NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1 Quality standard title

People’s experience using adult social care services

Date of quality standards advisory committee post-consultation meeting:
19 September 2018

2 Introduction

The draft quality standard for people’s experience using adult social care services was made available on the NICE website for a 4-week public consultation period between 19 July and 16 August 2018. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 23 organisations, which included service providers, national organisations, professional bodies and others.

This report provides the quality standards advisory committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the committee as part of the final meeting where the committee will consider consultation comments. Where appropriate the quality standard will be refined with input from the committee.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the committee should read this summary alongside the full set of consultation comments, which are provided in appendices 1 to 3.

3 Questions for consultation

Stakeholders were invited to respond to the following general questions:

1. Does this draft quality standard accurately reflect the key areas for quality improvement?

2. Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be to be for these to be put in place?

3. Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

4. Do you have an example from practice of implementing the NICE guideline(s) that underpins this quality standard? If so, please submit your example to the NICE local practice collection on the NICE website. Examples of using NICE quality standards can also be submitted.

4 General comments

The following is a summary of general (non-statement-specific) comments on the quality standard.

- Generally considered to address key areas for quality improvement
- Statements are too broad and open to interpretation by providers and commissioners
- The statements differ from the priorities identified by Quality Matters
- Working with voluntary and private sectors is important
- The equality considerations should include the needs of people with severe learning disabilities or who lack capacity to make decisions
- Some people may have fluctuating capacity and should be supported to take part in decision-making as far as possible
- People with autism should be considered to need an independent advocate, even if they appear to understand and communicate well
- Many service providers, practitioners and commissioners use digital opportunities to ensure information is accessible or to collect equality information
- The use of paper-based records and a lack of data sharing mechanisms between health and social care are barriers to commissioning and adoption of this quality standard

Consultation comments on data collection and measures

- The existing survey does not contain the detail in the quality standard meaning local surveys would also be needed
- The data suggested is not standard reporting so there would be a resource impact
- Local data from audits, care records and handovers may be difficult to collect in a consistent way
- People with communication impairments may be unable to complete satisfaction surveys leading to a disproportionate response
- The focus on collecting data on the outcomes people achieve using social care, instead of provider or commissioner performance metrics, was welcomed
- The measures are mostly about process, rather than outcomes

Consultation comments on resource impact

- People should receive an appropriate package of care but there is a limited resource package and this will always be a difficult balance
- Implementation will require a lot of administration
- Financial pressures and growing demand for social care means councils cannot meet some Care Act requirements and this will continue over the coming years
- Long term underfunding of social care, at a time when more people need support, has led to a lack of access to services and older people having unmet needs
- All quality statements depend on the existence of local care markets. This can be a particular issue in deprived or rural areas, for people needing support for specialised conditions and for some population groups
- Each of the statements in this draft quality standard could only be achievable by restricting access to services
- No opportunities for disinvestment were identified

5 Summary of consultation feedback by draft statement

5.1 Draft statement 1

People using adult social care services have a care and support needs assessment that takes into account their personal strengths, preferences, aspirations and needs.

Consultation comments

Stakeholders made the following comments in relation to draft statement 1:

- Suggestion to replace ‘using adult social care services’ with ‘with care and support needs’ because not everyone who has an assessment will use services
- Suggestion to replace ‘takes into account’ with ‘discusses and documents’ or ‘is centred on’
- The statutory guidance states that advocacy is only provided if the adult meets the criteria for ‘substantial difficulty with involvement’ and nobody is willing, able and suitable to act for them as an ‘appropriate person’
- Some people will need input from family members and skilled support
- Highlight in the rationale that eligibility for services is part of the assessment as not everyone with a care and support need will get a care and support plan
- Rationale suggests that care and support planning is undertaken with the practitioner carrying out the assessment but this is not always the case
- Suggestion to add measures on:
    - accessibility of care and support needs assessments
    - steps taken to ensure people with complex needs are included in the assessment
    - the provision of support at the assessment in line with NHS England’s Accessible Information Standard
    - involvement of people’s families in the assessment
    - assessment questions being sent in advance so the person can prepare
- Suggestion to include the views of unpaid carers as a data source, particularly if a joint assessment has taken place

- People having enough time with an advocate before the meeting may not be a relevant measure of whether they have a strengths-based assessment
- Service providers are not involved in the assessments so they cannot assess whether the practitioner assessing is suitably trained
- Practitioners should make the assessment person-centred, understand different conditions to fully recognise needs and give information on voluntary services
- Registered nurses should not be included in the social care practitioner audience descriptor and would not carry out this assessment
- People with dementia need regular reviews of the care and support needs assessment

Consultation question 2 – data collection

Stakeholders made the following comments in relation to consultation question 2:

- There is no national data collection which would show comparative performance on a consistent basis
- It may be possible to standardise the questions in experience surveys
- All councils could not carry out audits of the quality of assessment due to the resourcing levels required for this
- Some councils audit the quality of assessments, usually through file audit, and some survey people's experience soon after the assessment process
- Accessing data will rely on the availability of integrated digital records. Many allied health professionals working with people using adult social care services are from NHS services so measurement could be challenging
- A simple feedback form could be used to assess people's experiences of the support and care needs assessments

Consultation question 3 – resource impact

Stakeholders made the following comments in relation to consultation question 3:

- Good practice in these assessments, which take the time to consider people's strengths, preferences, aspirations and needs, may take longer to achieve

- This could achieve savings for local authorities if the assessments lead to solutions for people based on their strengths and community or family networks
- Many local authorities are investing in programmes which promote this type of assessment and support planning

5.2 Draft statement 2

People using adult social care services have as much control as possible over their allocated funds for purchasing care packages.

Consultation comments

Stakeholders made the following comments in relation to draft statement 2:

- ‘Purchasing care packages’ applies to support from providers and direct payments. Direct payments are one way people can receive their personal budget
- Some people will not want to be in direct control of their care and support, especially if they do not have support
- People who do not have capacity to do this will require additional support
- People need to be continually engaged to ensure that their decision, either to have an integrated personal budget or not, remains the best option for them
- Ongoing information and support to manage the budget should be provided
- Note that everyone who will receive a service for which there is a charge will have a personal budget
- Peer-led support services can be inappropriate and inaccessible for people with autism. Instead include a measure that support is specific to the person’s needs
- Include data sources on local surveys of:
  - the general public to assess awareness of support services and their rights
  - unpaid carers on how the person they care for was empowered to manage their care package funds
- Registered nurses would not have the knowledge to explain options to use funding in adult social care so remove from audience descriptor
- Involve family or carers in discussions on the allocation of funds in the audience descriptors
- Local authorities are responsible for telling people about the types of personal budget and the assistance available to help people manage it

Consultation question 2 – data collection

Stakeholders made the following comments in relation to consultation question 2:

- National data collection does not include the control people have over their funds
- Measurement will be challenging as relevant data is not routinely collected
- Some councils may address this through audits but not all can due to the resources required

Consultation question 3 – resource impact

Stakeholders made the following comments in relation to consultation question 3:

- Without resources to adequately fund care plans, or local service provision to meet needs and preferences, this will be hard to achieve
- Councils or health services may only allow budget holders to commission services from preferred providers, limiting flexibility in support arrangements
- Local authorities should consider whether care should be delivered this way if providing the appropriate resources is too difficult
- This statement is potentially achievable if local authorities, with partners including providers, take a whole systems approach to maximising control
- Some local authorities are working to make direct payments a more feasible choice for more people
- Some local authorities use individual service funds to give people control to manage day to day support and the local authority remains the commissioner

5.3 Draft statement 3

People using adult social care services have continuous and consistent care and support.

Consultation comments

Stakeholders made the following comments in relation to draft statement 3:

- Improving integration between the health and care systems will be key to this
- Staff turnover within the sector is 27.8% with a vacancy rate of 6.6%
- Consistency should include care across geographical areas and improved support following diagnosis
- Care of people with severe learning disabilities and behaviours that challenge is inadequate, particularly in the community
- ‘Continuous and consistent care and support’ implies lifelong dependence, it does not acknowledge people with fluctuating needs because of their condition
- Suggestion to replace ‘happiness’ with ‘wellbeing’ in the rationale
- Suggestion to include measures:
    - that are specific for people with certain conditions, especially autism
    - on the monitoring of support services following diagnosis
    - on carers visiting at a consistent time
    - on consistent care and support based on the person’s aspirations
- Suggestion to include the following data sources:
    - surveys of unpaid carers
    - audits of complaints and compliments about adult social care services
- Consistency of care depends on the number of carers
- Include in the audience descriptors that there are recording systems for care plans and people are supported by care workers who know their preferences
- Suggestion to include in the definition that all staff providing support have similar levels of understanding about the nature of disability
- Include NHS England’s Accessible Information Standard in the equality considerations

Consultation question 2 – data collection

Stakeholders made the following comments in relation to consultation question 2:

- There is no national data collection for this
- Some staff deployment systems could provide this data but many providers are small businesses who may not use sophisticated systems
- To measure this providers would need to collect data on numbers of staff who provide support for each person and how much change there is in staff overtime
- Local data collection will cause resource issues collecting and collating data

Consultation question 3 – resource impact

Stakeholders made the following comments in relation to consultation question 3:

- Continuity and consistency depend on systems maximising staff training and continuity, and low staff turnover which will require significant resources
- Continuity may mean having spare capacity in the system. Spare capacity has to be paid for and this would affect commissioning budgets

5.4 Draft statement 4

People using adult social care services' views are used to inform service improvement.

Consultation comments

Stakeholders made the following comments in relation to draft statement 4:

- Suggestion to update statement to support co-production
- Suggestion to involve people in the design and evaluation of services and staff training
- People may be concerned that negative feedback will impact on their own care
- Efforts should be made to ensure all people who use social care services are included, not just those whose responses are easy to access
- Specialised strategies are needed for some groups to be able to express their views clearly
- Suggestion to include a quality measure on complaints and compliments audits
- The views of carers should also be sought
- The social care practitioner audience descriptor suggests local authorities have power to support individuals in giving feedback which is not the case
- Audience descriptors should note that feedback should be sought in a variety of ways to take account of differing abilities

Consultation question 2 – data collection

Stakeholders made the following comments in relation to consultation question 2:

- There is no national data collection to measure how much this takes place
- This could possibly be incorporated into the existing annual survey of people using services being supported at home
- Most local authorities use general methods to engage with the whole population on service improvement but these are not specific to people using social care
- Local Healthwatch can provide data for measures as their statutory remit includes reporting on people's views and experiences of using social care

- There are simple ways to get feedback from service users of social care services, for example a simple feedback form

Consultation question 3 – resource impact

Stakeholders made the following comments in relation to consultation question 3:

- All local authorities produce an annual written survey of people's views if they are living at home, so asking how to improve services would have minimal extra costs
- Most local authorities have groups of existing customers and voluntary organisations they can ask for views on how to improve services
- Some methods of obtaining feedback, such as face to face conversations with individuals or focus groups, are beyond the means of local authorities
- Resources are needed to make all these methods accessible to all, for example easy-read versions of written materials, paid advocacy and transport to meetings

6 Suggestions for additional statements

The following is a summary of stakeholder suggestions for additional statements.

- A stakeholder stated that people with hearing loss will benefit from prevention support provided or funded by local authority sensory services to help them communicate and live independently in their own homes or in care homes.
- Stakeholders suggested the provision of information in an appropriate manner, based on the person's needs.
- A stakeholder suggested separating means-testing from the care and support needs assessment and having a simplified process.
- A stakeholder suggested dementia training and person-centred training for care support assessors and social care practitioners.
- A stakeholder suggested a statement on seamless and well co-ordinated care.
- Stakeholders felt that care and support needs assessments should be carried out quickly when a person reaches out or is referred. There can be difficulties contacting social services, referral letters are not being accepted and cases are being rejected.
- A stakeholder stated that people with dementia should have their care needs reviewed relatively frequently due to the progressive nature of the disease.
- A stakeholder noted there is no statement on ensuring people who are assessed are provided with the care they need.

Appendix 1: Quality standard consultation comments table – registered stakeholders

ID	Stakeholder	Statement number	Comments[1]
1	Action on Hearing Loss	General	Action on Hearing Loss, formerly RNID, is the UK's largest charity working for people with deafness, hearing loss and tinnitus. Our vision is of a world where deafness, hearing loss and tinnitus do not limit or label people and where people value and look after their hearing. We help people confronting deafness, tinnitus and hearing loss to live the life they choose, enabling them to take control of their lives and removing the barriers in their way. We give people support and care; develop technology and treatments and campaign for equality. Throughout this response we use the terms 'people with hearing loss' to refer to people with all levels of hearing loss, including those who are profoundly deaf. We use the term 'people who are deaf' to refer to people who are profoundly deaf who use British Sign Language (BSL) as their first or preferred language and may consider themselves part of the Deaf community, with a shared history, language and culture. Action on Hearing Loss welcomes the opportunity to comment on NICE's People's Experience Using Adult Social Care Services Quality Standard. We welcome the aims of the Quality Standard to improve the quality of care and support adults receive. At present, we are concerned that the Quality Standard does not fully reflect key areas for quality improvement that are important to people who are deaf or have hearing loss. The wording of the Quality Statements also needs to be changed in some instances to take account of the communication and information needs of people with disabilities and sensory loss, including people who are deaf or have hearing loss. In our response, we have provided feedback on the wording of the Quality Statements and answered the four consultation questions. For ease of reference, the key points from our response are summarised below: • A Quality Statement should be added on prevention services (see Comment 2). • Commissioners and health and social care practitioners implementing the Quality Statement 1 should use NICE's recently published Hearing Loss in Adults Guideline and NHS England's forthcoming JSNA guide to ensure care and support needs assessments consider the needs of people who are deaf or have hearing loss (see Comment 3). • A quality measure should be added to Quality Statement 1 on the accessibility of care and support needs assessments (see Comment 4).

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[1] PLEASE NOTE: Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its staff or its advisory committees.

ID	Stakeholder	Statement number	Comments[1]
			• Quality Statement 2 may be challenging to implement due to the lack of specialist care and support available for people who are deaf with multiple or complex needs. To help overcome these challenges, local authorities should refer to the Care and Support Statutory Guidance and Think Personal Act Local (TLAP) guidance (see Comment 6). • Health and social care practitioners implementing Quality Statement 3 should refer to NHS England's forthcoming 'What Works' guide on hearing loss and care homes; Action on Hearing Loss' Supporting Older People in Residential Care Settings guide; and TLAP guidance4 to improve the quality of care and support people who are deaf or have hearing loss receive (see Comment 9). A reference to the NHS England's Accessible Information Standard should be added to the Equality and Diversity Considerations section in Quality Statement 3 (see Comment 10).
2	Alzheimer's Society	General	**Clearer and more specific guidance necessary** – We think that all statements provide a good starting as they provide general guidance and principles for what we can expect from social care services. However, the scope of the statements is too broad and therefore open to interpretation for providers and commissioners. We think that more specific guidance is required in order to improve social care practice at the frontline.
3	Carers Trust	General	It is important for commissioners and service providers to use the views and experiences of carers when trying to improve services. Although these quality standards are focused on improving the care of people with care needs, one way of doing this is to ask the views of carers, as they are often navigating the care system on behalf of the person with care needs. Carers often rely on the adult social care system to enable them to take a break, access employment or volunteering and/or have a paid care support worker provide the care the carer is unable to, or not willing to, provide.
4	Carers Trust	General	The quality standards should make more reference to the upcoming NICE Guidance for Adult Carers and its associated quality standards. When the documents relating to support carers are published, these documents should link to each other to ensure they complement each other. The documents should work together to ensure that staff are aware of the need to support carers. It is important that staff see carers as partners in care, are made aware of the links between caring for the person with care and support needs, and identifying and supporting unpaid carers.
5	The Challenging Behaviour Foundation	General	Your equality and diversity statements do not cover the needs of people with profound and/or severe learning disability or people who may lack capacity to make decisions
6	Compassion in Dying	General	The document would benefit from greater specificity around the documentation of, rather than only the discussion of, personal care preferences, particularly with reference to the options available under the Mental Capacity Act 2005: Advance Statements, Advance Decisions and Lasting Powers of Attorney. Recognising that adults receiving social care often move between many health and care organisations (CQC, Beyond Barriers 2018), ensuring that they have key documentation with them (such as Advance Statements, detailed care plans including details of Lasting Powers of Attorney (LPA) would facilitate timely and informed decision-making.

ID	Stakeholder	Statement number	Comments[1]
			Compassion in Dying runs a free Information Line, which last year supported almost 6,000 people to discuss and record their care preferences. Our experience reveals the urgent need to support individuals to understand their rights and choices regarding future treatment and care. The CPD-accredited training workshops we hold for health and care professionals reveals of a lack of understanding among professionals about how to support mentally competent adults to set out their care preferences in a legally binding way. This has been reinforced by callers who say, for example, that their GPs do not know what Advance Decisions are and do not facilitate the completion and sharing of this important legal document. Therefore, if person-centred care is to become a reality, we suggest utilising every opportunity to promote people's rights and choices to plan ahead and to enable health and care professionals' to facilitate this.
7	Compassion in Dying	General	In the Equality and diversity considerations sections it would be worth noting that as well as help with communication, some people receiving social care services may also have fluctuating capacity and they should be supported to take part in decision-making as far as possible. This could include a reference to the Mental Capacity Act Code of Practice and the NICE guidance on Decision-making and mental capacity which is in development.
8	Department of Health and Social Care	General	Does this draft quality standard accurately reflect the key areas for quality improvement? In the attached email I suggested that the priorities were reflected in the Quality Matters actions (for year 1). I think that the quality standard picks up elements of actions 1, 2, and 3. 1. Acting on feedback, concerns and compliments 2. Measuring, collecting and using data more effectively 3. Commissioning for better outcomes 4. & 5. Better support and shared focus areas for improvement 6. Improving the profile of adult social care
9	Headway	General	This section lists other quality standards that should be considered when commissioning or providing adult social care services. While we appreciate that standards pertaining to individual conditions cannot be listed separately here, we note that there is an emphasis here on mental health management standards, supposedly due to its hidden nature. We therefore suggest that this section also includes the NICE guideline *Head injury: assessment and early management*, as head injury often results in hidden effects that can nevertheless cause the individual to require support from adult social care.
10	Healthwatch England	General	The local Healthwatch Network regularly use NICE guidance and standards to inform their work, in this way Healthwatch can help ensure that NICE guidance is effective and useful to people who use services, and helps to shape the way services are designed. As such, we would recommend that NICE looks to engage with and consider the needs of local Healthwatch as this standard is developed further, so that they can use it and implement as effectively as possible.

ID	Stakeholder	Statement number	Comments[1]
11	Isle of Wight Council	General	The existing statutory survey does not currently contain the detail they refer to in the proposed standard, presuming therefore they will use the PSS survey results (as referred to in the briefing docs) as “proxy measures”. Unless the intention is to align the stat survey with the NICE guidance, if not then local surveys would be needed in addition. Evidence would also be needed from the practice as much as any data sets in relation to the assessment processes; conversations and other local information to prove the standard has been met. This is not standard reporting and so would be an additional resource impact to deliver or pull together and report.
12	Local Government Association	General	• NICE asks if these 4 statements accurately reflect the key areas for quality improvement. Our view is that they do not, although they are of themselves important. • Given that NICE is a member of and co-signatory to Quality Matters (QM) , which supposed to be the one place where all partners agree on priorities, it seems somewhat odd that the 4 statements are different to the QM single shared view of quality, priorities, and steps to improve quality. This is important because it is difficult for providers and commissioners to work to different standards and it makes action planning for improvement more difficult. • We recommend that NICE set out more clearly how its own focus for quality fits in with the QM framework as well as with the CQC standards • Key gaps include: people experiencing seamless and well co-ordinated care, people and communities having sufficient information about the assessment and care planning process, services being well led.
13	National Autistic Taskforce	General	“People should have access to an interpreter or independent advocate if needed.” Autistic people should automatically be considered in need of an independent advocate, even if they appear to understand and communicate well. Their understanding of the whole meaning and intention of questions is often more limited than it appears. Authorities may respond that they offer different formats when they only mean large print, Braille and easy read. If they are not also offering detailed but non-technical information in advance then they are not meeting the specific communication needs of autistic people.
14	National Autistic Taskforce	General	A problem with virtually all measures is that responses to surveys of user satisfaction is considered a useful data source. Only those who have good support and/or who do not have significant impairments in administrative and communication tasks will be able to complete such surveys. You will have a disproportionate response from people without communication impairments such as autism and learning difficulties, particularly those with poor support. Surveys should be provided online and written in an autistic-friendly format which includes a mixture of closed and open questions.
15	National Autistic Taskforce	General	Unfortunately, in most cases where user feedback is used as an evidence source, it is those who are best supported who are most likely to be able to manage to send feedback. Efforts should be made to look specifically for a weighted distribution of service users from different user groups by all the usual demographics (age, ethnicity, gender) but in this case also specifically and importantly by condition. In many cases there are not specific categories for autistic people unless they also have a mental health problem or learning disability, so in order to make sure that people with these most

ID	Stakeholder	Statement number	Comments[1]
			significant communication impairments are recognised and heard, data collection should always include autism as a specific category, not grouping autistic people with other groups (learning disabilities or mental health conditions) who have very different communication needs as well as priorities for good care and outcomes.
16	NHS England	General	The office of the CAHPO (Chief Allied Health Professions officer) is unable to determine how widely adopted is this quality standard in the NHS or social care currently.
17	NHS England	General	The use of paper based patient record systems within a significant proportion of AHP services and the absence of appropriate data sharing mechanisms between health and social care where digital records exists will lead to barriers to commissioning and/or adoption of this quality standard.
18	Royal College of Nursing	General	It would be helpful to recognise in the statement that the person may need re-enablement, education or self-care training to support and develop their own strengths rather than simply providing care and support. This feeds through all the quality standards which would include purchasing services to support these needs.
19	Royal College of General Practitioners	General	As an ideal to be worked towards this document is excellent. People have rights to receive an appropriate package of care chosen within a limited resource package- this will always be a difficult balance. They also have duties towards those service providers and to make best use of the services provided. There is a good deal of administration in making this document work-personal budgets, regular quality/ satisfaction monitoring, arguably the resources for this should be capped at 5% of the whole package. The interface and choice to work with the Voluntary and private sectors is important. People choose a mixture of provision (private, family, state,) and there is a need to share data, expertise and skills across the spectrum between providers.
20	Royal Pharmaceutical Society	General	There are huge inequalities in the system depending on location and a person's mobility. Care home residents can take advantage of pharmacists providing clinical support (medicines reviews etc) but may not have access to the full range of community pharmacy services. Housebound residents receive little or no support in the form of pharmaceutical care and in many parts of the country they cannot even benefit from a simple medicines use review. As more and more people are expected to receive home based care this inequality will increase so urgent attention needs to be given to ensuring they have access to appropriate services to make sure they have access to the full range of pharmaceutical care provided and their medicines are optimised to ensure they obtain the most benefit from them.
21	Skills for Care	General	Many service providers, practitioners and commissioners are now using digital opportunities to ensure information is accessible or to collect information. It would be good to see this methodology reflected in this quality standard.
22	TLAP	General	Recommend that the 'who it is for' sentence has added '*people accessing care and support'* or words to that effect.
23	TLAP	General	Many Local Authorities would define Adult Social Care Services widely post Care Act and not all services are paid for out of the personal budgets of people who use these services. In particular, Local Authorities are shifting their investment upstream into more preventative services, and these are often accessed via referral routes across area wide Care and Health partnerships through interventions such as social prescribing, and provided by newer forms of more universally accessible support. There is a move towards encouraging citizens to do more to manage their own conditions within these

ID	Stakeholder	Statement number	Comments[1]
			partnerships and take advantage of these types of support as part of this. This is not reflected in this guidance or quality standard, hence measures to ensure this new and emerging agenda and resulting provision landscape is of high quality and designed and delivered informed by the experience of the people using these services are not articulated. In addition many Local Authorities are encouraging their social care practitioners to work with people to reduce their need for social care support paid through a personal budget, where this is possible, practicable and safe. This direction of travel and associated helpful practices, like budget pooling, flexible support through Individual Service Funds, and the sourcing of alternative more universally available support that could be lower cost/no cost is not covered either in the guidance or associated quality standards.
24	AGE UK	General	The challenge for social care providers and commissioners, even in times of reduced budgets and shrinking resources, is to ensure that quality improvement is embedded within their institutional culture. Demanding more than the statutory minimum will help improve clinical and care outcomes, maximise resources and serve as a driver of workforce recruitment and retention. Quality improvement is for all services, even those rated as outstanding by the regulators, who still need to challenge themselves to improve and share their good practice. NICE will need to consider what steps it can take to support the realisation of the quality standards, given the need for sustained improvement in people's experience of care. High quality care is not just about making sure peoples' essential needs are met but about how it can enable people to live as well as possible. Commissioners need to consider the ultimate goal of improving people's experience of care and how we can define success through improved social and cultural contributions and capital in our communities. Shared values of respect, dignity and self-determination can be fostered through reablement, facilitating independence and allowing people to play an enhanced role in their communities which benefit from their lifetime to of knowledge and experiences.
25	AGE UK	General	Measurements of quality standards that rely on locally collected data from audits, care records, handovers may prove challenging to collect in a consistent way. Care agencies will have their own records management system and methods of data collection. There is also a large and fragmented workforce which is of itself, a barrier to 'continuous and consistent care and support', as well as to collecting empirical evidence about it.
26	Healthwatch England	General	**2. If the systems and structures were available, do you think it would be possible to collect the data for the proposed quality measures?** Yes. We particularly welcome the focus on collecting data that reports on the outcomes people achieve from using social care, as opposed to a focus on provider or commissioner performance metrics. We also welcome the recognition that data and insight should be informed by people's experiences, particularly in relation to Statement 4. The local Healthwatch network should have a clear and explicit role in this, as it falls within their statutory remit. We recommend that the document clearly references this. Our research has shown that there are some considerable data gaps in the adult social care sector, particularly around access to and outcome of assessments for care and support. We found that people were waiting a long time to get an

ID	Stakeholder	Statement number	Comments[1]
			assessment and to receive services from their council, the average waiting time between requesting an assessment and getting services was 57 days last year. The data we collected suggests that councils are having to prioritise assessments for people in hospital, over those in the community to meet new Delayed Transfer of Care (DToC) targets. Last year the average waiting time in hospital was 34 days, compared to 60 days for those in the community. Only 31% of councils were able to provide this data, we believe that this in itself is a matter of concern and should be addressed. We suggest that NICE recommends as good practice, the need for councils to collect data like this on a routine, consistent and transparent basis.
27	Royal College of General Practitioners	Question 2	Not on access There is no evidence that feedback from referrers and users is effectively requested
28	AGE UK	Question 3	At the moment long term chronic underfunding of social care, at a time when more and more people are needing its support has resulted in a lack of access to services and older people ultimately having their needs unmet. . Age UK estimates that 1.4 million older people are living with some form of unmet social care need . Of these 1.4 million people, 164, 217 receive no help whatsoever from paid carers, family members or friends . It has also led to the current precarious state of the care market. This is not an environment conducive to the achievement of the quality standards. All the quality standards are dependent not just on financial resources, both private and state-subsidised, but on the existence of thriving local care markets. This can be a particular issue in deprived and rural areas and where people need support for specialised conditions, advanced dementia or particular population groups such as care services for people with hearing loss. Another key consideration for improvement is the variation in quality across different services. This is often the result of the inverse care law, whereby those in the greatest need often receive the poorest service as their local authority is underfunded as a result of a greater demand for state-funded care.
29	HealthWatch England	Question 3	3. Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment. We are not able to provide detailed costings, recommend resource allocation or disinvestment strategies. However, evidence does suggest that current financial pressures, as well as growing demand for social care driven by demographic

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			factors, has meant that councils are struggling to meet some of their Care Act requirements, and that they will continue to have to make difficult choices over the coming years. However, money alone is not the answer to the quality issues facing social care, there are a number of low cost, high impact initiatives as well as cultural changes that can effectively drive up quality in local areas. An example of this would be the implementation of a robust complaints and feedback process. As part of our work with the Quality Matters initiative, we developed a single complaints toolkit with the Local Government and Social Care Ombudsman, which provides authoritative guidance for people and social care professionals to make complaints, as well as explaining what to expect from the complaints process and for professionals, how to manage and effectively respond to feedback. Responding to feedback, and shaping services accordingly, can drive up quality in social care by making services more responsive and person-centred.
30	Royal College of General Practitioners	Question 3	Each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them, only by restricting access to the service A resource requirement is that funding services must meet capacity. Although the Care Act placed legal force behind personal budgets, responses to Community Care's survey suggest they are not offering the choice to recipients that was intended. In 2016 the National Audit Office called on the Department of Health to investigate how these savings were affecting the delivery of personalised care and service users, but no significant action resulted. The challenge of delivering personalisation as demand for social care progressively outstrips the resources the government is making available. Potential cost savings or opportunities for disinvestment - None identified, the general feedback is that social services are cut to the bone and needs more direct support It would be useful to have expert social care advisers sited in primary care as this would be more efficient and reduce communication barriers
31	Royal College of General Practitioners	Question 4	An example from practice of implementing the NICE guideline that underpins this quality standard: A community based social care clinic linked to a community integrated care team

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			See Frailty care in a community based clinic: maximising the potential for integration Mark Rickenbach presented to Royal College of Physicians 2018 link is at https://rcp2018-mciuk.ipostersessions.com/default.aspx?s=0D-B4-A5-0C-39-D0-9F-C3-7A-FB-18-2D-F6-02-BA-39&guestview=true
32	Action on Hearing Loss	Statement 1	The Quality Statement that adult social care service users should receive a needs assessment that takes into account their personal strengths, preferences, aspirations and needs is welcomed. Taking account of deafness and hearing loss during care and support needs assessments is crucial for good communication and care. Unaddressed hearing loss can have an adverse impact on people's health and quality life. People with hearing loss are more likely to experience feelings of loneliness and social isolation and are at greater risk of other health problems, such as depression. There is also growing evidence of an association between hearing loss, cognitive decline and dementia. A recent study identified hearing loss as the largest modifiable risk factor for dementia. If removed, the study states that 9% of dementia cases could be prevented. Without appropriate communication support, people who are deaf are risk of worse care and poor health. Consultation questions: This Quality Statement captures an important area for quality improvement for people who are deaf or have hearing loss. More needs to done to improve the way people who are deaf or have hearing loss access support to improve their wellbeing. Despite gold-standard evidence that hearing aids improve quality of life, reduce the risk of loneliness and depression, and may even reduce the risk of dementia; many more people could benefit from hearing aids than are currently doing so. Research shows that only two-fifths of people who need hearing aids have them. Hearing aids are most effective when fitted early, but evidence suggests that people wait up to ten years on average before seeking help for their hearing loss and the average age for referral is in the mid-70s. Negative stereotypes about hearing loss and hearing aids as well as fear of stigma itself can be a significant barrier stopping people from seeking help. Older people may view hearing loss as an inevitable part of the ageing process and may find it difficult to access support due to communication or memory problems caused by dementia or other long-term conditions. For example, it is estimated that over 80% of older people living in care homes need support for their hearing loss to maximise their independence and wellbeing, but this often goes undiagnosed or isn't properly managed. People who are deaf with multiple or complex needs may require specialist care and support that recognises the importance of good communication and/or takes account of the unique values and culture of the Deaf community. For example, people who are deaf with multiple or complex needs may require a specialist support worker who is trained to communicate in British Sign Language (BSL). Evidence suggests, that poor communication or lack of awareness of Deaf culture in care homes could lead to social isolation and deterioration in health and wellbeing.

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			As highlighted in Public Health England, NHS England and Health Education England's Making Every Contact Count consensus statement, health and social care practitioners are well placed to deliver targeted public health messages that tackle the determinants of health and wellbeing. This principle is especially important for people with hearing loss who may not realise how hearing aids and other forms of support can help them. With this in mind, it's vital that commissioners and health and social care practitioners have good knowledge of the different forms of support people who are deaf or have hearing loss may need. Without appropriate support, people who are deaf or have hearing loss are at risk of deteriorating health and wellbeing. Commissioners and health and social care practitioners implementing this Quality Statement should refer to NICE's recently published Hearing Loss in Adults Guideline, which provides clear guidance on the best approaches for diagnosing and managing loss. The Guideline highlights that delays in referral for hearing difficulties will reduce people's ability to "function at work and home" and make it harder for them to look after their own health. Commissioners should also refer to NHS England's forthcoming JSNA guide. This guide has been co-produced by NHS England, the Local Government Association, the Association of Directors of Public Health and other stakeholders, and will be published later this year. The guide provides data, evidence and insight to help local authorities and NHS commissioners develop robust hearing needs assessments that properly reflect local needs.
33	Action on Hearing Loss	Statement 1	A Quality Measure on the accessibility of care and support needs assessments should be added to this section People who are deaf or have hearing loss may need to access a range of support participate fully in discussions about their care and support: • Many people who are deaf or have hearing loss will find it difficult or impossible to use the telephone and may benefit from alternative contact options such as email, Text messages, Next Generation Text Relay (NGTR) or BSL Video Relay Services (VRS). • For face-to-face contact, people with hearing loss may need other people to follow simple communication tips such as speaking clearly and avoid obstructing their lip movements with hand gestures or other objects. • Some people who are deaf or have hearing loss will need support from a communication professional, such as a British Sign Language (BSL) interpreter or Speech-To-Text-Reporter (STTR). • English may not be the first or preferred language of people who are deaf, so information should be written in Plain English. While many people who are deaf can read and write English, some cannot, so services should consider producing BSL videos of key documents or other important information. Collecting evidence in these areas is therefore crucial for measuring the quality of care and support needs assessments. In the absence of a Quality Measure on accessibility, it will be difficult to assess the quality of needs assessments people who are deaf or have hearing loss - and people with disabilities and sensory loss more generally - receive. For example, a

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			social care service provider could score highly against Quality Measures a) and b), even if people with disabilities and sensory loss are unable to participate fully in discussions about their care and support due to poor communication or the lack of accessible information. Although these issues are covered to some extent by the Equality and Diversity Considerations section, we think a dedicated Quality Measure on accessibility is needed to properly capture the experiences of people with disabilities and sensory loss who receive care and support needs assessments. This would also bring the Quality Standard in line with the source NICE People's Experience in Adult Social Care Services Guideline, which states that adult social care services should meet the communication and information needs of people with disabilities and sensory loss, in line with NHS England's Accessible Information Standard. We recommend that the following wording should be added to the Structure sub-section: "c) Evidence of local arrangements to ensure people with disabilities and sensory loss receive appropriate support to participate fully in care and support needs assessments, in line with NHS England's Accessible Information Standard. Data source: local data collection, for example care records and surveys of people with disabilities and sensory loss who had a care and support needs assessment." The following should also be added to Process sub-section: "c) Proportion of people with disabilities and sensory loss having a care and support needs assessment who receive communication support and accessible information. Numerator – the number of people with disabilities and sensory loss who receive communication support and accessible information during care and support needs assessments. Denominator – the number of people with disabilities and sensory loss who have a care and support needs assessment"
34	Action on Hearing Loss	Statement 1	We welcome the recommendations and references to NHS England's Accessible Information Standard in this section. As stated in Comment 4, people who deaf or have hearing loss may require a range of support to participate fully in discussions about their care and support. It is positive that the needs of people with disabilities and sensory loss are highlighted in this section. We also welcome the references to NHS England's Accessible Information Standard7. The Standard provides clear guidance for NHS and adult social care services on meeting the communication and information

ID	Stakeholder	Statement number	Comments[1]
			needs of people with disabilities and sensory loss. It is therefore highly relevant for the successful implementation of Quality Statement 1.
35	Alzheimer's Society	Statement 1	We appreciate NICE's initiative to develop some quality metrics for social care. It acknowledges the importance of high-quality care for people receiving adult social care. It is, however, important to acknowledge and not forget why care and support needs assessments are made. This is because social care is means-tested. While care and needs assessments do take into account the level of care that a person needs, the means-testing nature of this assessment often means that the lowest level of support is offered instead of what people may need to live well, particularly if this care is to be funded through public funds. We welcome NICE's focus on people's strengths and aspirations alongside their needs and think that 'strengths' should also include social relationships alongside skills. Regular review of social care needs assessments – For people affected by dementia it is important to review their care needs and relatively frequently due to the progressive nature of the disease. Everyone experiences dementia differently but some of the most common symptoms include memory loss, confusion and difficulties with speech and understanding. Often, the changes tend to start small but gradually get worse over time, eventually affecting a person's daily life. Quality measures (data source) – A simple feedback form could be used to assess people's experiences of the support and care needs assessments which focuses on the degree to which they felt they were listened to and treated with respect. We would be happy to help with the development of a dementia-friendly feedback form.
36	British Association of Social Workers	Statement 1	Suggest that "using adult social care services" is replaced with "with care and support needs" because noteveryone who receives an assessment goes on to receive a service.
37	British Association of Social Workers	Statement 1	Suggest reference to the process of determination of eligibility prior to the last sentence. As it stands there is an implication that everyone with a care and support need with receive a care and support plan.
38	British Association of Social Workers	Statement 1	Last sentence needs to be amended because care and support planning is not always undertaken with the person carrying out the assessment.
39	British Association of Social Workers	Statement 1	Last sentence implies that people can have an independent advocate if they want one. This is not the case. The statutory guidance makes it clear that this service will only be provided if the adult meets the criteria for "substantial difficulty with involvement", and in addition there is nobody who is willing, able and suitable to act for them as the "appropriate person".
40	British Association of Social Workers	Statement 1	BASW is concerned that registered nurses are inappropriately identified as social care practitioners. In addition, we are not aware of any circumstances where they carry out care and support needs assessments. They certainly contribute towards them but do not usually have the knowledge and skills and organisational infrastructure to lead on such assessments.

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41	British Association of Social Workers	Statement 1	Re independent advocacy – see point 4.
42	Carers Trust	Statement 1	The quality standards at the moment give the example of “surveys on the experience of people who have had care and support needs assessment.” Carers Trust would recommend including unpaid carers as a possible data source. The views of carers should be critical when establishing whether providers are meeting NICE’s quality standards. This is particularly important if a joint assessment has taken place. Adding carers as a source of data and information could also have the added benefit of allowing those viewing the data if there is a divergent view between unpaid carers and the person they care for. NICE would also be able to disaggregate the data so it would be possible to see carers’ opinions of their own assessment as users of adult social care in their own right.
43	Carers Trust	Statement 1	The quality standards at the moment give the example of “surveys on the experience of people who have had care and support needs assessment.” Carers Trust would recommend including unpaid carers as a possible data source. The views of carers should be critical when establishing whether providers are meeting NICE’s quality standards. This is particularly important if a joint assessment has taken place. Adding carers as a source of data and information could also have the added benefit of allowing those viewing the data if there is a divergent view between unpaid carers and the person they care for.
44	Carers Trust	Statement 1	Carers Trust welcome the outline of what the assessment should entail and the inclusion of carers. Given the inclusion of unpaid carers in the list of what NICE expect the assessment to include, we believe it would be consistent to include unpaid carers as a potential data source. Adding carers as a source of data and information could also have the added benefit of allowing those viewing the data if there is a divergent view between unpaid carers and the person they care for. This is particularly important if a joint assessment has taken place. NICE would also be able to disaggregate the data so it would be possible to see carers’ opinions of their own assessment as users of adult social care in their own right.

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45	The Challenging Behaviour Foundation (CBF)	Statement 1	The standard has been written assuming that everyone is able to share their views and aspirations- and it should highlight that for some people this may be difficult, they may need additional skilled support and there may need to be input from others that know them well, including their families. It would be helpful to record the involvement of people's families in care and support needs assessment. Working and engaging with families and carers is an important consideration. This is especially important in the care of someone with severe learning disabilities who displays behaviours that challenge who may struggle to communicate their views and needs themselves Family carers and other people who know the individual well can be invaluable resources regarding communication, behaviour and choice. No mention has been made of measuring and recording the level of family involvement.
46	The Challenging Behaviour Foundation (CBF)	Statement 1	It would be useful to include what steps have been taken to ensure all people including those with complex needs (people with severe learning disabilities) would be included in a care and support assessment. It would be helpful to include how approaches have been personalised, adjustments made and the steps and efforts taken to meet the needs of people with complex needs.
47	Compassion in Dying	Statement 1	Quality statement – please replace "takes into account" with "…discusses and documents their personal strengths…". This proposed change would emphasise the importance of supporting the person receiving care to be actively involved in developing their care plan (wherever possible).
48	Compassion in Dying	Statement 1	Rationale – please amend last sentence as follows: - "They can then agree a care and support plan and if desired, complete key documents such as Advance Statements, Lasting Powers of Attorney and Advance Decisions, thereby enabling the achievement of preferred outcomes and resulting peace of mind." Whilst the focus of the Quality Statements is social care, many adults receiving social care will have significant health needs or be experiencing declining health. These documents, particularly the Advance Statement and LPA for Health and Welfare are very relevant in ensuring someone who lacks capacity or has fluctuating capacity is receiving the care and support they need.
49	Compassion in Dying	Statement 1	Under Process, please add a separate indicator as follows b) Proportion of people using adult social care services who have completed and shared detailed advance care planning documentation with relevant health and care professionals. Numerator – the number in the denominator who have completed and shared detailed advance care plans such as Advance Statements, Lasting Powers of Attorney and/or Advance Decisions Denominator – the number of people using adult social care services who had a care and support needs assessment. We understand GPs collect information on the number of people with advance care plans in place. Therefore it should be possible to include this indicator.

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50	Compassion in Dying	Statement 1	Service providers, second sentence – please add – "…have been trained on the legal mechanisms available to individuals to set out their care preferences and have the confidence to make the assessment person-centred." Service providers, third sentence – suggest amending wording to make the responsibility more active "…benefit from having on, the service provider makes arrangements to ensure…" Social care practitioners – please add to the last sentence – "…good understanding of all of the services available, including from the voluntary sector, that can help achieve this."
51	Headway	Statement 1	The rationale section states that "during the assessment, the person can identify how their needs impact on their wellbeing and ability to live an independent life, as well as their goals and preferred outcomes. They can then agree a care and support plan that supports them in this with the person carrying out the assessment." Input may also be required from a family member or carer, as a person with a brain injury may have communication problems, fatigue, memory problems, difficulties with making decisions or lack insight into the impact of their injury, and therefore be unaware of their needs or unable to express them. The family member or carer should, in such cases, be present at the needs assessment itself.
52	Headway	Statement 1	Service providers are to ensure that the practitioners carrying out the assessments have been trained to make the assessment person-centred. There should also be some provision of ensuring that the practitioners have experience and understanding of different conditions, such as brain injury, to ensure that they can fully recognise needs.
53	Independent Age	Statement 1	We want to see a future care system where older people are able to thrive, not just survive. In our work on defining good quality residential care, older people told us how important it was to them that the care setting goes beyond basic care needs to meet their cultural, religious and lifestyle needs as well. While we welcome the emphasis in statement one on older people's 'personal strengths, preferences, aspirations and needs' we know that 'taking account' of these can quickly become a box ticking exercise which has little impact on the care package that is offered. We would recommend using language that instead talks about care assessments that are centred on the personal strengths, aspirations and needs of the person being assessed.
54	Isle of Wight Council	Statement 1	Local data collection referenced in the standard will cause resource issues in relation to the collection and collation of data to evidence the standard: 1) Training records & assessment protocols (available but resource needed to pull for evidence) 2) Records of independent advocacy use (available but resource needed to pull for evidence) 3) Local surveys (resource intensive to send/analyse/report – any existing surveys will need to be reviewed and additional questions and cohorts included.)

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			4) Overall increase to reporting burden for councils
55	LGA	Statement 1	• NICE asks if there are local systems and structures in place to collect data for this quality measure, and how feasible it would be for these to be put in place. • There is no national collection which would show comparative performance on a consistent basis. Some councils may audit the quality of assessments, usually through file audit. . Some councils also do surveys of user experience fairly soon after they have been through the assessment process. • It might be feasible to standardise the questions asked of users in such surveys. It would not be feasible to require all councils to do audits of the quality of assessment, due to the resourcing levels required for this, unless central government decided to treat this as a priority and to fund it as an "added burden".
56	LGA	Statement 1	• NICE asks if the statement would be achievable by local services given the net resources needed to deliver them • Good practice in assessment of this nature, which takes the time to take account people's strengths, preferences, aspirations and needs, may take slightly longer to achieve. However this is more than compensated for by savings to the local authority if such assessments lead to solutions for people based on their own strengths and community/family networks, rather than service led assessments. For this reason many local authorities are investing in programmes which promote assessment and support planning to work in this way.
57	National Autistic Taskforce	Statement 1	There is no mention of whether advocates are trained in the specific needs of autistic people, including those who have fluent speech but social communication impairments that may cause difficulties expressing their needs in an assessment. Authorities can rate themselves highly on providing advocates, but that is not improving the patient experience if the advocates are not equipped to provide good and appropriate advocacy for the person's specific needs.
58	National Autistic Taskforce	Statement 1	There is inadequate mention of providing assessment questions in advance and otherwise preparing an autistic or cognitively disabled person for the assessment. Information should be available in digital form and it should be possible for service users to reply using digital means (e.g. email) including if they do not come up with answers until well after the assessment.
59	NHS England	Statement 1	Triangulation of data will rely on the availability integrated digital records. A significant proportion of AHP colleagues working with patients using adult social care services will be employed within NHS services. AHP intervention will be supporting social care colleagues and inform care planning which will make evidencing this standard challenging
60	NHS England	Statement 1	Individuals accessing social services may have intervention from a range of professions who will include strengths , preferences aspirations and needs in their assessment, these may not be captured in the numerator but will be considered by the MDT when care planning, inconsistency of digitisation of records and lack of integration will make this challenging to capture.
61	Royal College of Speech and Language Therapists	Statement 1	We would suggest also including an evaluation of Mental Capacity within this assessment if necessary. This should be facilitated by a speech and language therapist should communication difficulties be present.

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62	Royal Pharmaceutical Society	Statement 1	Although polypharmacy is not being considered as a separate topic within this standard statement 1 should specifically include a medicines review as part of the care and support needs assessment. Medicines are the most common intervention made in the NHS and many people are taking 10 or more medicines. A person-centred medicines review would ensure that medicines were optimised for the individual and help them to understand the need for the medicines prescribed for them.
63	Skills for Care	Statement 1	There are several elements to this that will be difficult for service providers. 1. They often do not have a say in how these assessments are carried out by social care practitioners. 2. It will be hard for them to assess whether the practitioner carrying out the assessment is suitably trained. Service providers will often complete their own assessments once they receive the one completed by the practitioner, these guidelines will be applicable to that assessment as well but maybe it needs to be clearer which one they have responsibility for?
64	TLAP	Statement 1	Query re measure “evidence of local arrangements to ensure that people have enough time with an independent advocate etc…” Not sure that this is a relevant or helpful measure of whether people receive a strengths-based assessment. It is also potentially misleading (see comment 8 below).
65	TLAP	Statement 1	Concern that the quality measures for this statement, and for the others, rest more or less exclusively on local data collection, which may cause a disproportionate burden on local authorities. Related to this is a concern that the measures are mostly about process, rather than outcomes. The best of the bunch is the proposed measure on satisfaction.
66	TLAP	Statement 1	Service providers – This is potentially confusing as written. Generally speaking it social care practitioners that will undertake assessments that may result in a personal budget and not service providers. Service providers should work closely with the person to translate their person centred care and support plan into day to day reality.
67	TLAP	Statement 1	People having a care and support needs assessment are involved fully in the assessment, with an independent advocate if they would like one.” Rightly or wrongly, under the Care Act the local authority is responsible for deciding whether someone needs an advocate, based on whether they think someone will have ‘’substantive difficulty’ in participating in an assessment. As drafted, the measure could be taken to imply that access to independent advocacy is of right. More important, is that people have access to the support they need for an assessment, which may take a variety of forms.
68	Action on Hearing Loss	Statement 2	The Quality Statement that adults who use social care services should have as much control as possible over their allocated funds for purchasing care packages is welcomed. As highlighted in Comments 2 and 3, more needs to be done to improve the way people who are deaf or have hearing loss access support to improve their wellbeing. Giving people more control over their allocated funds should help reduce the level of unmet needs. It should also help people who are deaf or have hearing loss access support they need to live safely and independently and communicate well at home or in the workplace. Consultation questions: This Quality Statement may be challenging to implement due to the lack of specialist care and support services available for people who are deaf with multiple or complex needs. In the absence of diverse social care

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			markets that cater for specialist needs, it will be difficult for people who are deaf to exercise true choice and control over the care and support they receive. As highlighted in Comment 3, People who are deaf with multiple or complex needs may need specialist care and support that recognises the importance of good communication and takes account of the unique language and culture of the Deaf community. At present, the availability of this specialist support depends to a large extent on where people live. For example, some local authorities who responded to our recent FOI request research9 told us that there is a shortage of specialist care and support services for people who are deaf with multiple or complex needs in their area. We believe that recent changes to commissioning practices in England have made it harder for local authorities to meet the needs of people who are deaf with multiple or complex needs. We have received reports of local authorities ceasing tendering for specialist sensory loss services, suggesting reduced availability of specialist care and support in some areas. Research by the National Audit Office (NAO) also found that some local authorities are reducing the number of social care providers they contract with to reduce contract monitoring costs and help providers achieve economies of scale. The NAO found that these changes limited the choice of providers for people purchasing their own care and support as part of personal budgets or direct payments. Research by the Care and Support Alliance (CSA) found that more than four out of five (83%) social workers said there wasn't enough variety in the care and support available in their area for people to exercise genuine choice and control over the social care they receive.
69	Action on Hearing Loss	Statement 2	We welcome the recommendations and references to NHS England's Accessible Information Standard in this section. As stated in Comment 4, people who deaf or have hearing loss may require a range of support to get information about personal budgets and direct payments and make decisions about their care and support. The Accessible Information Standard is a key source of guidance for health and social care practitioners looking to improve the way they communicate with people who are deaf or have hearing loss. It is therefore highly relevant for the successful implementation of this Quality Statement. Consultation questions: Action on Hearing Loss has worked with Helen Sanderson Associates to produce specialist care and support planning tools to help people who are deaf with multiple of complex needs get the care and support they need and want. To find out more, please visit: http://hsaonlinelearning.org/product/person-centred-thinking-to-support-people-who-use-british-sign-language/
70	AGE UK	Statement 2	Current evidence suggests older people are less likely to feel the potential benefits of self-directed support, greater control and choice, through a personal budget. A literature review on personal budgets for older adults using social care services concluded that 'generally older people reported no significant increased sense of control or autonomy over their life, compared to people who used more traditionally designed services'[1]. If the aim is to improve the quality and experience

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			of care, it is important to recognise that this may not be the case for many older people. Some older people will want to be in direct control of their care and support, others will find this potentially worrying or confusing - especially if there is no voluntary sector organisation or carer/family member able to support them. Our experience also shows that older people's needs can change significantly over time. Older people will need to be continually engaged to ensure that their decision, either to have an integrated personal budget or not, remains the best option for them.
71	AGE UK	Statement 2	Measurement of quality standard two may prove challenging as relevant data is not routinely collected. Age UK has previously noted that those assessed as eligible for care often have to wait for long periods for their support package to begin . Our awareness of this issue is through members of the public contacting our information and advice phone line rather than an analysis of centrally or locally collected data.
72	AGE UK	Statement 2	Quality standard two which calls for more control and choice over the delivery of care, however without the resources to adequately fund care plans or the existence of local service provision able to meet those needs and preference then this will prove hard to achieve. It would be a mistake to view the quantum of personal budgets as an adequate measure of quality for example.
73	Alzheimer's Society	Statement 2	When surveyed, more than half of all social care workers who responded (51 per cent) said their council was placing restrictions on what people could spend their personal budget on[2]. Transport, social activities, shopping and other domestic tasks were frequently listed as restricted activities despite their potential to impact positively on the Care Act's wellbeing indicators[3]. Councils or health services may also only allow budget holders to commission services from preferred providers, again limiting flexibility in support arrangements. Age UK would want to see an end to these restrictions so that it is older people, and not local authorities, who decide what would be most beneficial for improving their health and wellbeing. If providing the appropriate resources to support people using personal budgets is proving insurmountable, then local authorities will need to consider the extent to which care should be delivered in this way. [1] http://ssrg.org.uk/members/files/2013/09/ZAMFIR-7Jan141.pdf [2] http://www.communitycare.co.uk/2017/09/19/decisions-taken-hands-social-workers-care-cuts/ [3]https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets/care-act-factsheets Simplify access to personal budgets – There are clear benefits to people with dementia and carers using direct payments. However, the number of older people with dementia with a direct payment is unacceptably low. Local authority data shows that ten or fewer older people with dementia have a direct payment in 70 councils (NASCIS, 2014). Systems and processes must be streamlined so that accessing personal budgets, and direct payments in particular, is straightforward for people with dementia. This also implies accessible guidance and assistance on personal budgets for people with dementia who may have capacity issues. Provide adequate levels of personal budgets -- Adequate funding is essential to ensuring that personal budgets allow a person with dementia to pay for the care and support they need. In England, Alzheimer's Society is concerned that the

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			Health and Social Care Act will set personal budgets at the local authority care home rate, which is often not enough to pay for dementia services. Alzheimer's Society is also concerned that the Health and Social Care Act will continue the abuse of top-up payments to make up the difference between the cost of care and support and a person with dementia's personal budget. Data sources: We suggest in addition the implementation of regular local surveys with the general public to assess their level of awareness and understanding of support services and their rights with regards to social care/personal budgets.
74	British Association of Social Workers	Statement 2	A bit misleading. A direct payment is one of the means by which the individual receives their personal budget
75	British Association of Social Workers	Statement 2	Not sure if it is described correctly in "Denominator". Everyone who is to receive a service for which there is a charge (in principle), will have a personal budget identified – it is simply the amount of money that has been determined as being sufficient to meet their care and support needs.
76	British Association of Social Workers	Statement 2	It is not correct to say "direct payment or personal budget". See 7.
77	British Association of Social Workers	Statement 2	See point 4. We doubt that registered nurses would usually have the knowledge and skills to explain the options for using funding in relation to adult social care.
78	British Association of Social Workers	Statement 2	It is not correct to say "receive a personal budget or use direct payments". See 7
79	British Association of Social Workers	Statement 2	Note that expert opinion is to be provided to complete these. "Allocated funds" and "Care package" are misleading as they stand. We are happy to comment further once expert opinion has been provided.
80	Carers Trust	Statement 2	Carers Trust recommend surveying unpaid carers on whether they believe the person they care for has been empowered to manage their care package funds. It is really important that the views of carers are considered when evaluating the quality of care and whether a provider is meeting the quality standards set out by NICE. Adding carers as a source of data and information could also have the added benefit of allowing those viewing the data if there is a divergent view between unpaid carers and the person they care for. NICE would also be able to disaggregate the data so it would be possible to see carers' opinions of their own care packages as users of adult social care in their own right.
81	The Challenging Behaviour Foundation (CBF)	Statement 2	The statement is written assuming that everyone has capacity to do this. It is important to be explicit about standards for people who lack capacity and require additional support and the arrangements to facilitate this.

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			In addition to ensuring people are given information and support as required to be able to make an informed decision on selecting a budget structure that best meets their needs, it is important that ongoing information and support as required, in managing the budget is provided. The CBF has heard from families who manage a personal budget, who have shared that they receive no or little ongoing support with the practical aspects of managing the budget. Support should be provided by a practitioner who has specialised skills, experience and knowledge of the needs and issues of the group they are supporting.
82	Department of Health and Social Care	Statement 2	Service providers - This support and advice should cover the different ways that allocated funds from local authorities are provided, for example direct payment or personal budget. A direct payment is a form of personal budget. So, this could say 'a direct payment or a managed account'.
83	Department of Health and Social Care	Statement 2	Process a) Proportion of people using adult social care services who can decide how the money in their personal budget is spent. Is this just for people receiving direct payments? Or does it also include PBs in other forms - those held by LAs or other third party?
84	Department of Health and Social Care	Statement 2	Social care practitioners - This will give people the opportunity to consider how they wish to spend the funds and how they would like the funds to be held, for example if they will receive a personal budget or use direct payments. same as above - 'if they will receive a direct payment or have a managed account'
85	Department of Health and Social Care	Statement 2	People using adult social care services are told about the different types of funding they can receive to pay for their social care and the different options they have to use these funds. They can choose how they would like to receive these funds and how they would like to use them to pay for their social care. They have support to help them make these decisions if they wish. Same funding - different options on how they receive the payments
86	Headway	Statement 2	Funders must also be aware of the necessity to involve family or carers in discussions on the allocation of funds, as some brain injury survivors struggle with making decisions, may lack insight, and may lack capacity to manage their finances.
87	Independent Age	Statement 2	While giving people control over allocated funds to purchase care packages can help them achieve the outcomes important to them, we know that for some older people direct management of payments can be a stressful rather than liberating experience. This is particularly so for older people since they will often need to arrange care packages at a point of crisis. We were pleased therefore to see in the definition of terms that ‘as much control as possible’ has been defined as ‘as much control that the person would like and that they are able to have based on their personal circumstances’.
88	Isle of Wight Council	Statement 2	Local data collection referenced in the standard will cause resource issues in relation to the collection and collation of data to evidence the standard: 1) Audits of care and needs support assessments and care plans (available but resource needed to pull for evidence) 2) Audits of the availability of peer support eg: ULO/IL – (would need to develop this process and resource it)

ID	Stakeholder	Statement number	Comments[1]
			3) Personal Outcomes Evaluation Tool (POET) for adults in receipt of social care support – not currently used OR 4) Local surveys (need development – and resource intensive to send/analyse/report) 5) Overall increase to reporting burden for councils
89	LGA	Statement 2	• NICE asks if there are local systems and structures in place to collect data for this quality measure, and how feasible it would be for these to be put in place. • The current national data collection looks at how many people have personal budgets and how many people have direct payments, as a proportion of all adult social care customers. The collection does not go beyond this to look at how much control people experience, whether through direct payments or through local authority commissioned services. • Some councils may address this through audits. It would not be feasible to require all councils to do audits, due to the resourcing levels required for this, unless funded by central government
90	LGA	Statement 2	• NICE asks if the statement would be achievable by local services given the net resources needed to deliver them • This is potentially achievable if a local authority with its partners including providers take a whole systems approach to maximising control. Some are putting in place infrastructure to make direct payments a more feasible choice for more people. Others are using measures such as Individual Service Funds to give more control to customers and providers to manage day to day support even if the local authority remains the commissioner. In both cases, there have to be agreed rules for how choice operates within a context of value for money still needing to be achieve, and therefore there will always be some customers who do not believe that their aspirations were fully met.
91	National Autistic Taskforce	Statement 2	Peer-led support services are often inappropriate and inaccessible for autistic people. They are strongly oriented around physical disabilities and the desire of people with physical disabilities to be considered separate from their condition and their main difficulty is access to society. While these services may be provided for autistic people they are often inappropriate having a poor understanding of the pervasiveness of autism and the needs and preferences of autistic people, which may often be for solitary pursuits rather than access to mainstream activities. For peer support to be effective it should be provided by actual peers and this is not defined globally as ‘disabled people’ as there is no more in common between people with very different disabilities than there is between disabled people and non-disabled people. So in order to measure this accurately you would have to ask whether support suited and specific to the person’s needs is being provided and not consider ‘user-let independent living’ groups to be a universal solution for all disabled people.
92	TLAP	Statement 2	Query the use of the term ‘purchasing care packages’. This language seems more redolent of the era of care management rather than that of the Care Act. It could be read as only applying to support from providers. However, the same principle and the need for quality has to apply to direct payments. Consider revising.
93	TLAP	Statement 2	See comment 2 above regarding appropriateness of the term ‘care package’.

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94	TLAP	Statement 2	Query Data source c Evidence of local arrangements for accessible information on direct payments and personal budgets and peer support on using them. This implies that direct payments are not a form of personal budget. General point over whether the measures will create disproportionate burden at the local level and are too process rather than outcome orientated. Reference to the existing voluntary data collection from Personal Outcomes Evaluation Tool is welcome, as this is an existing tool and methodology. Assume In Control, who 'own it', are aware that POET is cited.
95	TLAP	Statement 2	Service providers – This is potentially confusing as written. It is primarily the responsibility of the local authority, through their practitioners, to make sure that people know what the different types of personal budget are and to give advice on the type and sources of assistance that are available to help people manage their personal budget. See also comment 10, at end of paragraph, there is an implication that direct payments are not a form of personal budget.
96	TLAP	Statement 2	Social Care practitioners – see comments 10 and 11, again at the end of the statement there is an implication that direct payments are not a form of personal budget.
97	Action on Hearing Loss	Statement 3	The Quality Statement that people who use adult social care services should receive continuous and consistent care and support is welcomed. As highlighted in the rationale for this statement, ensuring care staff have good knowledge of a person's care and support needs is crucial for continuity of care and for helping a person achieve the outcomes that are important to them. This principle is especially important for people who are deaf or have hearing loss. For example, older people living in care homes may find it difficult to access support for their hearing loss due to mobility problems caused by other long-term conditions such as frailty, sight loss or dementia, and may require transportation to audiology appointments or domiciliary care (if they are unable to travel). After being fitted with hearing aids, people with hearing loss will need further support to get the most out of them, especially if they find it difficult to use hearing aids due to other long-term conditions. Without ongoing hearing aid support, older people may find it difficult to adjust to hearing aids and may even stop using them altogether. As stated in Comment 3, people who are deaf with multiple or complex needs may require specialist care and support - such as a specialist support worker trained in British Sign Language (BSL) – to communicate well and live safely and independently. Ensuring care staff have good knowledge of different forms of support people who are deaf or have hearing loss may need is therefore crucial for good communication and care. Consultation questions: This Quality Statement reflects a key area for quality improvement for people who are deaf or have hearing loss. Research shows that hearing loss often goes undiagnosed or isn't properly managed in care homes. Our World of Silence report found that processes for managing hearing loss and looking after hearing aids in care homes are not always followed and are sometimes de-prioritised compared to other long-term conditions. For example, some

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			care staff who were interviewed as part of the study said that they relied on family members or older people themselves to notify them if hearing aid batteries or tubing needed replacing. Other staff reported that checks for ear wax were not carried out on a regular basis. Evidence suggests that if people who are deaf with multiple or complex needs cannot communicate in BSL in a meaningful way, this can result in reduced signing skills, deterioration in personal wellbeing and loss of cultural identity. To reduce loneliness and health inequalities, care homes supporting older people should refer to NHS England's forthcoming 'What Works' guide on hearing loss and care homes. This guide provides practical information and advice for NHS commissioners and providers, local authorities and care homes on the best ways of supporting older with hearing loss. In 2014, Action on Hearing Loss received funding from the Department of Health's Innovation, Excellence and Strategic Development Fund for a three year project to test out different approaches to improving the diagnosis and management of hearing loss in care homes. The project aimed to improve the experience of older people living in care homes by implementing a series of practical changes in seven care home settings in England. These changes included screening care home residents for hearing loss, training care staff on hearing loss and hearing aids, and providing personal listeners. The learnings from the project have been published as a guide, which includes top tips on spotting the early signs of hearing loss and looking after hearing aids. The guide also includes template care plans to help care staff support older people with hearing loss. To find out more, please visit: www.actiononhearingloss.org.uk/heartocare As a member of the Think Local Act Personal partnership, Action on Hearing Loss produced guidance for local authorities on personalising care and support services for people with sensory loss. To find out more, please visit https://www.thinklocalactpersonal.org.uk/Latest/Making-it-Real-for-people-with-sensory-impairment/
98	Action on Hearing Loss	Statement 3	A reference to NHS England's Accessible Information Standard should be added to this section. As stated in Comment 3, the Standard provides clear guidance for NHS and adult social care services looking to improve the way they communicate with people who are deaf or have hearing loss. Awareness of the Standard is therefore essential for ensuring care staff have the necessary knowledge and skills to support people with disabilities and sensory loss, including people who are deaf or have hearing loss. Including a reference to the Standard in this section would align the Quality Standard with the Providing Care and Support section in the source NICE People's Experience of Adult Social Care Services Guideline.

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99	AGE UK	Statement 3	"Age UK has heard through repeated calls to our information and advice line of the public expressing concerns about the continuity of care. Older people often described a ‘revolving door’ of care workers and describe the negative impact this has one their experience of care. We are concerned about those accessing reablement and intermediate care services who often have to wait for extended periods, and over the recommended guidance, for their support to begin. There are also examples of individuals having to wait for their care package to resume after a period of hospital admission. This highlights how improving integration between the health and care systems will be a big driver of improving continuous and consistent care and support.
100	AGE UK	Statement 3	Quality standard three would also need a consideration of the workforce requirements, especially when staff turnover within the sector stands at over a quarter (27.8 per cent) and with a vacancy rate of 6.6 per cent
101	Alzheimer’s Society	Statement 3	We agree that this is an important point and think it is important to specify what we understand by ‘continuous’ and ‘consistent’. Consistency of care – People living with dementia reported about the variability in the quality of care depending on the individual carer. Workforce retention is a challenge in the care provider market. According to skills for care the staff turnover rate as at 27.8% only last year. This can mean that a person with dementia can get visits from more than one formal carer, which can be very confusing and distressing. Providers, managers and commissioners need to create a supportive environment that empowers and enables care workers to deliver high quality care. We want to see more skilled roles centred around complex dementia care. Greater recognition and job satisfaction could help to increase the number of people who stay in the sector, as well as appeal to potential new recruits. Consistency across geographical areas – Various surveys highlight the general public are concerned about achieving a consistent standard of care both in social care services and the NHS and preventing a post-code lottery. People have different experiences of health and social care services, and different degrees of access to these services, based on where they live rather than what they need. However, it is critical that there are minimum standards for these services regardless of where people live. Closing the gap between diagnosis and post-diagnostic support – Post-diagnostic support consists of information, advice and emotional and practical support for people with dementia and carers. Many people affected by dementia report that they had no support at all from local providers after a dementia diagnosis. Many tried to get access to social care practitioners, but were unable to get their attention. Many carers told us that they did not get a call back from social care practitioners and that they feel abandoned by social care. National governments must guarantee and appropriately resource a minimum provision of information, advice and support to people with dementia and carers following a diagnosis. Improving performance in this area should be the focus of public policy on diagnosis over the next five years.

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			Data sources: Improved monitoring of post-diagnostic services – There is no nationally held data on what support is currently commissioned for people with dementia. There is a placeholder in the NHS Mandate on measuring outcomes for post-diagnosis support but little progress has been made on data collection. Alzheimer's Society wants to see progress on this commitment without delay.
102	Carers Trust	Statement 3	Carers Trust recommend surveying unpaid carers on whether they believe the person they care for has had continuity and consistency of care. Adding carers as a source of data and information could also have the added benefit of allowing those viewing the data if there is a divergent view between unpaid carers and the person they care for. Unpaid carers provide the vast majority of care, and their views should be sought. Carers can provide a valuable insight into the care and support given by paid care support workers.
103	The Challenging Behaviour Foundation (CBF)	Statement 3	It is important that the care of all people using adult social care is considered. There is much evidence indicating that the care of people with severe learning disabilities and behaviours that challenge is currently inadequate. Despite the national Transforming Care programme recognising that people with learning disabilities and behaviours that challenge should be able to get the right support in the community, this is not being provided. Individuals with learning disabilities and behaviour perceived as challenging are likely to: Live in places or with people they don't like, often a long way from their family home. Be given too much medication, or inappropriate medication. Be subjected to restraint. Be secluded and have their movement restricted. Many people with a learning disability have ended up in an inpatient unit due to a failure to provide or develop the right social care support and services in the local community. At the end of June 2018 there were 2,405 people with a learning disability in inpatient services. This issue was highlighted in the 2017 National Audit Office report which concluded that there is a lack of a workforce with the right skills to support people with learning disabilities in the community. A source of information is the support provider organisations who can provide information about staff levels, recruitment and retention and whether individuals they support have a consistent staff team. CQC should also be a source of information about staff consistency and levels of registered services. Local Authorities should provide information about their social care staff- and if people receive consistent support. CBF hears from many families that have relatives with lifelong complex support needs that do not have an allocated social worker for example– social workers and care managers are allocated on an "issue based" approach meaning there is no consistency as people are allocated the duty social worker when problems occur.
104	Compassion in Dying	Statement 3	Statement 3, outcome b – suggest including the audit of complaints and compliments received about the adult social care services.

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105	Compassion in Dying	Statement 3	Service providers, final sentence – please add "…providers should ensure that recording systems are in place for individuals' care plans and documents, and that staff are informed…"
106	Compassion in Dying	Statement 3	Please amend 3rd paragraph "…workers who are familiar with and respectful of their needs and preferences"
107	Headway	Statement 3	The guideline states that the staff providing care and support should all have similar levels of skills and competency. We would also suggest including similar levels of understanding about the nature of disability, as this can have an impact on the quality of care being given by staff.
108	Independent Age	Statement 3	We are pleased to see the emphasis on 'continuous and consistent' care. One of our eight quality indicators describes how in a good care home setting, staff will have knowledge of each individual resident and be familiar with their histories. Ideally this is achieved by having a consistent team of care workers. The quality standard also recognises the importance of detailed records of needs and preferences so that other members of a team can care for a person in a consistent way. The older people and families that we speak to often emphasise the importance of good handover as a key component of quality care.
109	Isle of Wight Council	Statement 3	Local data collection referenced in the standard will cause resource issues in relation to the collection and collation of data to evidence the standard: 1) Local care protocols on care worker handover arrangements. (would need to request/ develop this across the system) - Do you mean handover within a home or handover between organisations? 2) Local audits of care records including names of care workers (would need to request/develop this with providers, current audits in care home etc. do not audit names of care workers. Proces?) 3) Personal Outcomes Evaluation Tool (POET) for adults in receipt of social care support (we do not use this and only 4 LA's have embedded POET survey into their review process) OR 4) Local surveys (not in place to answer specific questions posed - resource intensive to develop/send/analyse/report 5) Overall increase to reporting burden for councils
110	LGA	Statement 3	• NICE asks if there are local systems and structures in place to collect data for this quality measure, and how feasible it would be for these to be put in place • There is no national data collection for this • To measure continuity and consistency of care and support with an emphasis on staff, it would be necessary for providers to collect data on numbers of staff who provide support for given customers and how much change there is in staff over time. It is possible that some staff deployment systems in use by providers could provide such data, but the LGA

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			is not able to comment on the whether this is so or if such systems are in widespread use. We are also mindful if the fact that a high proportion of providers are small businesses who may not use sophisticated systems.
111	LGA	Statement 3	• NICE asks if the statement would be achievable by local services given the net resources needed to deliver them • Such continuity and consistency depends on low staff turnover, on systems which maximise staff continuity for customers, and on training for staff • Achieving lower staff turnover of itself requires very significant resources, because the single biggest driver of turnover is pay rates, and we already know how challenging it is for providers in some parts of the country to pay at a level which matches competitors for labour. • Beyond this, we believe that providers will say that providing more continuity means having slack or spare capacity in the system, so that staff don't have to be redeployed from existing customers to meet unforeseen contingencies. Such spare capacity has to be paid for from somewhere, and given how stretched providers are it would be a call on commissioning budgets
112	National Autistic Taskforce	Statement 3	Whether care is consistent is going to depend on how many carers there are. Authorities may give data on whether a person is provided care by one agency, thus one 'team', for a specified period, but if that team has a high turnover of carers or if a large number of carers are involved in supporting the person that is not consistent. Also, there is no measure of whether the carers are arriving at a consistent time or if they are in a large window (e.g. 'morning') leaving the supported person not knowing when support will be there and being able to plan their day.
113	National Autistic Taskforce	Statement 3	Quality of life measures need to be specific for people with certain conditions, especially autism or autism and learning disabilities, as personal needs and priorities can differ radically from the non-autistic population. E.g. in some cases 'quality of life' requires varied experiences of going out in the community to new and different places. For autistic people, new and different are stressful, while routine and consistent outings can provide reassurance and enjoyment while at the same time providing a change of environment and stimulation. A good example is Autism Together in the Wirral, Cheshire, who have a canal boat so their autistic residents can enjoy a holiday with a change of scene while having the security and consistency of the same base (the boat) for their expeditions each time. If quality of life measures are based on standards of what a good life means to neurologically typical people, it can end up creating worse experiences for autistic people if their carers try to undertake the necessary steps to tick the boxes in a QoL instrument.
114	Outstanding Care Homes	Statement 3	The statement - People using adult social care services have continuous and consistent care and support. In my view quality should be assessed by the measurable outcomes achieved as a result of consistent care and support as per the services users aspirations. The question is? Do we have a standard tool to measure health and wellbeing quality outcomes at an individual level? How do we measure this at different levels i.e. Individual service providers, commissioners and Local authorities?

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			I would reconsider the statement to be rewritten as "People using adult social care services have continuous and consistent care and support which has resulted in MEASURABLE outcomes as per the aspirations of the person"
115	Royal Pharmaceutical Society	Statement 3	It is important that statement 3 includes ongoing monitoring and review of medicines as part of continuous and consistent care and support. It is important that strict medicines management regimes are met, for example for people with Parkinson's. As stated by the British Geriatrics Society 'polypharmacy is an important source of morbidity in community-dwelling older people with complex conditions and care home residents'. We agree that all older people with complex conditions and care home residents should have a regular medication review.
116	TLAP	Statement 3	Query the term continuous and consistent care and support. Whilst this may imply an aspiration of quality it also may imply lifelong dependence. It does not fit well for those with fluctuating needs as a result of their condition. Consider revising, suggest adding 'when needed' at the end of the statement.
117	TLAP	Statement 3	Rationale – Suggest replace the term happiness with wellbeing so that it reads Having continuity and consistency of care and support has a considerable impact on a person's wellbeing and quality of life…" General point over whether the measures will create disproportionate burden at the local level and are too process rather than outcome orientation.
118	Action on Hearing Loss	Statement 4	The Quality Statement that adult social care services should gather service user's views and feedback in welcomed. As highlighted in Comment 3, people who are deaf or have hearing loss may need a range of support to access adult social care services and get the care and support they need. Gathering feedback on services will help identify the accessibility challenges people face and should improve the overall quality of the care and support people who are deaf or have hearing loss receive. This Quality Statement also supports the aims of NHS England's Accessible Information Standard, which states that NHS and adult social care providers must carry out quality assurance reviews to ensure they are meeting the communication and information needs of people with disabilities and sensory loss. This includes a requirement to publish an Accessible Communications Policy which sets out how service meet the requirements of the Standard.
119	Action on Hearing Loss	Statement 4	We welcome the recommendations and references to NHS England's Accessible Information Standard in this section. As stated in Comment 3, people who are deaf or have hearing loss may require a range of support to give feedback on the care and support they receive. The Accessible Information Standard is a key source of guidance for health and social care practitioners looking to improve the way they communicate with people who are deaf or have hearing loss. It is therefore highly relevant for the successful implementation of this Quality Statement.

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120	AGE UK	Statement 4	Age UK held listening events with older people and their representatives earlier this year. The attendees at these events spoke of how they often don't feel listened to in their interactions with providers and local authorities and that the support is often not person-centred . This demonstrates the need for services to aim for more comprehensive involvement with older people and their representatives, so they are at the heart of shaping service delivery.
121	AGE UK	Statement 4	Quality standard four and its call for the views of the individual to improve services, may by its very nature prove challenging, particularly for hard to reach groups. In the context of care it is also important to note that people may face additional barriers to providing feedback – in particular they may be concerned that negative feedback will be impact on their own care.
122	Alzheimer's Society	Statement 4	We agree with this statement and think that this requires some additional clarification in terms of how this can be done. User-centred approach to commissioning/service development and reviewing of services – Social care users need to be put at the centre of the health and social care system when designing/commissioning support. The Three Nations Dementia Working Group supports commissioners and providers to get the views of people with dementia on different subject matters that affect them and other people with this condition. Getting feedback from service users – As highlighted above we think there are simple ways to get feedback from service users of social care services. A simple feedback form could be used to assess/understand people's experiences of the social care services they interacted with. We would be happy to help with the development of a dementia-friendly feedback and evaluation process.
123	British Association of Social Workers	Statement 4	a) Note that the definition of social care practitioners is missing b) See point 4 c) There is a misleading implication in the last sentence that there is a power that is conferred upon local authorities that they can chose to exercise to support individual's in giving feedback. The whole tenor of statutory guidance in relation to supporting people with significant difficultly is about what is mandatory – i.e. there is no permissive element. However, the duties do not extend to giving feedback after the event, they only relate to supporting the individual in participating in their assessment and care and support planning.
124	Carers Trust	Statement 4	Carers Trust recommend that the views of carers are sought. It is really important that carers have faith and confidence in the adult social care system as they often rely on these services to enable them to go to work or take a break from caring. Adding carers as a source of data and information could also have the added benefit of allowing those viewing the data if there is a divergent view between unpaid carers and the person they care for. NICE would also be able to disaggregate the data so it would be possible to see carers' opinions of their own care packages as users of adult social care in their own right.

ID	Stakeholder	Statement number	Comments[1]
125	Compassion in Dying	Statement 4	Suggest including a point about people knowing how to raise concerns or complaints about the care they are receiving and that clear information is provided about how these would be dealt with in a timely manner without any disruption to their care.
126	Compassion in Dying	Statement 4	Statement 4, an additional quality measure could be an audit of complaints and compliments received about adults social care services.
127	Headway	Statement 4	Service providers are asked to ensure that people using services are encouraged to voice their opinions and that their opinions are actively sought. There should be a variety of ways in which this feedback is sought, to accommodate for differing abilities. For instance, while drop-in sessions and comment cards would be options for some, others may find it difficult to attend drop-in sessions, or write on cards, and things such as phone calls, internet forms and letters could also be used.
128	Healthwatch England	Statement 4	In reference to Statement 4, using people's views to improve services, it is missed opportunity that the role of local Healthwatch has been overlooked. Their statutory remit includes reporting on people's views and experiences of using social care. In terms of measuring the success of the implementation of this statement they will be an invaluable source of data, information and insight
129	Independent Age	Statement 4	While use of feedback is important, we would like to see this statement go further. Rather than just using people's views to improve services, the best quality care will involve people upfront in determining what the services look like in the first place. We would recommend this statement is expanded to cover involvement in the design of services as well as their evaluation.
130	Isle of Wight Council	Statement 4	Local data collection referenced in the standard will cause resource issues in relation to the collection and collation of data to evidence the standard: 1) Records of individual and group meetings, surveys and comment forms. (available but resource needed to pull for evidence) 2) Evidence of local arrangements for supporting people using adult social care services to provide feedback on their experience using services. (available but resource needed to pull for evidence and partner agreement to this occurring? Additional reporting burden 3) Records of meetings with people using services and posters and leaflets explaining changes made as a result of feedback from people using services. (not currently in place additional burden) 4) Audits of the groups of people using services, which could be based on geographical location, the type of needs people have or protected characteristics. (not currently in place would need to develop – additional burden)

ID	Stakeholder	Statement number	Comments[1]
			5) Overall increase to reporting burden for councils
131	LGA	Statement 4	• NICE asks if there are local systems and structures in place to collect data for this quality measure, and how feasible it would be for these to be put in place. • There is no national data collection to measure how much this takes place • It could possibly be incorporated into the existing annual survey of service users being supported at home, to test whether people think they have been asked • Beyond this, most local authorities have ways to involve citizens and customers collectively in service improvement, but they are tailor made to the local authority and its communities, and often are based on methods used by the local authority to engage with its citizens overall not just in social care. It would therefore not be feasible to collect such data consistently. • Healthwatch have a statutory role in this area, so it may be worth asking Healthwatch England if there is any appetite to standardise any Healthwatch work for the purpose of consistency of measurement
132	LGA	Statement 4	• NICE asks if the statement would be achievable by local services given the net resources needed to deliver them • Resourcing for this depends on the intensity of effort required. All local authorities have to do an annual written survey of people's view if they are still living at home, so asking them for how to improve services would have minimal extra costs. • Most local authorities will have groups of existing customers and of voluntary organisations where they can ask for views on how to improve services. What does require more resource and is increasingly beyond the means of local authorities are more intensive methods such as face to face/phone conversations with individuals, or focus groups. It also requires resources to make all these methods accessible to all, for example easy-read or translated versions of written materials, paid advocacy, transport to meetings, or signing/intrepetation at meetings
133	National Autistic Taskforce	Statement 4	In seeking input from patient groups it is particularly important that some groups are sought out and not expected to pro-actively attend consultations and feedback workshops. People with autism and/or learning disabilities are often only represented by their parents at such events. As with all communication, specific and specialised strategies are needed in order to get these groups, as well as many people with mental health problems, to be able to express their views clearly. For autistic people with good language abilities, consultations are most accessible if they are available in multiple formats and allow submissions to be made online or as a follow-up to a live meeting. Councils that are only using paper surveys for their feedback are missing out on the experiences of many individuals from these groups who may not be able to manage the administrative tasks involved.
134	The Challenging Behaviour Foundation (CBF)	Statement 4	It would be important in this standard to include how consideration should be given to ensure all people who use social care services (including those with severe learning disabilities and challenging behaviour) are included, not just those whose responses are easy to access and how this can be achieved.
135	TLAP	Statement 4	Could this be worded more strongly to support coproduction? Also, people who use services should also be involved in quality assessment of services and training of the workforce.
136	Action on Hearing Loss	Additional areas	A Quality Statement should be added on improving access to high-quality prevention services.

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			Under the Care Act 2014, local authorities in England have a legal duty to prevent, delay or reduce care and support needs. Under the Act, local authorities are legally required to carry out interventions that minimise “the effect of disability or deterioration for people with established or complex health conditions.” This includes a requirement to provide intermediate care, including reablement, free of charge for up to 6 weeks, and also provide assistive equipment up to the value of £1000. People who are deaf or have hearing loss will benefit from prevention support (usually provided or funded by local authority sensory services) to help them communicate with other people, manage their hearing loss better, get out and about, and live safely and independently in their own homes or in care homes. This could include: · Assistive equipment such as flashing smoke alarms, amplified telephones and personal listeners. · Peer support groups such as hearing loss or Deaf clubs. · Information and advisory services to help people get information on hearing loss, use local services and apply for benefits. People who are deaf may benefit from information and advice in BSL. · Mobility training and Communicator Guides to help people who are Deafblind move around safely. Lipreading classes teach people with hearing loss to recognise lip shapes and patterns and use context and facial expressions to help them make sense of conversations. Lipreading support is a valuable skill that can reduce feelings of loneliness at home or in the workplace. Lipreading classes also provide an opportunity for people with hearing loss to meet, support each other and share their experiences. Our Not Just Lip Service report identified a range of benefits lipreading classes can bring for people with hearing loss, such as: · A better understanding of communication skills to help people understand speech. · Increased confidence and assertiveness in talking to others about their hearing loss and asking them to change their behaviour to facilitate good communication. · Feeling less negative about their hearing loss and being able to manage their hearing loss better in social situations and in the workplace. Despite these benefits, our recent FOI research suggests that people who are deaf or have hearing loss may face difficulties accessing assistive equipment and rehabilitation support in some areas due to informal eligibility criteria or local authorities incorrectly applying the Care Act. A small number of local authorities in England told us that they only provide equipment and rehabilitation support to people with moderate or severe hearing loss. Others said that they only fund assistive equipment for the home if the person cannot afford to buy it themselves. Worryingly, a small number of local authorities also said that they apply the Care Act’s national eligibility criteria for the provision of equipment and

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			rehabilitation support. The Care and Support Statutory Guidance clearly states that these services should be offered to all people who are deaf or have hearing loss with care and support needs, whether their needs meet the Care Act's national eligibility criteria for care and support or not. We have also received reports of variations between areas in terms to types of assistive equipment and rehabilitation support offered by local authorities. Evidence suggests that there is unmet need for peer support groups and other forms of rehabilitation support. Participants in focus groups carried out to support the development of our 2018 – 23 strategy reported that community groups and local authority disability services in their area had closed down or they had to pay for services that had previously been free, such as lipreading classes. All focus group participants agreed that community groups such as deaf clubs or hearing loss clubs were a valuable source of support, but many reported that these services were unavailable or only aimed at older age groups. Our Not Just Lip Service report shows that rising course fees and reduced availability in some areas have deterred some people from attending lipreading classes. Our Managing Hearing Loss When Seeking or in Employment report also shows that seven out of 10 (70%) of survey respondents have not used lipreading classes, even though a similar proportion (68%) said they would find it useful to attend group lipreading sessions. Improving the availability and quality of assistive equipment and rehabilitation support has been identified by NHS England as a national priority. NHS England's Action Plan on Hearing Los lists improved access to choice of support to help people manage their hearing loss better as a key outcome measure for service improvement. Without appropriate support, people who are deaf or have hearing loss are at risk of deteriorating health and reduced personal independence. For example, unaddressed hearing loss can be a major barrier to employment; it is estimated that the UK economy lost £24.8 billion in potential economic output because too many people with hearing loss were unable to work. We therefore call on NICE to add a Quality Statement on this important issue to ensure the People's Experience of Adult Social Care Services Quality Standard properly reflects key areas for quality improvement that are important to people who are deaf or have hearing loss.
137	Alzheimer's Society	Additional areas	Getting access to care and support needs assessment – We are conscious that many vulnerable elderly people do not get access to social care support in the first place. According to Age UK the number of older people who don't get care and support has soared to a record high of 1.4 million. According to some evidence in 2016 nearly 700,000 older people do not receive any help at all, from either paid or family carers, and that a further 487,400 receive some help but not enough. This means that more people who have difficulties with activities of daily living – such as washing, eating or going to the toilet – do not have the support they need. We know 28% of people assessed get no support at all, and another 28% just get information or signposting as a result, which barely covers their initial needs for support (NHS Digital). Tens of thousands of people with dementia are left with no help, resulting in more than 50,000 hospital admissions per year and poorer health outcomes.

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			Separate means-testing from care and support needs assessment – We think that it is possible to separate the means-testing assessment from the care and support needs assessment. This would improve the experience of care and support needs assessment from the perspective of the user. The timeliness of the care and support needs assessment is equally important as to how the care assessment is carried out. These should happen as soon as someone reaches out to social care support and that dementia friendly information is provided that clearly explains what the process will be. We know from evidence that people usually reach out to social care, when they have a crisis. It is therefore important for social care practitioners to act on people's call as quickly as possible. Regular review of social care needs assessments – For people affected by dementia it is important to review their care needs and relatively frequently due to the progressive nature of the disease. Everyone experiences dementia differently but some of the most common symptoms include memory loss, confusion and difficulties with speech and understanding. Often, the changes tend to start small but gradually get worse over time, eventually affecting a person's daily life. Simplify processes of care and needs assessments – Many people affected by dementia find the process of getting social care support overly-bureaucratic, complex and long. Processes and forms need to be simplified and made much more accessible, especially to people with dementia who, as their condition progresses, may increasingly lose their cognitive and communication skills. Dementia training for care support assessors – While 2/3 of the social care user group is constituted by people living with dementia, many practitioners reported not to have been trained in dementia. Our evidence shows that at the root of poor quality care assessment is a lack of understanding of dementia from the care support assessors, tied to training, support and leadership. Care and support assessors have a critical role for the level of support that people living with dementia will get. Poor assessments due to a lack of understanding of the condition often leads to social care support packages which are too small. We want to see a funded and sustainable approach to providing the training our social care workforce needs to provide quality support to people with dementia. This training should reflect Tier 2 of the Department of Health and Social Care backed Dementia Core Skills Education and Training Framework. This programme would need to be matched by a drive to prioritise quality of dementia care assessment. Person-centred training for social care practitioners – People who have been subject to a social care needs assessment highlighted that the way questions were asked influenced strongly the decision on whether and what type of care they were able to get. Some social workers were praised for their high level of empathy and listening skills, and their effort to

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			really understand the person, their preferences, needs and aspirations. Other social workers, however, seemed to treat this exercise as a tick-off exercise, which meant that they were unable to uncover unmet need. We feel, it is critical for social workers or practitioners who undertake care and support needs assessments to develop good listening and observational training. The reality of most people is that they don’t necessarily understand what is important for their wellbeing. They will therefore need some support with verbalising these things. And this is a role that social workers need to fulfil when they conduct an assessment.
138	Healthwatch England	Additional areas	1. Does this draft quality standard accurately reflect the key areas for quality improvement? The quality standards do reflect some of the key areas for quality improvement, however, we feel that some areas have been overlooked. Firstly, the Draft Statement does not make direct reference to the importance of the provision and accessibility of universal information and advice services. Councils are compelled to develop and maintain such a service under the Care Act 2014, though our research and conversations the local Healthwatch Network have had with the public suggest that there is a considerable gap in statutory information and advice provision. This is an issue for people who are using social care services now as well as people who might be considering their own future care needs, or for a family member. Deliberative research we conducted found that people do not know where to find reliable information and advice about social care, public polling we conducted showed that 78% believed that their local GP would be the most reliable source of guidance. This could pace additional and avoidable pressures on GPs, as a service that is not best resourced to provide an information and advice service. However, GP surgery’s given their prominence and public perception as a trustworthy source of information and advice, could be more effectively used to refer people to more appropriate, dedicated information and advice providers. We suggest that the Draft Statement includes reference to the need for councils to evidence an effective and well utilised information and advice service. The local Healthwatch Network has a role to play in this, they provide information and advice provider, last year they provided guidance to 176,000 people in England on health and social care. Councils might consider resourcing their local Healthwatch to deliver it’s statutory information and advice duties. Another key area for quality improvement that people have told us about, that we feel is overlooked in this statement, is waiting times for assessments and for reviews of existing care packages. Data collected by NHS Digital shows that in

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			2016/17 only 67% of people receiving long-term social care received a review during the year. The Care Act states that all care packages should be reviewed at least annually, though good practice is too keep care plans under constant reviews.
139	Independent Age	Additional areas	We would also suggest adding that a care and support needs assessment must also be timely. We know from callers to our helpline that it is not unusual for older people to wait up to two months for an assessment. In the meantime, the older person may be living without the support they need and their health and wellbeing can quickly deteriorate. In our view the quality statement should also acknowledge the importance of a rapid assessment.
140	Local Government Association	Additional areas	• Key gaps include: people experiencing seamless and well co-ordinated care, people and communities having sufficient information about the assessment and care planning process, services being well led.
141	National Autistic Taskforce	Additional areas	All of the statements are good goals that should help to ensure good care experiences for adults in receipt of social care. There is no statement for whether the people who are assessed are provided with the care they need.
142	Royal College of General Practitioners	Additional areas	The draft quality standard does not accurately reflect the key areas for quality improvement. Quality of care once in the system is relevant but misses the major issue of access to care. Recently access has become harder due to austerity cuts with many local areas reporting that phone calls are not handled, referral letters are not accepted and cases being rejected. The main issues are access to social services and time to be seen · Time to answer phone calls · Ease of access and response to referrals · Criteria set to accept client on case load
143	Royal College of Speech and Language Therapists	Additional areas	A large number of adults using social care services are likely to have conditions where their communication skills are impacted. This has been recognised in each statement, under the 'Equality and diversity considerations' where communication needs are singled out as an example where adaptations may need to occur to ensure the standard can be met. Due to its widespread impact, we suggest one quality standard may be beneficial which would specifically target the need for information relating to someone's social care to always be communicated in an appropriate manner attending to an individual's needs (written, verbal, visual etc.). This should involve all individuals with suspected communication difficulties being assessed by a Speech and Language Therapist to advise on best practice. Meeting this standard would enhance attainment of all other standards listed, and would be easy to measure.
144	Elcena Jeffers Foundation	Other	"Care is from Pre-Birth to Post-Death. Is measured in time and space. No one has to date has firsthand knowledge of being dead. most thing can be guess. Care is very precious in real life it is an individual thing

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145	Elcena Jeffers Foundation	Other	"Un-born is a different type of care. So far only some women can verify this. This is possible based on the world population.
146	Elcena Jeffers Foundation	Other	"New Born Care. Lucky people live to become adult using care. Parenting skills has a great deal to do with this life Journey.
147	Elcena Jeffers Foundation	Other	"Adults and Care. There is a system that the human uses. Somewhere between the ages of 10 and 80 individuals
148	Elcena Jeffers Foundation	Other	"If a person is lucky enough to get to the age of Eighty Plus Social Care. Social Care as the person aged. This again turn up a different type of care, especially if the person had the opportunity to live life on the right side of existence In life trials and using good and bad care.
149	Elcena Jeffers Foundation	Other	"Post death can be from birth to130 years. More real life people activities occur after a person dies. Every passed person has a story that needs to be told.
150	Care England	No response	Apologies but we will not be responding on this occasion.
151	Royal College of Physicians	No response	The RCP will not be responding on this occasion.

Registered stakeholders who submitted comments at consultation

- Action on Hearing Loss
- Age UK
- Alzheimer’s Society
- British Association of Social Workers
- Carers Trust
- Compassion in Dying
- Department of Health and Social Care
- Elcena Jeffers Foundation

- Headway
- Healthwatch England
- Independent Age
- Isle of Wight Council
- Local Government Association
- National Autistic Taskforce
- NHS England
- Outstanding Care Homes
- Royal College of General Practitioners
- Royal College of Nursing
- Royal College of Speech and Language Therapists
- Royal Pharmaceutical Society
- Skills for Care
- The Challenging Behaviour Foundation
- Think Local, Act Personal