information; use of photos; getting-to-know-you-time; and enhanced communication (signing, symbols) (p300).	

68. Willis P, Maegusuku-Hewett T, Raithby M et al. (2016) Swimming upstream: the provision of inclusive care to older lesbian, gay and bisexual (LGB) adults in residential and nursing environments in Wales. Ageing and Society 36, 282–306

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim The study uses interviews with LGB people who are prospective users of residential and nursing homes, and with staff and	**Participants** People receiving social care – The 29 individual interviewees were prospective receivers of social care, as none of them was actually living in a residential or nursing home.	**Framework areas** Respect, dignity and control – The study reveals the wishes of the LGB participants that if they enter residential care they would wish to be treated with respect and dignity.	**Overall score** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
managers of residential and nursing homes, to explore how these places provide heteronormative environments, and how this could be addressed to ensure they provide suitable environments for older people with diverse sexual identities. **Methodology** Qualitative study – The study used 5 focus group interviews with care and nursing staff and managers, and individual interviews with older LGB people. **Country** UK – Wales. **Source of funding** Government – 'This research was funded by the National Institute for Social Care and Health Research	Professionals/practitioners – Residential and nursing home staff and managers: 14 staff and 27 managers. **Sample characteristics** Sex – The service user participants included 19 women and 10 men, of whom 1 identified as a cross-dressing male. Of the managers interviewed, 23 were female and 4 male. Of the staff, 12 were female and 2 male. Sexual orientation – Of the service user participants, 18 women identified as lesbian and 1 described herself as a 'dyke'. Nine participants identified as gay and 1 as bisexual. All managers identified as heterosexual. Thirteen staff identified as heterosexual, and 1 as a lesbian. Disability of users – Not stated. Ethnicity – All service user participants are identified as white, with 26/29 'of British descent' (p290). Twenty-five managers were white British and 2 'were of non-white descent' (p290). Ten staff were white, and 4 identified as 'Asian/Chinese/ mixed ethnic' background.	Personalised support – The findings show that LGB participants desired that preferences for the type of residential home they lived in should be respected. Care and support for people's needs – The LGB participants interviewed wanted their particular needs as LGB individuals, and their sexual identities, to be recognised within any care homes they entered. They wanted to be able to feel safe, not to feel disapproval of their sexual identities, for their existence to be acknowledged, and for the homes not to be based upon heteronormative assumptions. **Narrative findings** The study compared the expectations of LGB people about future residential care provision with the reality of what was described by managers and staff currently working in residential care settings. Staff and managers did recognise care homes as 'sexualised spaces in which staff and residents are frequently engaged in intimate interactions across a number of domains'. (Authors, page 299). However, 'care environments are seen as hetero-sexualised spaces in which the discussion and expression of non-heterosexual identities and sexual practices is glaringly absent…non-normative sexual identities are located as separate or irrelevant to providing care to others; and care is framed as sexually neutral' (Authors, p299). As a result, LGB identities are largely invisible. This situation was reflected in feedback from many of the interviews with LGB older people who disliked the potential situation of being presumed to be straight by care staff:	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
(NISCHR), Welsh Government' (p303).	Sample age – Twenty-three service users were aged between 50 and 69 years, and 6 were aged between 70 and 76 years. Level of need – None of the service users was living in a residential or nursing home, so their level of need was not at the level which would be required to move into these types of accommodation. Socioeconomic position – The socio-economic position of the service users is not provided, although the study does state that they had a high level of educational attainment, as 18 held degrees or higher degrees. **Sample size** Sample size – 29 service users, 14 care staff, 27 care managers. **Costs?** No	*'I don't want people making jokes about boyfriends, you know, and 'what did your husband do dear?', yes, I suppose that's what it's about really, just the same as now when I have a conversation with somebody I don't want them assuming that I'm straight . . . and it's the same for when I'm old and needy'* (Female participant , p293). Equally, several participants expressed concerns about having to go 'back into the closet' if they moved into a care home: *'I suppose I can't imagine being in a place where everybody around you would not know that you had spent all of your life as a lesbian, I mean that would be, there is no point in living, that would be the worst thing for me if you had to be completely in the closet with nobody knowing about you and you couldn't talk about your life…'* (Female participant, p293). A number of women expressed fear of losing control over their personal dress and appearance while in the receipt of care, sharing living spaces with male residents or having intimate contact with male carers. This was particularly so for some lesbian and gay women who had very little contact with men and were dependent on mainly women-only networks within their local communities: *'…and again I think it is about being a woman, somebody of the same sex, I wouldn't want a man coming in to give care . . . I'm sure that's the same with a lot of women, it's not just a lesbian thing, it's about just feeling more secure with another woman as opposed*	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		to a man, that's important…' (Female participant, p294). Over half the sample (13 women, 2 men) expressed a preference to live in LGB-specific facilities. These were 'imagined environments in which heterosexual norms and assumptions would not feature in the delivery of care and participants could anticipate feeling safe and valued as LGB adults' (Authors, p294). *'My ideal in terms of care would be to be in a sort of sheltered accommodation that was just for lesbians… because I wouldn't particularly want men around, to be honest, gay men or straight men'* (Female participant , p294). This description by staff and managers fitted with the expectations of LBG prospective residents, who had experienced homophobia across their life course. However, although LGBT-specific retirement homes operate in some other European nations and some US states, the authors report that this would run against the implementation of the 2010 Equalities Act which requires providers to supply a non-discriminatory service, and recommend that, instead, care staff and providers 'need an understanding of discrimination endured by LGB individuals across their life course and how this impacts on LGB individuals' present and future interactions with health and social care professionals' (p300).	

69. Willis R, Evandrou M, Pathak P et al. (2016) Problems with measuring satisfaction with social care. Health & Social Care in the Community 24, 587–595

Research aims.	**PICO (population, intervention, comparison, outcomes).**	**Findings.**	**Overall validity rating.**
Study aim 'The focus of this paper was the measurement of satisfaction with social care services' (p588). In doing so, the researchers aimed to address deficiencies identified by other academic papers in existing formats for patient satisfaction questionnaires, which include not having their reliability and validity tested, erroneous underlying assumptions, and not addressing diversity of language and culture among participants. **Methodology** Qualitative study In-depth individual interviews with adult service users and informal carers from white British and South Asian	**Participants** People receiving social care 46 Carers/family members 36 **Sample characteristics** Ethnicity 39 South Asian and 43 white British. Sample age 18 to 90, with the majority aged over 65. **Sample size** 82 to 46 service users and 36 carers. **Costs?** No	**Framework areas** Care and support for people's needs. **Narrative findings** Key findings The study has two main concerns. One is to examine, given the lower satisfaction ratings given to adult social care services by BME communities, whether South East Asian service users in the studies area were satisfied and dissatisfied with the same aspects of care services as the white British sample. The other concern of the study was to inquire in greater depth, using qualitative methods, what service users' satisfaction rating meant. <ins>Satisfaction ratings</ins> Few participants were completely satisfied with their experience of social services, yet the research found a bias towards positive satisfaction ratings as reported in prior research (Collins and O'Cathain 2003). The global (single) question of satisfaction required participants to reduce their whole, varied experience to a single user satisfaction rating. For some individuals, this was problematic, e.g. if some elements of experience had been good and some bad it was hard to decide on a rating.	**Overall score** +

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
ethnic groups in three Local Authority regions. **Country** UK Hampshire, Portsmouth and Southampton. **Source of funding** Government National Institute for Health Research (NIHR) School for Social Care Research (SSCR)		Some asked the interviewer how they should resolve this problem to answer the question 'correctly': *'My main thing is that what they said that they were going to do, they didn't do, and it's been over a year. I am not satisfied with that but with everything else I would say that I am very satisfied. So which one should I tick?* (laughs)' (Service user 14, SA, p592). The authors note that it is interesting to explore how the participants justified their positive satisfaction rating despite their poor experiences. Some participants did this by omitting the dissatisfactory aspect of care, e.g. *'But, otherwise [not enough staff at the day centre], they were excellent, I wouldn't, wouldn't decry them at all. It was just silly little things, you know, but they're only minor irritations, they're not major problems so we don't worry about them'* (Service User 04, White British, p592). Some participants were willing to overlook even potentially serious matters when making their satisfaction judgement: *'I would say that apart from that one incident [medication mistake while in respite care], I was totally satisfied there, very satisfied, yes*' (Service User 39, White British, p592). Some participants mentioned mitigating factors to justify the positive satisfaction rating, despite experiencing problems.	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		'She [my social worker] was fantastic, so I was extremely satisfied with her, and I felt that she heard me, and I felt that she got through the whole process as quickly and as effortlessly as possible given the situation' (Service User 31, South Asian, p592). Another difficulty with the satisfaction question is that it does not allow for change over time: *'So that's when it kind of went from very satisfied – well it went from extremely satisfied when she had two guys that she knew very well who were there for most of the time …but then like I said, there was a change in provider by the council . . . and when that happened it started to become a little bit fragmented and disjointed in terms of consistency of who came to see them and the times which they came to see them. So she kind of slipped towards the other end of the scale [of satisfaction]. So I can't really give you like one definitive [answer]. It's more temporal'* (Carer 33, WB, p592). <u>The meaning of 'quite satisfied'</u> The meaning of the Likert scale categories was questioned in some of the interviews. There were different understandings of what 'quite satisfied' means. For example, one participant gave a rating of quite satisfied despite the negative treatment provided to her husband, the care recipient. Another participant defines 'quite satisfied' as 'alright' but 'nothing brilliant'. In other words, the care was adequate.	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		Satisfaction comparison between ethnic groups The study found that both the white British sample expressed dissatisfaction with the same aspects of the adult social care service. However, South East Asian participants also wanted linguistic assistance, either by survey questionnaires being translated, or by a translator helping them to fill the questionnaires in. The researchers also noted that 'the two people who mentioned fear of retribution for making a negative evaluation were South Asian' although this did not necessarily 'suggest that South Asian service users are more likely to feel this way; the sampling approach adopted for this study makes such generalisations unwise' (p594).	

70. Willis R, Khambhaita P, Pathak P et al. (2016) Satisfaction with social care services among South Asian and White British older people: the need to understand the system. Ageing and Society 36, 1364–1387

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Methodology Qualitative study **Country** UK – Hampshire, Portsmouth and Southampton. **Source of funding**	**Participants** People receiving social care – 46 Carers/family members – 36 Administrators, commissioners, managers – 'Thirty-nine service provider/practitioners were also interviewed, but those data are not the focus of this paper' (p1368). **Sample characteristics**	**Framework areas** Continuity of care and transitions (including access) Care and support for people's needs **Narrative findings** The authors report that the main theme that distinguished satisfied from dissatisfied participants was understanding of the social care system. The authors	**Overall score** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Government – National Institute for Health Research (NIHR) School for Social Care Research (SSCR)	Ethnicity – 39 South Asian, 43 white British. Various religions, including Hindu, Sikh, Muslim and Christian. Sample age – Service users: 25 to 90, modal age category 70 to 79. Family carers: 18 to 82, modal age category 60 to 69. Level of need – 'The needs of service users, and those cared for by family carers, included physical disabilities, chronic health conditions, mental illnesses, dementia and learning disabilities' (p1368). **Sample size** Sample size – Eighty-two: 46 service users and 36 family carers. Thirty-nine practitioners also interviewed, but their data is not part of this research paper.	discuss that this theme was more important than ethnicity in explaining reasons for satisfaction. The authors also reported that continuity of care and good workforce skills were important factors in satisfaction ratings. The authors report that social care experiences were 'broadly similar' among the White British and South Asian participants. Key themes emerging from the data were as follows: Understanding of the social care system: participants were reported to have a good understanding of how social care services were organised, funded and operated. These participants associated problems with structural factors rather than individuals, for example: *'I think the actual provision of these services in most cases is very good and the carers do a very good job under very difficult circumstances with a very wide spectrum of needs and personalities of the person they're providing the care for. It's just the whole red tape and the amount of paperwork, how it's funded is always seen as an issue*' (Participant – carer, p1371). In contrast, the authors argue these dissatisfied accounts show a lack of understanding about the system: *'Well, I used to go to [day centre] … And they've taken on different people – I had a letter to say I was not suitable to go. And I think they're taking people that take a while to learn things–have difficulty in learning–and are paying to go there. I don't know*	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		much about it, really. All I know is I had a letter to say I can't go' (Service user participant, White British, p1371). *'So that lady told me, that, sorry, she says, you are not physically disabled or anything. You can do all that, so we can't take you as a member [of a carers' group]. I said why not? If all people are coming here then why are we not?'* (Service user participant, South Asian, p1371). Working with the system: The authors use this quote to demonstrate that asking for help is facilitated by knowing how to ask the right question: *'The next participant could be said to have asked for help but not received it, because they did not ask in the right way: Some magic wording … we don't know. How did they get that? I don't know (laughs)'* (Service user participant, South Asian, p1372). And this quote to demonstrate knowledge about what is available for service users to access is crucial: *'There are so many things they [social services] provide, but we don't understand what is available and what is not available. There must be so many things we don't know yet. We don't know what we are entitled to or not. How can we get things if we don't know they exist?'* (Service user participant, South Asian, p1372).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		Continuity of care: As this account exemplifies, it was important to services users that case workers and carers know their cases before visiting: *'We'd like it to be the same people but they aren't and you have to explain what's got to be done and what's not got to be done, which isn't a good thing in my reckoning. I think it would be better if we had the same people looking after you all the time and they know what's what and what's good for you and what's not. Because one carer came in and put a lot of soap in the water and it brought my skin up something terrible, only because of not looking into things properly'* (Service user participant, South Asian, p1375). Workforce skills: Accounts in this section demonstrated that having carers with adequate skills was considered important, for example: *'The staff are really, genuine caring, genuinely caring people and again you see, for elderly people that's so reassuring'* (Service user participant, South Asian, p1376). And the authors comment that while professional and interpersonal skills of social care staff were discussed positively and negatively by many White British participants, these skills were less discussed by the study's South Asian participants. Issues specific to Asian participants: the authors discuss how having culturally appropriate care is important to service users – even just checking if service users require anything specific:	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		'I will say that upon assessment I was asked whether there are any specific cultural needs that needed to be noted, i.e. did I need to be in contact with my local Gurdwara [Sikh temple] or whatever it was that I needed' (Service user participant, South Asian, p1376). *'Like in [daycentre] there was quiet silent room that you would need for prayers and I appreciated that they gave me a room for prayers'* (Service user participant, South Asian, p1378). The authors conclude that: *'Developing a good understanding of the social care system is central to satisfaction, so it is worth considering how membership of a minority ethnic group relates to opportunities for this development*' (Service user participant, South Asian, p1379). They also comment that the link between language and low satisfaction was strong, with South Asian participants requesting that language needs be met, but this did not necessarily have to be through ethnic matching or through the provision of culturally specific services. The authors point out that language matching is not the same thing as ethnic matching. Having said that, they argue that there is a need for culturally specific services, especially to meet dietary requirements.	

71. Wilson CB and Davies S (2009) Developing relationships in long-term care environments: the contribution of staff. Journal of clinical nursing 18, 1746–55

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Study aim The aim of this study was to consider how relationships in care homes influence the experience of older people, their families and staff. The main objective reported in this paper considers how these relationships are developed and the contribution that staff make to this process through the routines of care. **Methodology** Qualitative study 'The study employed a constructivist design where the different perspectives held by participants were explored and shared to develop a joint construction of how relationships influenced their experiences' (p1746).	**Participants** Older people receiving social care Professionals/practitioners Carers/family members **Sample characteristics** *Level of need* Care home 1 – complex physical healthcare needs and some with cognitive frailty. A high proportion of residents requiring full-time registered nursing care. Care home 2 – Home for residents with enduring mental health issues and complex healthcare needs. A high proportion of residents requiring full-time registered mental health nursing care. Care home 3 – Residents with complex health need including mental health problems. A high proportion of residents requiring full-time registered nursing care. **Sample size** Three care homes were chosen incrementally to reflect variations in size, location and residents (Table 1). Purposive sampling was undertaken within homes to ensure that partici-	**Framework areas** Personalised support Info and comms **Narrative findings** Staff adopted three approaches to care delivery and these influenced the type of relationships that were developed between residents, families and staff. The three approaches were described as 'individualised task-centred'; 'resident-centred'; and 'relationship-centred'. The findings suggest that relationships evolve in the context of care routines and the approach staff adopt in care delivery is a key influence on these relationships. Each of the methods of care delivery (above) existed across the three homes. But, it was the method routinely adopted within each home that seemed to influence the type of relationships that developed between staff, residents and families. When staff adopted a resident- or relationship-centred approach to care, there was some evidence to suggest that these methods of care delivery supported the most positive experiences for residents, their families and staff. BARRIER (p1750): Getting to know the resident through the routines – Staff who developed knowledge about each resident's personal care routine felt it was a good way of providing good care and anticipating need. However, researcher observations suggested that, for some residents, staff were so	**Overall score** +

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
Country UK	pants were able to address the research question. Sixteen residents were interviewed. **Costs?** No	task-centred and pressured that attention to personalised care was often lacking. One resident talked about the impact this approach had on her experience of meal times: 'I have dinner more or less on my own…I'm sitting there for ages before my meal and I have no-one to speak to. Then when I get it (my meal), the carers are always in a mad rush as though they haven't got time to do it. (Female resident, the Beeches).' FACILITATOR (p1750): Finding out what matters to the resident – Developing an understanding of a resident's life story through, e.g. staff initiating conversations using photos during care routines, helped staff to see the resident as the person they had been, as well as the person they were now. This helped staff understand the significance of doing 'the little things' in the residents' care routines and the potential to make a difference to each resident's experience: 'Well a little bit of lipstick, it cheers you up. Oh yes, I've always worn makeup and the girls, they'll sit on the stool and they'll put my cream on my face' (Female resident, Chestnut Lodge, p1750). FACILITATOR (p1751): Developing shared understandings – This process included planning and organising care routines to take into account the needs of all residents, staff and families. Shared understandings seemed to promote negotiation and compromise, and the development of reciprocal relationships. For example, in one home, if the needs of a resident could not be met in their desired way, staff were seen	

Research aims.	PICO (population, intervention, comparison, outcomes).	Findings.	Overall validity rating.
		to begin a dialogue with the resident which moved beyond a simple statement such as, ‘there are others I have to deal with first’ to include an explanation of why the needs could not be met at that time with other options provided. As the needs of both the residents and staff were identified, this enabled a compromise to be reached where everyone’s needs were met within the relationship: 'Just now I asked and they said can you wait until we get G down and I said yes, so they got her down and then they took me. I would hate to think that G was stuck upstairs because I had to go to the toilet.’ (Female resident, the Beeches).	

72. Yeung EYW, and Partridge M and Irvine F (2016) Satisfaction with social care: the experiences of people from Chinese backgrounds with physical disabilities. Health & Social Care in the Community 24, e144–e154

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim The study aimed to fill a gap in the literature, which suggests that BME communities are less satisfied with social care provision than members of majority groups by focusing on the experiences of people with Chinese	**Participants** People receiving social care – All interviewees were receiving adult social care services. Three were living in residential care, the remainder at home. Carers/family members – The report states that family members were present at and took part in some of the interviews, but does not state in how many interviews this was the case.	**Framework areas** Continuity of care and transitions (including access) - Social care services were difficult for participants to access. They described not knowing what services were available, what the role of social workers was, and where and how to access services. They did not know what they were entitled to, or the procedures for accessing services. Care and support for people’s needs – The report described the ways a number of needs specific to the Chinese community were being met or not being met:	**Overall score** ++

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
backgrounds living in England. **Methodology** Qualitative study – Individual interviews with 26 people from Chinese backgrounds with physical disabilities aged 18–70 who use adult social care services, followed up by focus group interviews with the same individuals in 3 groups. **Country** UK – England. **Source of funding** Government – National Institute of Health Research for Social Care Research in England.	Although the views of some carers are quoted, the study does not deal primarily with the experience of carers, and their views are presented insofar as they illustrate the experiences of people using social care services. **Sample characteristics** Sex – 15 men, 11 women. Sexual orientation – Not stated. Disability – All participants were described as having a physical disability. Twenty-one are described as having 'movement impairment', of whom 3 are wheelchair users, 3 have visual impairment, and 2 have movement impairment and visual impairment. Ethnicity – All participants are ethnic Chinese. Sample age – The recruitment age range aimed for was 18–70. In the table of participants' characteristics the youngest age given is 19 and the oldest is 69, so this spread was nearly achieved.	– Linguistic needs: participants described social workers and practitioners sometimes using family members and friends as interpreters and translators for convenience, which could compromise their confidentiality and their ability to ask for particular needs to be met. In addition, information about services was often not provided in a language the participants understood, so they did not know what they could ask for. – Those who spoke English were more aware of their entitlements and of procedures, but still felt frustrated and disappointed with the bureaucracy of the referral process and the unresponsive attitudes towards meeting their needs. – Social care workers' attitudes: although some participants were very happy with the care being provided, some stated that the carers did not have very caring attitudes, including all three participants living in residential care. – Complaining: participants and their families were very reluctant to make formal complaints because they were worried about reprisals and did not think they would be listened to. Some families preferred to make private arrangements to pay for care rather than complain. – Some participants expressed appreciation of receiving Chinese-specific services, e.g. where there were Chinese staff or by taking part in activities at a Chinese community centre. Others living in residential care described only being provided with western food that they found difficult to eat and were unused to.	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
	Level of need – All were in need of being provided with adult social care services. Socioeconomic position – Not stated. **Sample size** Sample size – 26 **Costs?** No – Not provided.	**Narrative findings** The study found that: – Although participants were struggling to manage with their physical impairments, they often had to manage for long periods with limited support from their family and friends networks before accessing social care services. They were unaware of how to access services, which often did not kick in until there was a crisis such as hospitalisation. For example, one participant says: *'My wife is the main carer. She wants to visit her family in Hong Kong but she can't, she cannot leave me alone. There are only two of us. If she goes, I cannot manage'* (Service user participant, page e150). – Using culturally specific services was discussed as important to Chinese service users as exemplified by these accounts: *'If there is Chinese staff helping me, that's much better. At least we can understand each other. However, there is nothing I can do; I am pleased with the service they provide'* (Service user participant, page e150). *'At the moment, there are people from the Chinese Association, they really help me. I am fortunate to have them to help me. Otherwise, it's a headache'* (Service user participant, page e150). – Language was a significant barrier to receiving services, if literature about services was not available in their mother tongue, which is why services were often	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		not accessed until crisis point. Social workers could find it difficult to arrange independent interpreters, and there were some concerns about the quality of translation where people from participants' social networks did the interpreting. For example, one participant in hospital described not understanding the role of the social worker: *'I didn't know she was a social worker, I didn't know what social worker did. My boss's wife interpreted for me . . . but at the beginning; I didn't understand anything they said. Actually the social worker found the boss's wife didn't translate everything for me'* (Service user participant, p148). – Participants who spoke English were more aware of their entitlements and found it easier to navigate the system and challenge bad practice, but still found the bureaucracy difficult to deal with. – Authors report that service users were heavily reliant on Chinese welfare organisations to meet their social and dietary needs: *'I like going to the Chinese community centre for recreational activities such as Tai Chi, Mahjong (a game originally from China and is played by four players)'* (Service user participant, page e150). *'In the care home, they only have western food. They give me a few chips and cold salad. The chips are very dry and I have to drink water to swallow them. I*	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		want our hot soup' (Service user participant, page e150). *'Our food is different from theirs (the English). At the end of the day, we are not used to what they eat. We like rice porridge, rice, noodles'* (Service user participant, page e150). – Although some participants were very happy with the services they received, some described care staff as uncaring, and all three living in care homes complained about the services they received, with one finding the staff in her care home 'frightening'. The authors report that participants were reluctant to complain, as they felt they were not entitled to better services and were worried about reprisals. – Some families did not ask for help because they were concerned that it would be perceived as them not being able to care for their own. However, because most of them were migrants they were cut off from the support networks and social connections that would have been available for them in their home countries. One participants described his awareness of the impact his impairment has had on his wife: *'I used to work and we had a comfortable life. Now, I have to rely on my wife. She has to go to work and make sure there is food in the house for me. I try to help, try to clean the floor but I can't even see whether the floor is clean. I am such a burden to her'* (Participant, p150).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		– The availability of culturally specific services was valued by participants, while those not being provided with them noted the lack, e.g. of the food they liked and were used to. – Participants living in care homes felt particularly isolated, unhappy and vulnerable.	