National Institute for Health and Care Excellence
Older people with social care needs and multiple long-term conditions
Guideline Consultation Table

Date of consultation from 1st June 2015 – 13th July 2015

Stakeholder	Comment No	Document	Page number	Line number	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
Action on Hearing Loss	1	General	General	General	Action on Hearing Loss is the charity formerly known as RNID. 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. We enable them to take control of their lives and remove the barriers in their way. We give people support and care; develop technology and treatments and campaign for equality. Our response will focus on key issues that relate to people with hearing loss. Throughout this response we use the term 'people with hearing loss' to refer to people with all levels of hearing loss, including people who are profoundly deaf. We are happy for the details of this response to be made public.	Thank you for your comments on the guideline. We have separated out the previous reference to 'sensory loss' to read 'hearing and sight loss' to make clear that these are distinct issues. The need to ensure people have access to specialist support that addresses their needs is encompassed by recommendations 1.2.5, 1.4.1, 1.5.12, 1.7.3. We could not, within the scope of this guideline, examine evidence on effectiveness of specific interventions for hearing and sight loss. The Committee members recognised the importance of providing 'joined-up' assessment, care and support for people and a number of the recommendations are focused on collaborative working and involvement of health professionals.

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					Action on Hearing loss welcomes the NICE guideline on the social care of older people with complex care needs and multiple long-term conditions. We support the broad aims of the guideline to improve the quality of social care services for older people through better planning and co-ordination between health and social care professionals. We agree that preventing or slowing the progression of long term conditions are crucial for maintaining the overall health and wellbeing of older people. Older people of multiple long term conditions require a holistic approach to social care which takes account of multiple needs, including communication. Hearing loss is a long term condition which affect more than ten million people in the UK have hearing loss, about 1 in 6 of the population. The prevalence of hearing loss increases with age. Over 71.1% over 70 year olds have some form of hearing loss, and of these 40% have moderate or severe hearing loss1.	

[1] Action on Hearing Loss. (2011). Hearing Matters. www.actiononhearingloss.org.uk/hearingmatters

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					Without treatment, hearing loss can have older people with hearing loss may find it difficult to communicate with others and are at greater risk of developing other health problems. Being unable to hear properly can lead to a loss of confidence in social situations, reduced social activities and feelings of social isolation2. People with hearing loss are more likely to develop paranoia, anxiety and depression3. Hearing loss has also been associated with more frequent falls4, diabetes5, stroke6	

[2] Gopinath et al (2012). 'Hearing-impaired adults are at increased risk of experiencing emotional distress and social engagement restrictions five years later'. Age and Ageing 41(5): 618–623; Monzani et al (2008) 'Psychological profile and social behaviour of working adults with mild or moderate hearing loss'. Acta Otorhinolaryngologica Italica. 28(2): 61-6; Arlinger (2003). 'Negative consequences of uncorrected hearing loss – a review'. InternationalJournal of Audiology 42(2): 17-20

[3] Cooper (1976) 'Deafness and psychiatric illness'. British Journal of Psychiatry 129: 216-226; Saito et al (2010) Hearing handicap predicts the development of depressive symptoms after three years in older community-dwelling Japanese. Journal of the American Geriatrics Society 58(1): 93-7; Monzani et al (2008) Psychological profile and social behaviour of working adults with mild or moderate hearing loss. Acta Otorhinolaryngologica Italica 28(2): 61–66; Eastwood et al (1985) Acquired hearing loss and psychiatric illness: an estimate of prevalence and co-morbidity in a geriatric setting. British Journal of Psychiatry 147: 552–556

[4] Lin and Ferrucci (2012) Hearing loss and falls among older adults in the United States. Archives of internal medicine 172.4 (2012): 369-371

[5] Kakarlapudi et al (2003) The effect of diabetes on sensorineural hearing loss. Otology and Neurotology 24(3): 382-386; Mitchell et al (2009) Relationship of Type 2 diabetes to the prevalence, incidence and progression of age-related hearing loss. Diabetic Medicine 26(5): 483-8; Chasens et al (2010) Reducing a barrier to diabetes education: identifying hearing loss in patients with diabetes. Diabetes Education 36(6): 956-64

[6] Formby et al (1987) Hearing loss among stroke patients. Ear and Hearing 8(6): 326-32; Gopinath et al (2009) Association between age-related hearing loss and stroke in an older population. Stroke 40(4): 1496–1498

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					and sight loss7. There is also strong evidence of link between hearing loss and dementia. Research has shown that people with mild hearing loss are almost twice as likely to develop dementia compared to people with normal hearing. The risk increases three fold for people with moderate hearing loss and fivefold for people with severe hearing loss8. Where both conditions are present, treating hearing loss and dementia separately may lead to misdiagnosis and inappropriate support. Underdiagnoses of hearing loss may mean the difficulties with communication may be misdiagnosed as dementia, or dementia may be worse than it appears due to undiagnosed hearing loss9. Hearing loss should be diagnosed and	

[7] Chia et al (2006) Association between vision and hearing impairments and their combined effects on quality of life. Archives of Ophthalmology 124(10): 1465-70

[8] Lin FR et al. (2011) 'Hearing loss and incident dementia'. Archives of Neurology 68 (2): 214-220

[9] Burkhalter CL et al. (2009) Examining the effectiveness of traditional audiological assessments for nursing home residents with dementia-related behaviors. Journal of the American Academy of Audiology 20 (9): 529-38; Boxtel van MPJ et al. (2000) 'Mild hearing impairment can reduce verbal memory performance in a healthy adult population'. Journal of Clinical and Experimental Neuropsychology 22 (1): 147-154.

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					treated at the earliest opportunity to ensure older people with multiple long term conditions are able to communicate and avoid deteriorating health. Evidence suggests there is a ten year delay in people seeking help and when people finally do contact their GP, referral rates for hearing assessments are low. Hearing aids are most effective when provided at an early stage of hearing loss. People with mild hearing loss find it easier to adapt to hearing aids and derive more benefit from them over the longer term10. Timely access to hearing aids improve communication and enable people with hearing loss to communicate with friends, family and health professionals. Hearing aids have also been shown by numerous studies to improve quality of life11. Hearing aids reduce the risk of social isolation and depression12, and new evidence suggests	

[10] Davis et al (2007) Acceptability, benefit and costs of early screening for hearing disability: A study of potential screening tests and models. Health Technology Assessment 11: 1–294
[11] Mulrow et al (1990) Quality-of-life changes and hearing impairment, a randomized trial. Annals of Internal Medicine 113(3): 188-94;
[12] Mulrow et al (1990) Quality-of-life changes and hearing impairment. A randomized trial. Annals of Internal Medicine. 113(3): 188-94; National Council on the Aging. (2000) The consequences of untreated hearing loss in older persons. Head and Neck Nursing 18(1): 12-6; Acar et al (2011) Effects of hearing aids

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					they may even reduce the risk of dementia13. As a general point, the recommendations should include ensuring that regular hearing tests are available and accessible for older people with multiple long term conditions. In line with NICE's quality standard for the mental wellbeing of older people in care homes14, social care managers and practitioners should be alert to the early signs of hearing loss, record instances of hearing loss and also be aware of the GP referral pathway for assessment and treatment.	
Action on Hearing Loss	2	Full	11-12	272-290	"ensure the person's communication needs are met during the assessment" should be added to Recommendation 1.1.3. People	Thank you for your comment. The issue of communication needs was discussed at the most recent meeting of the Guideline

on cognitive functions and depressive signs in elderly people, Archives of Gerontology and Geriatrics, 52(3): 250-2; Mulrow et al (1992) Sustained benefits of hearing aids. Journal of Speech & Hearing Research 35(6): 1402-5; Goorabi et al (2008) Hearing aid effect on elderly depression in nursing home patients. Asia Pacific Journal of Speech, Language and Hearing 11(2): 119-123; Cacciatore et al (1999) Quality of life determinants and hearing function in an elderly population: Osservatorio Geriatrico Campano Study Group. Gerontology 45: 323-323

[13] Dawes et al (2015) Hearing Loss and Cognition: The Role of Hearing Aids, Social Isolation and Depression. PLoS ONE 10(3): e0119616; Gurgel et al (2014) Relationship of hearing loss and dementia: A prospective, population-based study. Otology and Neurotology 35(5): 775-81; Lin et al (2011) Hearing loss and incident dementia. Archives of Neurology 68(2): 214-220; Lin et al (2013) Hearing loss and cognitive decline in older adults. Internal Medicine 173(4): 293-299; Uhlmann et al (1989) Relationship of hearing impairment to dementia and cognitive dysfunction in older adults. Journal of the American Medical Association 261: 1916-1919

[14] NICE (2013) Mental wellbeing of older people in care homes. QS50

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					with hearing loss may require communication equipment to participate fully in social care needs assessments including: - Hearing loops which transmit sound through magnetic field to a hearing aid to improve speech clarity and understanding - Speech-to- text reporters – type verbatim (word for word) accounts of what is being said and the information appears on screen in real-time for users to read. - Notetakers – produce a set of notes for people who can't take their own because they are lipreading or watching a sign language interpreter. They are most commonly used in schools, colleges and universities, but also at work, on training courses and at other events. An electronic notetaker takes notes using a laptop whereas a manual notetaker takes handwritten notes. People who are deaf may use British Sign Language (BSL) as their main language and may require may require a qualified BSL interpreter or video relay services (where a BSL interpreter provides translation for a	Committee (July 2015). It was agreed that the guideline would reference the NHS England Accessible Information Standard, which it now does. We have separated out the previous reference to 'sensory loss' to read 'hearing and sight loss' to make clear that these are distinct issues. We could not, within the scope of this guideline, examine evidence on effectiveness of specific interventions for hearing and sight loss.

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					video call). If the person lipreads, staff carrying out the assessment should ensure the room is well it and they face the person whilst speaking. They should speak clearly and slowly, and avoid obstructing their face with their hands or other objects.	
Action on Hearing Loss	3	Full	11-12	272-290	"ensure contact methods and correspondence are in a format the person can understand" should be added to Recommendation 1.1.3. People with hearing loss unable to use a telephone may require alternative contact methods such textphone, text relay, email or SMS. BSL users may require a BSL interpreter or video relay.	Thank you for your comment. The issue of communication needs was discussed at the most recent meeting of the Guideline Committee (July 2015). It was agreed that the guideline would reference the NHS England Accessible Information Standard, which it now does. We have separated out the previous reference to 'sensory loss' to read 'hearing and sight loss' to make clear that these are distinct issues. We could not, within the scope of this guideline, examine evidence on effectiveness of specific interventions for hearing and sight loss.
Action on Hearing Loss	4	Full	12	284-285	"ensure information is provided in a format the person can understand" should be added to Recommendation 1.1.3. People	Thank you for your comment. We note your comments on emphasising accessible communication and this was also discussed

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					who are deaf may require BSL translation of written information, either through a qualified BSL interpreter or BSL translated video.	at the most recent meeting of the Guideline Committee (July 2015). It was agreed that the guideline would reference the Accessible Information Standard, which it now does, to avoid repeating this throughout. This is on the basis that accessibility should underpin all the recommendations.
Action on Hearing Loss	5	Full	11-12	272-290	Recommendation 1.1.3. should make reference to requirements under the Equality Act 2010 to make reasonable adjustments to ensure disabled people have equal access to their services, and also duties under the Care Act 2014 to ensure assessments and social care information are accessible for people with sensory impairments. It should also mention NHS England's recently published Accessible Information Standard15 [ISB 1605] which sets out what adjustments people with hearing loss should expect when accessing health and social care. The standard, which is mandatory for NHS and adult social care services, provides clear guidance on what these services must do to ensure people	Thank you for your comment. Communication needs and sensory loss were discussed at the most recent meeting of the Guideline Committee (July 2015). It was agreed that the guideline would reference the NHS England Accessible Information Standard, which it now does. We have separated out the previous reference to 'sensory loss' to read 'hearing and sight loss' to make clear that these are distinct issues. We could not, within the scope of this guideline, examine evidence on effectiveness of specific interventions for hearing and sight loss.

[15] NHS England. (2015). Accessible Information Standard. Availabe at: http://www.england.nhs.uk/ourwork/patients/accessibleinfo-2/

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					with hearing loss understand the information they are given and can participate fully in treatment discussions.	
Action on Hearing Loss	6	Full	11	278	We welcome the inclusion of "communication needs" in list of considerations when undertaking assessments in recommendation 1.1.3. As discussed in comment 1, hearing loss is long term condition that affects people ability to communicate with others. If untreated, people with hearing loss may become isolated from friends and family, which may lead to feelings of social isolation, depression and deteriorating health over the longer term.	Thank you for your comment and your support.
Action on Hearing Loss	7	Full	13	314-315	"access relevant support services" should be added to recommendation 1.2.2. For people with hearing loss, these include having a hearing assessment, getting and using hearing aids, support services that may be available through the local authority, such as lipreading classes, counselling or hearing therapy	Thank you for your comment. The need to ensure people have access to specialist support that addresses their needs is encompassed by recommendations 1.2.5, 1.4.1, 1.5.12 and 1.7.3. We could not, within the scope of this guideline, examine evidence on effectiveness of specific interventions for hearing and sight loss.
Action on Hearing Loss	8	Full	13	320-322	We recommend including a list of adaptions relevant for people with hearing loss including: - Amplifier telephone	Thank you for your comment. We could not, within the scope of this guideline, examine evidence on effectiveness of specific interventions for hearing and sight loss.

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					- Hearing Loop - Flashing light or doorbell - Text relay - Textphone - Vibrating alarm clock - Vibrating/flashing light smoke alarm - Conversor (wireless listening device worn by user which provides enhanced sound and clarity)	
Action on Hearing Loss	9	Full	14	337-350	Recommendation 1.2.7. should be revised to make it clear that information on personal budgets, continuing healthcare budgets, individual services funds and direct payments should accessible be for people with hearing loss (See comment 4 on information for BSL users).	Thank you for your comment. The recommendation about providing this sort of information would apply to all older people with multiple long-term conditions and social care needs including those with hearing loss.
Action on Hearing Loss	10	Full	16	403-404	"for example, providing information on hearing assessments" should be added to recommendation 1.4.1	Thank you for your comment. We have not provided specific examples here as this is intended to be an over-arching recommendation. However, the need to ensure specialist support is available to meet their needs is reflected throughout the guideline, for example, in recommendations 1.2.5, 1.4.1, 1.5.12, 1.7.3.
Action on Hearing Loss	11	Full	17	432-441	We welcome recommendation 1.5.4 on the suitability of the care home environment for good communication and provision of	Thank you for your comment and your support.

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					assistive equipment such as hearing loops and TV listeners.	
Action on Hearing Loss	12	Full	17	432-441	A recommendation should to be added to recognise the important role played by care home staff in facilitating good communication. Our research A World of Silence16suggested that large number of care home residents have undiagnosed hearing loss. Many residents did not want to address their hearing loss and care home staff found it difficult to encourage them to seek help. Although the care staff we interviewed displayed good awareness about ways of improving communication and the importance of reducing background noise, they also admitted that hearing loss was sometimes overlooked compared with other issues such sight loss, pain or safeguarding. Some care staff did not know about hearing loops and other assistive equipment such as amplified telephones and TV listeners. Others lacked the training to carry out basic hearing aid maintenance.	Thank you for your comment. We have expanded recommendation 1.7.2 to make clear that practitioners need to 'consider the impact of' and 'respond to' a range of common conditions – including hearing and sight loss - rather than simply be able to identify them. This would include understanding how to support, and communicate with, people with particular needs.
Action on Hearing Loss	13	Full	19	491-493	We welcome Recommendation 1.5.17 on review of "information needs". This is in line the Accessible Information Standard which	Thank you for your comment. The issue of communication needs was discussed at the most recent meeting of the Guideline

[16] Echalier, M (2012). A world of silence. Available at: www.actiononhearingloss.org.uk/aworldofsilence

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					states that communication needs must be regularly reviewed and if necessary updated to identify whether a person's communication needs have changed and the most appropriate means of meeting those needs.	Committee (July 2015). It was agreed that the guideline would reference the NHS England Accessible Information Standard, which it now does.
Action on Hearing Loss	14	Full	20	507-508	Recommendation 1.5.19 should be revised to make it clear that information on particular conditions should accessible for people with hearing loss (See comment 4 on information for BSL users).	Thank you for your comment. The issue of communication needs was discussed at the most recent meeting of the Guideline Committee (July 2015). It was agreed that the guideline would reference the NHS England Accessible Information Standard, which it now does.
Action on Hearing Loss	15	Full	21	533-545	We welcome Recommendation 1.7 on ensuring health and social care practitioners have the necessary training. In 'a World of Silence' we found that NVQ qualifications in social care neglected the viewpoints and needs of people with hearing loss. Training programmes should be revised to incorporate good practice from elsewhere, notably in dementia training, so they can give staff an appreciation of what hearing loss feels like17.	Thank you for your comment and your support.
Action on Hearing Loss	16	General	General	General	Please read the checklist for submitting comments at the end of this form. We	Thank you for your comments and support for the guideline. Commissioning is out of

[17] Echalier, M (2012). A world of silence. Available at: www.actiononhearingloss.org.uk/aworldofsilence

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					cannot accept forms that are not filled in correctly. 1. How will you use the recommendations in the guideline? We will use the recommendations to lobby health and social care practitioners, as well as government and professionals, to improve social care provision for people with hearing loss. 2. Which recommendations do you think are the most important? And why? Action on Hearing Loss welcomes recommendation 1.1.3 which states that communication needs should be included in social care needs assessments. This is important given the relationship between hearing loss and health and wellbeing. recommendation 1.5.4 recognises the importance of reducing background noise, encouraging face-to-face contact and providing communication equipment such as hearing loops and TV listeners. This is a positive step should improve the quality of life of people with hearing loss in care homes. 3. In what ways can the recommendations be made more specific to the care of older people with long-term conditions? The recommendations need to explicitly	scope for the guideline but your comments about the importance of local authority involvement will be considered as part of implementation work. It was not in scope to review the evidence on effectiveness of communication equipment and support during social care needs assessments however the issue of accessibility was discussed at Guideline Committee meeting 12 and reference to this features in the introduction. Recommendation 1.7.2 makes explicit reference to the need for practitioners to be able to identify, understand the implications of and respond to the needs of people with hearing and sight loss and 1.7.3 refers to the importance of specialist services. These would include responding to people's communication needs. Recommendation 1.2.5 emphasises the need to ensure all needs, including communication needs, are logged in the care plan. It was not in scope to assess the effectiveness of lip-reading classes, counselling services or hearing therapy nor

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					state that communication equipment and support should be provided during social care need assessments, and that social care information and correspondence must be accessible for people with hearing loss. The recommendations should make reference to NHS England's Accessible Information Standard ISB1605, which states that communication must needs must be identified, recorded and acted upon by all health and social care organisations. 4. What should practitioners be doing, or doing better, to care for this population that is not already covered in this guideline? Care home providers should ensure there are robust processes for recording communicating needs. Communication needs must also be specified in care plans and acted upon by care staff. 5. Does the guideline cover all the challenges in caring for this group'? The guideline should also cover the need for ongoing local authority support through lip-reading classes, counseling or hearing therapy and also promoting timely access to hearing assessments. 6. The intention of the guideline is that all recommendations should be considered in conjunction with the person and taking into	did we seek evidence on the timing of, or access to hearing assessments.

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					account their views. Does the guideline make this clear? Are there ways in which this could be made clearer in the guideline? Yes, please see comments 2,3,4,5,9, and 14	
Alzheimer's Society	1	Full	General	General	Alzheimer's Society welcomes these guidelines as they reiterate many of the positive elements in the Care Act guidance. However, our concern is that the guidelines (also the shorter format) are lengthy and so similar to the Care Act guidance that these guidelines will not be taken on board by practitioners. Alzheimer's Society recommends including a section at the start of guidelines making it clear the audiences for these guidelines and how they should be used.	Thank you for your comment. NICE have revised the short version of the guideline so that it will be easier to navigate online. A reference to the audiences has been included.
Alzheimer's Society	1	NICE	General	General	Empowering older people and carers to choose and manage their own support Alzheimer's Society agrees that this is area could have a big impact on practice and be challenging to implement. Firstly, data sharing between different services, especially between health and social care services presents challenges making it difficult for practitioners to access information from other service providers, although this has improved in some areas. Secondly, some practitioners may	Thank you for your comment. This is useful information for the implementation work we will be doing to accompany the guideline.

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					underestimate the capabilities of a person with dementia with regards to being involved in decisions about their care. There must be more concerted efforts to ensure correct implementation of the Mental Capacity Act 2005 so that the capacity of people with dementia is assessed depending on the decision, and they are supported to make decisions as far as possible. Finally, local authorities must make sure that personal budgets and direct payments are accessible to people with dementia, and not assume that a personal budget is not suitable for them.	
Alzheimer's Society	2	Full	General	General	Alzheimer's Society welcomes that the guidelines state that individuals, carers, care co-ordinators and other professionals involved in a person's care should be involved in assessments and care planning. Alzheimer's Society recommends that the guidelines reference, where appropriate, the Mental Capacity Act, ensuring that people with dementia are supported to make decisions as far as possible. The Mental Capacity Act is often implemented incorrectly and so its inclusion would help raise awareness of this important legislation.	Thank you for your comment. The issue of consent was discussed at Guideline Committee meeting 12 (July 2015) and this has been referenced in the introduction.

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Alzheimer's Society	2	NICE	General	General	Empowering older people and carers to choose and manage their own support Alzheimer's Society would like every person with dementia to have access to a Dementia Adviser (or equivalent), from the point of diagnosis, who can coordinate between the complexities of health and social care services. Dementia Advisers are specifically trained in the skills to support people with dementia and can signpost to appropriate services and support which meet the needs of the individual. This means that they can make informed decisions in managing their own support. An evaluation for the Department of Health showed that Dementia Advisers can have a positive impact on the quality of life and wellbeing of a person with dementia, as well as their carer. The evaluation also found that there could be cost-saving implications of Dementia Adviser services.	Thank you for your comment. We did not find any evidence on the effectiveness of dementia advisers for supporting this population. The Guideline Committee did, however, recognise the prevalence of dementia within the population in question and this condition is referenced explicitly throughout the guideline, to emphasise this (for example, in recommendations 1.5.5 and 1.7.2)
Alzheimer's Society	3	Full	11	269	Alzheimer's Society is concerned that these guidelines are using the words 'substantial' and 'critical'. This is not the legal terminology used in the Care Act 2014. Alzheimer's Society recommends rewording this point to: "whose social care needs are likely to increase to have a significant impact on a person's wellbeing". Doing so	Thank you for your comment. This text has now been amended so it is aligned with the wording of the Care Act.

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					would reflect the language used in the Care Act.	
Alzheimer's Society	3	NICE	General	General	Empowering and valuing practitioners so they can deliver person-centred care Alzheimer's Society recognises this as a challenge. As the All-Party Parliamentary Group on Dementia found in tis 2014 inquiry, there is a need for a culture shift to improve the status and morale of care work. The quality of care can only be improved by tackling the ingrained culture. This must start at a management level and filtered down to front line staff. There is also a need for professionals in each sector to understand the other sector and how their actions impact on the other.	Thank you for your comment, which we will consider as part of our work on implementation. The importance of empowering practitioners was discussed extensively as part of guideline development and features in the implementation priorities.
Alzheimer's Society	4	Full	12	289-290	We welcome that the guidelines recommend that practitioners ask whether a family member or friend has caring responsibilities. However, this may be more complex than asking if a person is a carer as often family carers will not perceive that they are carers. Alzheimer's Society recommends that practitioners ask what the family member does day-to-day to look after the person with dementia. This should be made more explicit in the guidelines.	Thank you for your comment. Recommendation 1.1.5 has been updated to reflect this point.

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Alzheimer's Society	4	NICE	General	General	Empowering and valuing practitioners so they can deliver person-centred care Implementation of research into practice – a care home training programme to reduce use of harmful antipsychotics Antipsychotic drugs are currently over-prescribed to people with dementia, particularly in care homes. They are known to be harmful, causing severe side effects and increasing the risk of mortality. The FITS (Focused Intervention for Training of Staff) programme is based on a study that was funded by Alzheimer's Society. It is an extensive training programme for care home staff based on principles of person-centred care. The research trial showed that the programme, which comprises a 10-day training course followed by a nine-month supervision and monitoring process, reduced the use of harmful antipsychotic drugs in people with dementia by 40%. The findings were published in the British Medical Journal (Fossey et al, 2006). The FITS programme was then made into a training manual. This has now been scaled up and completed by staff in 67 care homes across the UK, in what is one of the largest	Thank you for this example of a care home training programme. It will be helpful for the implementation work to support this guideline.

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					formal evaluations of a training programme ever conducted. Over 100 care homes were recruited to take part in the programme – which equips staff to understand complex behaviours in people with dementia and to deliver person-centred care as an alternative to harmful antipsychotics. When medication was reviewed, residents were more alert, communicative and active, with improvements in mobility, eating, sleeping and in achieving personal goals.	
Alzheimer's Society	5	Full	14	337-350	Alzheimer's Society welcomes the inclusion of personal budgets in these guidelines. Nevertheless, there should be reference here to people who lack capacity, or where practitioners can look for further information on this. It must be made clear in these guidelines that a lack of capacity does not exclude a person from having a personal budget.	Thank you for your comment. The issue of capacity was discussed at Guideline Committee meeting 12 (July 2015) and this has been referenced in the introduction.
Alzheimer's Society	5	NICE	General	General	Integration of different care and support options to enable person-centred care This area presents particular challenges for commissioners; therefore, we agree with this area being identified. Commissioning to meet the needs of the population is a	Thank you for your comment, which we will consider as part of our work on implementation.

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					challenge, even more so when individuals will have more control over the services they choose. Commissioners should move away from generic commissioning and focus on providing high-quality specialist services with staff who understand how to support the needs of older people with complex needs. Although this can result in fewer options, this will allow individuals with needs to access specialist services. As local authorities face difficult budgeting decisions. Specialist services may be more costly to commission; however, the commissioners must look at the evidence to support their commissioning and consider the outcomes of individuals with needs. It can be the case that specialist services improve outcomes, thus preventing or delaying needs from worsening.	
Alzheimer's Society	6	Full	17	420-452	Alzheimer's Society welcomes these recommendations as they could potentially improve the quality of life of people with dementia living in care homes. Previous research from Alzheimer's Society (2013) found that, although the quality of care in residential care is usually good, there are low expectations with regards to the quality of life.	Thank you for your comment and your support.

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Alzheimer's Society	6.	NICE	General	General	Integration of different care and support options to enable person-centred care Case study – Tower Hamlets integrated care programme Tower Hamlets commissioned a whole range of new services, with a coherent community pathway that was entirely integrated across health and social care. This included a diagnostic memory clinic, a Community Dementia Team and an extra care sheltered scheme for people with dementia As part of the community awareness-raising activities, an employee of the Alzheimer's Society trained 120 local Imams to understand dementia and its issues. This resulted in the Imams delivering special sessions devoted to teaching the local community about dementia in their mosques. When someone attends the Memory Clinic they are offered post-diagnostic counselling and pastoral support by the Alzheimer's Society Dementia Adviser Service, which is co-located with the Memory Clinic. Any person with a diagnosis of dementia in the borough is now offered the telephone	Thank you for your comment, and the case study example, which we will consider as part of our work on implementation.

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					number of a health and social worker who works in the dementia pathway. This could be a Dementia Adviser, if the person has mild problems associated with their dementia, or a doctor or nurse from the Community Dementia Team, if they have more complex problems. The Community Dementia Team provide on-going support for anyone with moderate to severe needs and also provides outreach into care homes and into primary care. The team also provides various therapeutic groups. Tower Hamlets also commissioned a range of social care services. In addition to the existing specialist day centre, there are also very well attended dementia cafés provided by the Alzheimer's Society. One café provides specific support for the Bengali community and one is for all comers. Tower Hamlets has shown that integrated services can deliver improved diagnosis rates and financial savings. Within a year referrals to the memory service doubled, with a particular proportionate increase in the Black and Minority Ethnic community, and in 2012 the diagnosis rate increased by 9.6% to 50% making Tower Hamlets the most improved organisation in England over	

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					this period. As the new services proactively supported people closer to home, Tower Hamlets worked closely with their neighbouring areas of Newham and City & Hackney to reconfigure inpatient dementia beds as all three areas are served by the same partnership trust. These have been reduced from 44 to 21, with a resulting release of £1million of funds. As of October 2013, there were only 8 patients on the ward.	
Alzheimer's Society	7	Full	18	458	Alzheimer's Society welcomes the inclusion of dementia cafes in this recommendation. Peer support and social interaction is important to people with dementia to help them maintain a good quality of life.	Thank you for your comment and your support.
Alzheimer's Society	8	Full	18-19	471-478	We welcome that incontinence is recognised in these guidelines. Alzheimer's Society recommends that carers are also mentioned in this section. Carers of people with dementia often hit a crisis point when the person with dementia becomes incontinent. Therefore, carers will also need information on managing incontinence.	Thank you for your comment. The Guideline Committee agreed that continence promotion is an important issue for older people with multiple long-term conditions. This guideline focuses on the importance of recognising continence as a symptom and promoting dignity. There is already NICE clinical guidance which provides more specific recommendations on the practicalities of continence management: - Urinary Incontinence: https://www.nice.org.uk/guidance/

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						cg171 - Faecal incontinence https://www.nice.org.uk/guidance/cg49 We have emphasised throughout the guideline the importance of both care involvement and the provision of information to carers (e.g. in recommendations 1.2.3 and 1.5.3) which would include planning for and responding to concerns about continence.
Alzheimer's Society	9	Full	20-21	513-532	Alzheimer's Society welcomes these recommendations. A survey of people with dementia in 2014 (Alzheimer's Society, 2014) found that 40% of people with the condition had felt lonely recently. As research shows, loneliness can lead to an early mortality.	Thank you for your comment and your support for the recommendations.
Alzheimer's Society	10	Full	20	529-532	Alzheimer's Society is concerned that the onus in this recommendation is placed on the voluntary sector to work with local authorities. The voluntary sector often uses innovative ways of supporting people to remain active; however, voluntary and community groups depend on funding from local authorities. Alzheimer's Society recommends that this wording is changed in this recommendation to: "Local authorities	Thank you for your comment. Commissioning is not in scope for NICE guidance however the role of commissioners in implementation will be considered as part of implementation.

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					should consider collaborating with the voluntary and community sector to develop…"	
Alzheimer's Society	11	Full	21	534-546	Alzheimer's Society welcomes these recommendations. As people with dementia are core users of health and social care services. Nearly all practitioners in health and care services will support a person with dementia at some point. Alzheimer's Society would also like to see here a recommendation on diagnosis, ensuring that practitioners are confident to make referrals for diagnosis.	Thank you for your comment and your support.
Alzheimer's Society	12	General	General	General	1. How will you use the recommendations in the guideline? Alzheimer's Society will use these guidelines to highlight to health and care practitioners and service providers their duties with regards to working with older people living with multiple long-term conditions. 2. Which recommendations do you think are the most important? And why? The identification and assessment recommendations are important to people with dementia. We welcome that the guidelines state that health care practitioners should consider older people to the local authority for an assessment of	Thank you for your comment. Diagnosis (and the effectiveness of specific medical interventions) was not in scope for this guideline. The Guideline Committee did, however, recognise the prevalence of dementia within the population in question and this condition is referenced explicitly throughout the guideline, to emphasise this (for example, in recommendations 1.5.5 and 1.7.2)

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					social care needs. This is particularly important for people with dementia who should be referred for a needs assessment at the point of diagnosis. The Society welcomes the recommendations on integrating health and social care planning. As people with dementia are core users of health and social care, they have much to be gained from integrated care planning. The point on seamless referrals must be retained in the final guidelines as people with dementia often report disjointed care between practitioners. With regards to the delivering care, Alzheimer's Society believes that the recommendation on offering opportunities for peer support and interactions with other people is important as living with dementia can be an isolating and lonely experience. Finally, we strongly support the recommendations on training health and social care practitioners and believe that all health and social care professionals must be able to recognise and understand how to support people with dementia. 3. In what ways can the recommendations be made more specific to the care of older people with long-term conditions?	

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					4. What should practitioners be doing, or doing better, to care for this population that is not already covered in this guideline? Alzheimer's Society would like to see more health and care professionals referring a person they suspect has dementia for a diagnosis. Under the section on training, Alzheimer's Society recommends including a point which states that professionals need to be confident to refer a person for a diagnosis of any long-term condition. 5. Does the guideline cover all the challenges in caring for this group? The guidelines do not cover the issue of diagnosis. People with dementia can face challenges in getting a diagnosis, an issue which is common to many long-term conditions. Alzheimer's Society recommends including diagnosis in these guidelines so that people with dementia can be directed to specialist support which enables them to live well with the condition. 6. The intention of the guideline is that all recommendations should be considered in conjunction with the person and taking into account their views. Does the guideline make this clear? Are there ways in which this could be made clearer in the guideline?	

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					This is made clear throughout the guidelines. It also firmly embedded in the Care Act 2014, so if the two are used in conjunction, health and care practitioners should involve the person, as well as their carer in any assessments and decisions. See section 3.9 of Developing NICE guidance: how to get involved for suggestions of general points to think about when commenting.	
Barchester Healthcare	1	Full	General	General	**NICE Consultation: Social care of older people with complex care needs and multiple long-term conditions** **Introduction** Barchester Healthcare is a major independent provider of social and health care in the UK, with over 200 homes providing high quality nursing care, residential care, close care (assisted living linked to residential schemes) and supported living services. We offer support predominantly to frail older people and older people with dementia but we also provide neuro-rehabilitation services, support younger adults with traumatic brain injuries and others in need of specialist support. We are committed to our staff ensuring the people we support have	Thank you for your comment.

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					dignity, independence, choice and control but accept that this must be ensured for people with complex needs who may find it difficult to exert real control over their lives. In common with other providers approximately 80% of the residents we support are living with some degree of dementia. Taken together with the fact that the majority of our homes are nursing homes (only about 10% of our homes are residential care homes) and the increasing frailty of individuals referred to us through local authorities very few of our residents do not have complex care needs and multiple long term conditions: we have to ensure that we respect the rights of individuals who may find it difficult to assert those rights. We manage seven independent hospitals for people with mental health issues, often linked to facilitating transitions for people with long-term care needs moving back into the community. We provide a number of intensive shorter-term rehabilitation and re-ablement services, tied to outcome-based care planning, working with integrated care pathways. These are rooted in agreements encompassing health commissioners, clinical commissioning	

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					groups and the independent sector, reflecting localised support needs. We support approximately 11,000 residents and patients in our homes and hospitals. We employ around 17,000 people, of whom about 2,400 are registered nurses. Given our varied experience and our care homes' client population we believe Barchester Healthcare is well placed to respond to the NICE consultation on social care of older people with complex care needs and multiple long-term conditions. We are responding to this consultation in our capacity as an independent provider.	
Barchester Healthcare	2	Full	General	General	*Question 1: How will you use the recommendations in the guideline?* The recommendations are interesting and would improve the lives of people with complex care needs and multiple long-term conditions if implemented. However, they are made in the context of unprecedented pressure on local authorities. The UK's current social and political realities are grounded in a sustained period of austerity	Thank you for your comment. NICE guidance focuses on 'what works'. It is beyond the remit of NICE guidance to make recommendations about funding. We are pleased to hear your organisation will find the recommendations useful and that you already have plans to support us in implementing the guidance.

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					with no clear end in sight. This raises many challenges to implementations of the guidelines, the most urgent of which is sustained underfunding of local authorities (a 26% cut over 4 years according to ADASS). In honesty it is difficult to see how local authorities will be able to deliver on the ambitious agenda set by the NICE guidelines. From our own perspective Barchester Healthcare already meets many of the recommendations specific to care homes. There will be homes that need to improve, however, and there are areas where all homes will have to think through new approaches. We will use the recommendations as the basis for a briefing for all home managers. We will run a training session for home managers and their managers and ask for checks on performance. We will also use the recommendations as a basis for re-writing our welcome pack, accommodating the recommendations on tariffs, for example, and emphasising the right to control, which seems to us an empowering way of describing a the rights offered to the individuals we support that we believe	

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					should characterise our services.	
Barchester Healthcare	3	Full	General	General	*Question 2: Which recommendations do you think are the most important? And why?* Barchester Healthcare believes the most important recommendations are: • 1.4 Integrating health and social care planning • 1.5 Care in care homes Barchester Healthcare believes '1.4 Integrating health and social care planning' and '1.5 Care in care homes' are important for a number of reasons. As a provider organisation we have consistently argued for the integration of health and care services almost from our inception. We support many older persons with complex care needs and multiple long-term conditions in our homes. We believe we could offer the same support to many people who are admitted to hospitals. For older people generally and people living with dementia in particular time spent in hospital can be confusing and disempowering, not infrequently with distressing long-term effects. Managing needs in care homes is less expensive,	Thank you for your comment and your support for the recommendations. This was discussed at Guideline Committee meeting 12 (July 2015). The Guideline Committee agreed to continue to aim recommendations at 'providers' rather than being more specific about roles recognising that in different organisations, different people undertake different functions. They did recognise however the pressures on providers and note that NICE will be publishing a costing statement alongside the guideline. NICE guidance focuses on 'what works'. It is beyond the remit of NICE guidance to make recommendations about local authority funding of care homes. We are pleased to hear your organisation will find the recommendations useful and that you already have plans to support us in implementing the guidance.

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					offers a better quality of life and preserves or improves life skills that hospitals offer no opportunity to exercise. The guidelines content specific to care homes represents a great deal of current best practice, which we are pleased to support. Some of the proposed targets will be stretching, which is as it should be: we expect NICE to help us move towards improvement. We are pleased to see an emphasis on multi-disciplinary teams working together to tackle problems for individuals with complex care needs and multiple long-term conditions. The idea of a named care coordinator is a sensible and helpful approach, and goes some way to begin to address the inequities in health provision for older people that the guidelines identify. However, we would welcome the guidance being more specific about who it sees as taking this role (e.g. a care manager or a medical professional?) and the extent to which they are accountable or must be held accountable by providers. This is not made clear in the NICE guidelines. We would ask NICE to note that to affect real change for older people with complex care needs and multiple long-term	

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					conditions (and to assist providers in ensuring such change) it is vital that this be unambiguous. We would ask NICE to note that care homes are currently notoriously underfunded by local authorities, a situation that current interpretation of the Care Act looks likely to exacerbate. There is also the issue of an unfunded rise in minimum wages for care staff, which will put a great deal more pressure on homes already struggling financially. Quite simply it will make homes funded entirely by local authority payments unviable. It is a genuinely dangerous position, which will drive small homes out of business - and which militates against any improvement in care home standards for older persons with complex care needs and multiple long-term conditions and others.	
Barchester Healthcare	4	Full	General	General	*Question 3: In what ways can the recommendations be made more specific to the care of older people with long-term conditions?* Two effective ways to make the recommendations more specific to older people are:	Thank you for your comment and your support for the recommendations. NICE guidance focuses on 'what works'. It is beyond the remit of NICE guidance to make recommendations about funding of care and support. At their most recent meeting (July 2015),

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					• Provide specific, accountable funding to improve care for such individuals • Make the named coordinator and lead practitioner/assessor roles clearly accountable	the Guideline Committee discussed the issue of ensuring accountability, to respond to consultation comments. In response to the comment about ensuring the named coordinator is clearly accountable, rec 1.2.1 now references the need for this person to work within local arrangements.
Barchester Healthcare	5	Full	General	General	*Question 4: What should practitioners be doing, or doing better, to care for this population that is not already covered in this guideline?* In general, Barchester Healthcare believes that the guidelines covers what needs to be done for older persons with complex care needs and multiple long-term conditions. However we believe that some of the ambitions embodied by the guidelines are difficult or impossible to deliver upon. These include: **The thoroughgoing assessment suggested by the guidelines and the related meeting of medical needs.** This will be difficult to deliver in terms of time and available qualified personnel **The thoroughgoing assessment of carers'**	Thank you for your comment and your support for the guideline. The Guideline Committee and the NCCSC recognise that many of the recommendations are aspirational and will require new ways of working and possibly investment from a range of stakeholders. While the primary audience for the guideline are health and social care providers and practitioners, the guideline is also of relevance to commissioners and others and we will consider your comments in respect of these groups as part of the implementation work. Aligned with your comment about GP involvement in care planning, the group thought it important to develop a recommendation in this area though

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					need suggested by the guidelines and the related meeting of medical needs. This will be difficult to deliver for the reasons above. **The linking of both assessments to sustaining interests and active community relationships.** This will be impossible to achieve with the resources currently available to local authorities. **GP involvement in care plans.** While Barchester Healthcare applauds this idea our experience strongly suggests that many GPs will not be able to find time for meaningful engagement with care planning for older people with complex care needs and multiple long-term conditions in the community: it is certainly true that GP engagement with such individuals resident in care homes is minimal more often than not. **Care plans to include a life story.** Again, Barchester applauds the Guidelines' ambition but thinks it is unlikely to be delivered. Our experience shows that life story work sufficiently detailed to be genuinely useful is a time-consuming process. This applies particularly to people	recognised this may be aspirational in some localities. Thank you for your support for inclusion of life story work in care planning. We recognise that this is aspirational however the Committee thought it important to include for the reasons you identify. In respect of personal budgets, the Committee discussed potential conflicts of interest but thought it important to include a recommendation in this area, recognising that lack of support can mean people do not take up this mechanism or can find it anxiety-provoking to do so. In terms of choosing a care home, the overall emphasis is on enabling the individual (and their carers, as appropriate) to exercise choice and control. We have added in some text to 1.6.3 to make clear that information should be provided.

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					living with dementia, the individuals who need it most. We do not believe that multi-disciplinary teams in the community will be trained sufficiently, or able to find the necessary time. **Support to be given to individuals managing personal budgets.** The considerations of time required for such support are identical to those above. There would also be serious questions about expertise and potential conflicts of interest. **The named coordinator to offer advice on choosing a home to older persons with complex care needs and multiple long-term conditions.** This is the only area of the guidelines that Barchester Healthcare disagrees with completely. It is clearly well-intentioned – and it is true that some people struggle with choosing the work involved in choosing a care home, perhaps particularly older people with complex care needs and multiple long-term conditions. However, our experience as providers of residential shows that decisions about homes have to be taken by the individual or by family members. The factors that influence successful choices are entirely personal. If advice goes beyond the	

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					recommendation of a particular type of home and indication that several homes should be visited it may well lead to poor choices. We take the guidelines to be recommending advice stronger than this, which we strongly believe would be unhelpful. Again, the issue of potential conflicts of interest would have to be considered, too. Considered overall, the extent to which we believe targets set by the proposed guidelines cannot be achieved is worrying: setting a large number of targets that will not be achieved devalues the guidelines and runs the risk of the many targets that are achievable and useful simply being ignored.	
Barchester Healthcare	6	Full	General	General	*Question 5: Does the guideline cover all the challenges in caring for this group?* While there is much useful in the guidelines Barchester Healthcare believes they do not cover all the challenges involved in caring for this group. Areas that need further thought are: • A need for funding adequate to allow for the ambitions of the guidelines and for an insistence on sustainable fees for homes is required.	Thank you for your comment. NICE guidance focuses on 'what works'. It is beyond the remit of NICE guidance to make recommendations about funding of care and support. In response to the comment about ensuring the named coordinator is clearly accountable, rec 1.2.1 now references the need for this person to work within local arrangements. The recommendations in section 1.2 on

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					• The roles of named coordinator and lead practitioner/assessor must be made accountable. The guidelines could useful say more on integration, the potential role of care homes in care and reablement and the accountability of commissioners. Commissioners at present have no oversight: commissioning is ill-disciplined as a result, with almost no commissioners commissioning to outcomes, for example, despite repeated exhortations from the Department of Health and many others. Communications difficulties for people living with dementia are inadequately addressed by the guidelines. Barchester Healthcare notes that the guidelines research recommendation are interesting and seem to us pertinent and well chosen, if occasionally likely to be difficult to deliver.	Care Planning have been re-ordered to make clearer when there are recommendations aimed at collaborative working. The aim is for these to support integration. Intermediate care including reablement will be addressed by a separate NICE guideline. Please see: http://www.nice.org.uk/Guidance/InDevelopment/GID-SCWAVE0709 While the primary audience for the guideline are health and social care providers and practitioners, the guideline is also of relevance to commissioners and others and we will consider your comments in respect of these groups as part of the implementation work. We recognise that people with dementia may experience particular communication difficulties. Dementia is referenced specifically as common condition affecting older people with multiple long-term conditions (1.7.2) and this recommendation has been expanded to make clear that practitioners need to 'consider the impact of' such conditions, which would include

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						impact on communication. We have also cross-referenced to the Quality Standard on Mental Wellbeing of Older People in Care Homes, which is relevant to this issue. There is also an update in progress of the NICE Dementia guideline. Thank you for the support for the research recommendations. These are intended to reflect the gaps in evidence and areas the Committee identified as priority, but we recognise they may be aspirational.
Barchester Healthcare	7	Full	General	General	*Question 6: The intention of the guideline for lead practitioner is that all recommendations should be considered in conjunction with the person and taking into account their views. Does the guideline make this clear? Are there ways in which this could be made clearer in the guideline?* Barchester Healthcare believes the guidelines make it admirably clear that all recommendations should be considered in conjunction with the individual concerned. We are particularly struck by the phrase 'control' to describe the position that the supported individual should occupy: we will add it to our list of rights for the individuals we support.	Thank you for your comment and your support for the guideline.

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					Barchester Healthcare thanks NICE for the opportunity to respond to the consultation on older people with complex care needs and multiple long-term conditions.	
British Specialist Nutrition Association	1	Full	17	424-427	Any recommendations on ensuring all persons have a nutritious diet should focus on managing malnourished patients or patients at risk of malnutrition. Guidance should reflect current evidence and should provide clear and practical advice about how and when to use different forms of nutritional intervention. Malnutrition can have significant consequences including a particularly high adverse impact in the older person18 impairing independence.19 Malnutrition is also associated with poorer quality of life and increased mortality.20 Malnourished hospital patients experience significantly higher complication rates than well-	Thank you for your comment. We have reworded recommendation 1.5.13 to make clear that provision of food and drink should 'address particular nutritional and hydration requirements'.

[18] Stratton RJ, King CL, Stroud MA, Jackson AA, Elia M. Malnutrition Universal Screening Tool predicts mortality and length of hospital stay in acutely ill elderly. *Br J Nutr* 2006; 95(2):325-330

[19] Elia M, Russell C. Combating Malnutrition: Recommendations for action. Report from the Advisory Group on Malnutrition, Led by BAPEN. 2009. Redditch, BAPEN. Ref Type: Report

[20] Stratton RJ, Green CJ, Elia M. Disease related malnutrition: an evidence based approach to treatment. Wallingford: CABI Publishing; 2003

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					nourished patients; for example, the risk of infection is more than three times greater in hospitalised malnourished patients.21;22 The average length of hospital stay may also be increased by 30% in and in the community malnourished patients visit family doctors more often and have more frequent hospital admissions than well-nourished patients.23;24	
British Specialist Nutrition Association	2	Full	21	541-542	The British Specialist Nutrition Association (BSNA) suggests ensuring this recommendation has taken the Department of Health's Care and Support Statutory Guidance Issued under the Care Act 2014 into account, whereby 6.133 (2)(b)(iv) under the Carers' eligibility decision process states "managing and maintaining nutrition".	Thank you for your comment. NICE guidance is intended to complement existing guidance. It is helpful to have this reference as we consider our implementation work.
British	1	Full	General	General	Thank you for asking the British Thoracic	Thank you for your comment.

[21] Sorensen J, Kondrup J, Prokopowicz J, Schiesser M, Krahenbuhl L, Meier R et al. EuroOOPS: an international, multicentre study to implement nutritional risk screening and evaluate clinical outcome. Clin Nutr 2008; 27(3):340-349
[22] Schneider SM, Veyres P, Pivot X, Soummer AM, Jambou P, Filippi J et al. Malnutrition is an independent factor associated with nosocomial infections. Br J Nutr 2004; 92(1):105-111
[23] Elia M, Stratton RJ, Russell C, Green CJ, Pang F. The cost of disease-related malnutrition in the UK and economic considerations for the use of oral nutritional supplements (ONS) in adults. 2005. Redditch, BAPEN. Ref Type: Report
[24] Guest JF, Panca M, Baeyens JP, De MF, Ljungqvist O, Pichard C et al. Health economic impact of managing patients following a community-based diagnosis of malnutrition in the UK. *Clin Nutr* 2011; 30(4):422-429

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Thoracic Society					Society to comment on this NICE guideline. The Society welcomes guidance in this area, but was were disappointed to note that no physician, either respiratory or care of the elderly, was on the Guideline Development Group. While the Society recognises that the focus of this consultation/guideline is around aspects of social care, the medical aspects cannot be excluded, and we feel the document is perhaps weaker because of the absence of physician, nursing, physiotherapy and other clinical involvement.	The Guideline Committee included representation from a pharmacist and an occupational therapist. In order to keep the GC to a manageable size we were unfortunately not able to have representatives from all disciplines present. The Committee members recognised the importance of providing 'joined-up' care and support for people and a number of the recommendations are focused on collaborative working and involvement of health professionals.
British Thoracic Society	2	Full	General	General	We wish to highlight a major deficiency in the guideline which is the lack of reference to where discussions of end of life take place. Clearly these are important for such patients throughout their journey, and especially when patients are resident in nursing/care homes.	Thank you for your comment which the Guideline Committee discussed at their most recent meeting (July 2015). They agreed end-of-life care is important and this is now referenced in recommendations 1.2.5 and 1.7.2. There is also a NICE guideline on Care of the dying adult in development.
British Thoracic Society	3	Full	General	General	The Society notes that the model of care you highlight is one of multi-morbidity, but it is disappointing that aspects of symptom control are not included. This is an area to consider, for example, the management of	Thank you for your comment. The effectiveness of medical interventions on symptom control was not within the scope of this guideline.

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					an individual who is breathless. This may be both cardiac or respiratory in origin and may also occur in individuals who are terminally ill with cancer. Such a symptom approach, while medical, should be considered.	
British Thoracic Society	4	Full	General	General	The British Thoracic Society has recently undertaken a programme of work on integrated care which looks at patient centred care and a report on this topic will be available in the near future	Thank you for your comment and your support.
Care and Repair England	1	Full	General	General	We are concerned there is very little mention of the role of housing in providing person centred planning for social care for people with long term conditions despite the recognition in the Care Act of the role good housing plays in wellbeing and in view of the comments we made on scoping document. For information we have produced a briefing on making the connections to housing in the Care Act which identifies where housing issues need to be addressed http://careandrepair-england.org.uk/wp-content/uploads/2014/12/Briefing-on-main-housing-references-in-Care-Act-Guidance-Oct-14.pdf	Thank you for your comment. This was discussed again at the most recent meeting of the Guideline Committee. The Committee agreed on the importance of accommodation in terms of health and wellbeing. While it was out of scope to search the housing literature – and it was therefore not possible to make specific recommendations on housing – the recommendations apply to people wherever they live and this is made clear in the Scope. In addition, we have added a reference to 'accommodation' in 1.1.3 to make clear that this is one of the many aspects of people's support needs that should be considered in care planning.

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					Without repeating the issues and evidence we raised in our previous submission we would like to make the following general points about why a consideration of housing is important to providing good social care for people with long term conditions • Many of the chronic health conditions people face are exacerbated by poor and inappropriate housing and can be alleviated by improving and adapting people's homes. • There is an expanding evidence base that considers the value of housing interventions to care and health planning and provision. We recognise that there is more to do in this area but suggest later in our submission that this would be an area for further research. We also identify work we are already doing in this field to improve the evidence base • Whilst we would not expect social care practitioners to deal with	

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					housing issues per se we would argue that housing needs to be considered in any social care assessment and that social care staff need to know about the common housing issues and who to contact locally to ensure that people's housing circumstances are addressed in so far as they impact on a persons' wellbeing. • Unless there is collaboration strategically between health, care and housing the document misses a trick in terms of the planning and commissioning of truly integrated services at an individual level. Housing needs to be integrated with social care and health issues at both the strategic and individual assessment level • It seems a real shame that the guidance has missed an opportunity to highlight what good practice might look like when housing solutions and factors have been considered. This would help to solidify the role of housing and ensure that housing factors are	

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					considered to meet people's needs. • There is an expectation in the Care Act that housing factors are a part of an integrated assessment. This is not followed through at all in the Guidance which is disappointing	
Care and Repair England	1	NICE	General	General	Whilst we agree the areas identified as those that would have the biggest impact we would want the section on 'integration of different care and support options' to include housing and housing organisations as well as those in health and social care. We would also suggest that the section on 'empowering older people and their carers' should focus much more on advice and information and should also reflect the Guidance set out in the Care Act on local council's duties to establish and maintain information and advice – which again includes housing. Older people and their carers will not be empowered until they have access to this. This should include details on how to access both local and national services offering this advice and information – First Stop and Foundations for example which are both mentioned in	Thank you for your comment. The Committee agreed on the importance of accommodation in terms of health and wellbeing. While it was out of scope to search the housing literature – and we therefore cannot make specific recommendations on housing – the recommendations apply to people wherever they live and this is made clear in the Scope. In addition, we have added a reference to 'accommodation' in 1.1.3 to make clear that this is one of the many aspects of people's support needs that should be considered in care planning. The Guideline Committee agreed on the importance of ensuring people have information and advice to enable them to make informed choices, and have restructured the order of the recommendations within the 'Delivering

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					the Care Act guidance and earlier in comment no 7. It is no good empowering older people and their carers without having the services available that they need and want. There is an argument therefore to ensure that the services are developed and integrated so making commissioning of services and support a really important area for implementation. It is suggested that the area on integration the different options (including housing) will be a critical first step.	Care' section, to make these more prominent.
Care and Repair England	2	Full	7	183 - 188	There is recognition that good social care can reduce inappropriate hospital admissions. But there is no similar recognition of the importance of good housing in reducing costs on the health sector. How much more valuable would it be to assess people's housing circumstances alongside their social care needs in this context? As an example the Building Research Establishment has identified, in its recent Briefing The Cost of Poor Housing, that poor housing costs the NHS £1.4 billion. http://www.bre.co.uk/page.jsp?id=3611 A number of reports have also identified	The Committee agreed on the importance of accommodation in terms of health and wellbeing. It was out of scope to search the housing literature for this review and we therefore could not make recommendations about the cost-effectiveness of housing interventions. We have, however, added a reference to 'accommodation' in 1.1.3 to make clear that this is one of the many important aspects of people's support needs that should be considered in care planning.

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					how housing interventions can prevent hospital admissions and help people to leave hospital. The guidance should recognise this	
Care and Repair England	2	NICE	General	General	To support users to overcome challenges we would reiterate the work of First Stop in providing tools and resources to help people to make choices in relation to their housing and care options and related finance. First Stop includes a range of practical resources on its website that would support implementation See http://www.firststopcareadvice.org.uk/resources-partners.aspx There are also a number of learning resources available to deal with specific aspects of implementation Care and Repair England for example has produced a briefing on the Care Act and how housing is connected mentioned earlier in this submission – see http://careandrepair-england.org.uk/wp-content/uploads/2014/12/Briefing-on-main-housing-references-in-Care-Act-Guidance-Oct-14.pdf We have also just developed a set of	Thank you for your comment and for the link to resources which we will consider as part of our implementation work.

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					cameos and a briefing on good practice in the use of adaptations. See https://homeadaptationsconsortium.wordpress.com/good-practice/ Other resources on linking housing and health/care include • The Housing Lin has developed its health Intel resources that aim to help people understand the health and housing landscape • The Kings Fund with the National Housing Federation has developed a Learning network on integrating housing care and health • The NHS Alliance has produced its housing for health resource for GPs	
Care and Repair England	3	Full	11	259	This section does not consider the assessment of housing circumstances yet the Care Act refers to an integrated assessment including housing – see Chapter 6 of the Care Act Guidance	The Committee agreed on the importance of accommodation in terms of health and wellbeing. It was out of scope to search the housing literature for this review and we therefore could not make recommendations about the cost-effectiveness of housing interventions. We have, however, added a reference to 'accommodation' in 1.1.3 to make clear that

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						this is one of the many important aspects of people's support needs that should be considered in care planning.
Care and Repair England	4	Full	12	291 – 296	This draws out telecare as a specific area to address yet there is no reference to housing factors such as adaptations (Disabled Facilities Grants), community equipment and integrated information and advice on housing, care and related finance. These areas are all identified in Care Act Guidance and should be covered in this guidance too	Thank you for your comment. The Committee agreed on the importance of housing in terms of health and wellbeing. While it was out of scope to search the housing literature – and we therefore cannot make specific recommendations on housing – the recommendations apply to people wherever they live and this is made clear in the Scope. In addition, we have added a reference to 'accommodation' in 1.1.3 to make clear that this is one of the many aspects of people's support needs that should be considered in care planning.
Care and Repair England	5	Full	16	399 onwards	This section on integrating health and social care planning makes no reference to housing practitioners alongside those in health and care and in other disciplines. We believe housing practitioners should be added	Thank you for your comment. While it was out of scope to search the housing literature – and therefore cannot make specific recommendations for housing practitioners – the recommendations apply to people wherever they live and this is made clear in the Scope. In addition, we have added a reference to 'accommodation' in 1.1.3 to make clear that this is one of the many aspects of people's support needs

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						that should be considered in care planning. Also, we note that, while health and social care staff are the key audience for the guideline, it will also be relevant to other stakeholders.
Care and Repair England	6	Full	17	420	Whilst there is a section focused on improving social care in care homes - given that most people live in their own homes and in mainstream housing - it would have been helpful to include a section on improving social care for people in their own homes too which includes housing issues such as repairs, adaptations, telecare, equipment, housing advice etc.. and would, again, have drawn close attention to the importance of housing for good social care	Thank you for your comment. We have re-ordered the recommendations on delivering care to make clear that only one element of this relates to care homes – the remainder of the section is relevant to all older people with multiple long-term conditions. The Committee agreed on the importance of housing in terms of health and wellbeing. We did not identify effectiveness literature in respect of housing aids and adaptations for this particularly population. However, we have added a reference to 'accommodation' in 1.1.3 to make clear that this is one of the many aspects of people's support needs that should be considered in care planning.
Care and Repair England	7	Full	21	533	Add after 546 that health and social care practitioners should be able to identify common factors in housing which might exacerbate long term conditions such as	Thank you for your comment. We have added in a reference to addressing accommodation and environment needs as part of 1.1.3 and 1.2.5, recognising that

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					damp and cold homes, factors that might prevent falls in the home, accessibility issues in the home etc... and know where people can obtain help and advice locally on dealing with these issues such as First Stop http://www.firststopcareadvice.org.uk/ housing and care advice services, Home Improvement Agencies http://www.foundations.uk.com/home/ etc...	housing plays an important part in wellbeing. Thank you for the links which we will consider as part of implementation work.
Care and Repair England	8	Full	547	General	Research Recommendations We would add the impact of housing interventions on health and social care. This is important for the reasons set out in our general comments on the guidelines. Care and Repair England has been looking at how to stimulate fresh research in this field bringing together researchers and key stakeholders to work on projects that have practical application. (In a project called Catch 22 http://careandrepair-england.org.uk/?page_id=205) Work developing in this field includes the cost benefits of adaptations, impact and evidence on falls prevention and work on housing decision making. We would be happy to share progress	Thank you for your comment. Housing was not in scope for this guideline and research recommendations can only be made where we have searched the literature and found there to be gaps in evidence. The Guideline Committee agreed, however, that housing is important for wellbeing and, to this end, added a reference to 'accommodation' in 1.1.3 to make clear that this is one of the many aspects of people's support needs that should be considered in care planning.
Care and	9	General	General	General	1. How will you use the	While it was out of scope to search the

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Repair England					recommendations in the guideline? 2. Which recommendations do you think are the most important? And why? 3. In what ways can the recommendations be made more specific to the care of older people with long-term conditions? We would like to see housing given much more consideration in the document which we believe would make the recommendations more specific to the care of older people with long term conditions 4. What should practitioners be doing, or doing better, to care for this population that is not already covered in this guideline? Joining up to see the whole person, listening to what people say and want, ensuring people have advocates and assessing people's housing needs and circumstance 5. Does the guideline cover all the challenges in caring for this group'? It does not touch on the importance of housing 6. The intention of the guideline is that all recommendations should be considered in conjunction with the person and taking into account their views. Does the guideline	housing literature – and therefore cannot make specific recommendations on house – the recommendations apply to people wherever they live and this is made clear in the Scope. In addition, we have added a reference to 'accommodation' in 1.1.3 to make clear that this is one of the many aspects of people's support needs that should be considered in care planning. The Committee members recognised the importance of providing 'joined-up' assessment, care and support for people and a number of the recommendations are focused on collaborative working and involvement of health professionals.

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					make this clear? Are there ways in which this could be made clearer in the guideline? See section 3.9 of Developing NICE guidance: how to get involved for suggestions of general points to think about when commenting.	
Care Inspectorate	1.	Full	General	General	The Care Inspectorate health improvement team access and use NICE guidance on medicines, treatments and devices to establish current good practice and we also share this guidance and evidence internally and externally. In our opinion, this draft guidance also ties in with the recent NHS CEL letter about NHS continuing care and more individuals with complex needs who, in the future will require continuing care and will receive this in the social care sector supported by NHS colleagues.	Thank you for your comment and your support for the guidance. We will consider how this links to other guidance as part of implementation.
Care Inspectorate	2.	Full	General	General	Although the guidance references English sources, mainly the Care Act 2014 – in our opinion most of the information could be easily applied under Scottish legislation and practice.	Thank you for your comment and the suggestion that the recommendations may have applicability more widely than England. NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in

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						the Welsh Government, Scottish Government, and Northern Ireland Executive.
Care Inspectorate	3.	Full	General	General	We are pleased to see the inclusion of continence promotion although in our opinion the guidance does not go into the practicalities around this and we suggest that this subject could be a section on its own.	Thank you for your comment. The Guideline Committee agreed that continence promotion is an important issue for older people with multiple long-term conditions. This guideline focuses on the importance of recognising continence as a symptom and promoting dignity. There is already NICE clinical guidance which provides more specific recommendations on the practicalities of continence management: - Urinary Incontinence: https://www.nice.org.uk/guidance/cg171 - Faecal incontinence https://www.nice.org.uk/guidance/cg49
Care Inspectorate	4.	Full	General	General	When identifying and assessing social care needs, we suggest that this should list the areas to be assessed and include (as they appear in the document) emotional and psychological needs, sensory, communication, general health needs, continence, social activities, mobility,	Thank you for your comment. This was discussed at Guideline Committee meeting 12 (July 2015). It was agreed that it would not be appropriate to include an assessment checklist as this would not be aligned with the person-centred focus of the Care Act, nor did we review any

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					medicines, self care, budgeting/financial management hydration and nutrition, crises support(s), anticipatory care, and end of life care.	evidence on effectiveness of structured tools in assessment.
Care Inspectorate	5.	Full	General	General	Environment should have its own section as it will play a big part in how well people are able to be cared for at home, and should include IT and tele-healthcare. Environment will dictate a lot in relation to care at home, including the health and safety of workers and carers.	Thank you for your comment. Recognising its importance, we have added a reference to 'environment' within recommendation 1.1.3. The importance of environment is also referenced in a number of recommendations within section 1.5 on Care in Care Homes.
Care Inspectorate	6.	Full	General	General	Funding should be a section on its own, along with finances and personal budgets.	NICE guidance focuses on 'what works'. It is beyond the remit of NICE guidance to make recommendations about funding of care and support.
Care Inspectorate	7.	Full	General	General	Prevention and control of infection needs to be addressed where carers and care staff may be dealing with body fluids, dressings, incontinence aids, etc. We would also suggest that consideration be applied to the situation if a person develops an infection such as Noro virus.	Thank you for your comment. It was not within the remit of this guideline to develop recommendations on good practice in prevention and control of infection. There is already, however, a range of published NICE guidance on this topic including on: - Infection https://www.nice.org.uk/guidance/cg139 - Prevention and control of healthcare associated infections https://www.nice.org.uk/guidance/

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						ph36
Care Inspectorate	8.	Full	General	General	Relating to the subject of capacity and right to treat/intervene, we note that there is no reference to capacity in the recommendations (pages 11-21). In our opinion, this needs to be explicit in the initial and on-going assessments.	Thank you for your comment. We discussed this at Guideline Committee meeting 12 (July 2015) and have included this within the introductory text.
Care Inspectorate	9.	Full	General	General	We suggest that there should be a section on medicines management.	Thank you for your comment. The recommendations on medicines management relate specifically to the need for health and social care practitioners to communicate effectively. There is already NICE guidance on: - Medicines adherence http://www.nice.org.uk/guidance/cg76 - Managing medicines in care homes http://www.nice.org.uk/guidance/sc1 - Medicines optimisation http://www.nice.org.uk/guidance/ng5 NICE is also developing a guideline on Managing medicines for people receiving social care in the community. http://www.nice.org.uk/guidance/indevelopment/gid-

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						managingmedicinescommunitysocialcare
Care Inspectorate	10.	Full	General	General	We suggest that there should be a section on specialist equipment, regarding assessment for, obtaining, training in use, care and return. Please note that if required for reference, Scotland has developed a framework for accessing equipment.	Thank you for your comment. We recognise the importance of equipment to support people living with multiple long-term conditions. Equipment was not specifically in scope and therefore we did not search for evidence in this area. .
Care Inspectorate	11.	Full	General	General	We suggest that there should be a section on contracts.	Thank you for your comment. Contracting is out of scope for NICE guidance.
Care Inspectorate	12.	Full	General	General	We note that younger adults have not been included in this draft- we note that the scoping exercise speaks of increasing discrimination for older people and therefor we would question why younger adults were not also included. However, it also is ignoring the need to plan for the future of the younger adults who have to live with a life limiting condition. We think there is a gap / missed opportunity in this guideline.	Thank you for your comment. This issue was discussed extensively as part of scoping work. Further information can be found in the Equality Impact Assessment https://www.nice.org.uk/guidance/GID-SCWAVE0715/documents/social-care-of-older-people-with-complex-care-needs-and-multiple-longterm-conditions-equality-impact-assessment2
Care Inspectorate	13.	Full	General	General	We are concerned that younger adults have not been included in this draft- the scoping exercise speaks of more discrimination for older people hence why not included? However, it also is ignoring the need to plan for the future of the younger adults who have to live with a life limiting condition. We think there is a gap / missed opportunity in this guideline.	Thank you for your comment. This issue was discussed extensively as part of scoping work. Further information can be found in the Equality Impact Assessment https://www.nice.org.uk/guidance/GID-SCWAVE0715/documents/social-care-of-older-people-with-complex-care-needs-and-multiple-longterm-conditions-equality-impact-assessment2

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Care Inspectorate	14.	Full	8	General	We suggest amending the reference to 'self funders' to read 'individuals who self fund their care'.	Thank you for your comment. This has been edited throughout to 'people who pay for their own care'.
Care Inspectorate	15.	Full	11	272	The assessment involves a person, so we suggest that consideration is given to their 'consent' to the initial assessment, and consent to the sharing of information.	Thank you for your comment. The issue of consent was discussed at Guideline Committee meeting 12 (July 2015) and this has been referenced in the introduction.
Care Inspectorate	16.	Full	13	334	With the person's agreement, their carers or advocate can be involved in the planning process. In our opinion, the word 'consent' may make this more meaningful.	Thank you for your comment. The issue of consent was discussed at Guideline Committee meeting 12 (July 2015) and this has been referenced in the introduction.
Care Inspectorate	17.	Full	13	General	We note that there is mention of the need to "Develop care plans in collaboration with GPs and representatives from other agencies that will be providing support to the person in the care planning process". In our opinion, this is very important as it represents a positive approach. If this could be developed it would encourage more multi-disciplinary working - which may also encourage more 'anticipatory care plans' to be developed. We note that anticipatory care planning is not mentioned in this guideline and would suggest that this could be included.	Thank you for your comment and your support. We did not identify any effectiveness evidence on anticipatory care planning and therefore did not make recommendations on this.
Care	18.	Full	17	424	In our opinion, it should be noted that as	Thank you for your comment. We have

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Inspectorate					well as the care home having a choice of foods, it is key that people are asked about their likes and dislikes. This could be added to the standard recommendation and may encourage more outcomes focused planning for people in the community and care homes.	included a reference to 'choice' in recommendation 1.5.14 and person-centred care, and respecting preference, underpins all the recommendations.
Care Inspectorate	19.	Full	21		The training of health and social care practitioners is an important area and we note that this is identified by the literature in the guideline by the National Collaboration for Integrated Care and Support (2013) on page 7, where it is recognised that there is a lack of training (and support) for social care staff.	Thank you for your comment.
Care Inspectorate	20.	Full	21	535	In our opinion, staff should have the necessary training and be competent in medicines management and there should also be a monitoring role for the care staff around medicines and being able to evaluate their effectiveness in the care plan.	Thank you for your comment and your support.
Care Inspectorate	21.	Full	21	541	This section in the guideline mentions the need to "Ensure health and social care practitioners are able to recognise – ''common conditions and care needs'' such as nutrition, hydration and skin integrity. It would be important to also refer to a preventative approach ie assessing and	Thank you for your comment. The importance of prevention is highlighted in the context but there was an absence of effectiveness evidence on preventative approaches. There is a research recommendation in this area.

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					identifying risk as part of care planning.	
Care Inspectorate	22.	Full	21	543	In our opinion, there is a need not only to identify and recognise a person's end of life care needs but also their earlier palliative care needs. Once recognised it is important that staff then know how to support a person's palliative and end of life care needs, including bereavement care to be more specific. We note that there is no mention of assessing a person's palliative and end of life care needs in this guideline. As the people referred to are getting older and have multiple co morbidities, the likelihood of people requiring palliative and end of life care increases. As mentioned earlier it is very important that social care staff have the knowledge and skills to address these needs and therefore this could be further highlighted in this guideline.	Thank you for your comment. We have added a reference to addressing palliative needs within recommendation 1.2.5.
Department of Health	1	General	General	General	I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.	Thank you for your comment.
Grünenthal Ltd	1	Full	13	327	We fully endorse the inclusion of information on medicines, and particularly the implications of non-adherence, into care plans (recommendation 1.2.4). Fully acknowledging the need for collaboration	Thank you for your comment and your support.

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					with GPs and other healthcare professionals in care planning (recommendation 1.2.5)	
Grünenthal Ltd	2	Full	18	461 - 470	We similarly endorse the recommendations for health and social care practitioners to follow up any issues related to medicines management, including changes to medicines (recommendation 1.5.10) and any concerns about prescribed medicines such as side effects or reluctance to take medicines (recommendations 1.5.11 & 12)	Thank you for your comment and your support.
Grünenthal Ltd	3	Full	21	535 - 538	The requirement for commissioners and providers to ensure health and social care practitioners have the necessary training and are assessed as competent in both medicines management and the ability to recognize common conditions (recommendations 1.7.1& 1.7.2) will be important to deliver the degree of integration between health and social care set out in these guidelines.	Thank you for your comment and your support. Implementation challenges have been identified throughout guidance development through analysis of consultation responses and key project documents (for example meeting minutes) and implementation-specific feedback from Guideline Committee members. Those deemed most critical to address have been included in the short NICE guideline to inform implementation work accompanying publication.
Grünenthal Ltd	4	Full	21	539 - 545	Given its burden, in terms of numbers of sufferers and impact on older people's lives, more should be done to address the under-diagnosis and inadequate treatment of persistent pain. To this end pain should be explicitly included in recommendation	Thank you for your comment. We have updated 1.7.2 to include reference to chronic pain.

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					1.7.2, i.e. 'Ensure health and social care practitioners are able to recognise: • common conditions, such as pain, dementia and sensory loss, and • common care needs, such as nutrition, hydration, pain management and skin integrity, and …' The Long Term Conditions Compendium of Information1 (referred to in the introduction to the guideline) highlights that almost half of all people with a LTC report moderate or extreme pain, rising to 80% of people with three or more conditions. 25-76% of older people living in the community and 83-93% of those living in residential care experience chronic persistent pain that persists for 3 months or more2. This translates to approximately 5.5 million older people suffering from chronic persistent pain in the UK each year, more than the combined number of older people experiencing falls, dementia or stroke3. For each of these millions of older people pain will have a substantial impact on their health, their carers and the health economy:	

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					• Pain is associated with fatigue, sleeping problems, depressed mood, cognitive impairment and is a strong risk factor for falls • Older people identify pain as the most common symptom which causes problems with everyday activities, such as bathing, eating and walking • The presence of pain affects older adults' relationships and intimacy with family As a result, pain has a greater impact on older people's sense of wellbeing than age or number of chronic diseases4. Despite its prevalence and the substantial impact pain has on older people's lives, in the UK, 22% of older people were not offered pain relief when they experienced new onset of pain5 1 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_134487 2 Guidance on the Management of pain in older people. Age and Ageing 2013; 42: i1-	

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					i57 3 Age UK, Later Life in the United Kingdom. February 2015. http://www.ageuk.org.uk/Documents/EN-GB/Factsheets/Later_Life_UK_factsheet.pdf Accessed on the 14th February 2015 4 Leveille S, Fried L, Guralnik J. Disabling symptoms: What do older women report? J Gen Intern Med 2002; 17:766-73 5 Steel N, Bachmann M, Maisey S et al. Self-reported receipt of care consistent with 32 quality indicators: national population survey of adults aged 50 or more in England. BMJ 2008; 337: a957	
Grünenthal Ltd	5	General	General	General	1. How will you use the recommendations in the guideline? To ensure the support we provide for the healthcare of older people with multiple long-term conditions is integrated into their social care. 2. Which recommendations do you think are the most important? And why? The requirement for commissioners and providers to ensure health and social care practitioners have the necessary training and are assessed as competent in both medicines management and the ability to recognize common conditions. The latter	Thank you for your comment and your support for the guideline. A range of NICE clinical guidelines address the effectiveness of specific interventions for persistent pain (http://www.nice.org.uk/guidance/published?type=CG) We have also updated recommendation 1.7.2 to make explicit reference to chronic pain.

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					recommendation should explicitly include the most common condition experienced by older people, which is pain. 3. In what ways can the recommendations be made more specific to the care of older people with long-term conditions? 4. What should practitioners be doing, or doing better, to care for this population that is not already covered in this guideline? Given its burden, in terms of numbers of sufferers and the impact it has on older people's lives, more should be done to address the under-diagnosis and inadequate treatment of persistent pain. 5. Does the guideline cover all the challenges in caring for this group'? The reluctance to recommend a model of care, will lead to variability in the provision of social care in different parts of the country. 6. The intention of the guideline is that all recommendations should be considered in conjunction with the person and taking into account their views. Does the guideline make this clear? Are there ways in which this could be made clearer in the guideline? See section 3.9 of Developing NICE guidance: how to get involved for	

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					suggestions of general points to think about when commenting.	
National Community Hearing Association (NCHA)	1	General	General	General	"Do you agree with the areas that have been identified as having a big impact on practice and challenging to implement? Let us know if you would give priority to other areas and why." We welcome this guideline and specifically its aim to tackle important issues such as social isolation. Research shows that when people with long-term conditions are active partners in their care they have better outcomes, so we also welcome the statement that "older people with multiple long-term conditions and their carers should have choice and control over all aspects of their lives, and support should be person-centred to enable this" (p. 18). Unfortunately, older people might be denied a choice based on assumptions about their preferences – e.g. research has shown people over the age of 80, while valuing choice of hearing care provider, were less likely to be offered a choicei. We therefore agree with NICE that a challenging area for implementation is empowering and valuing practitioners in social care so that	Thank you for your comment. We have separated out the previous reference to 'sensory loss' to read 'hearing and sight loss' to make clear that these are distinct issues and to emphasise the importance of each element.

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					they can deliver person-centred care, because to do so they will have to challenge colleagues – e.g. referring GPs and other teams in the NHS. Overall, we think this is a good guideline, but we would give greater priority to unsupported age-related hearing loss, which is intrinsically linked to social isolation, depression and cognitive decline in older people (evidence below). NHS England, the Department of Health and the World Health Organisation acknowledge age-related hearing loss is a major public health issue that needs to be tackled in order to support the population to age well. Early hearing intervention and ongoing support can improve quality of life by reducing the psychological and social effects associated with age-related hearing loss. Good hearing, or supported hearing loss, is key to good communication. Good communication is paramount in supporting older people with complex care needs and multiple long-term conditions and ensuring individuals have choice and control over their social care – i.e. hearing is at the heart of successful implementation of this guideline.	

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					We feel given the prevalence of hearing loss in older people (>70%) and the impact it has on quality of life, this guideline should make the hearing needs of older people more explicit. This would make the guideline more specific to the needs of older people. We provide detail and evidence below.	
National Community Hearing Association (NCHA)	2	General	General	General	Question 3: "In what ways can the recommendations be made more specific to the care of older people with long-term conditions?" This NICE guideline can be made more specific to the care of older people by acknowledging that social care should consider this group's hearing needs (i.e. rather than including it under the 'sensory needs' typology). This is because • age-related hearing loss is a long-term condition - there is no medical or surgical treatmentii • the prevalence of hearing loss increases exponentially with age – e.g. 1.8% of people aged 17 to 30 have a hearing loss compared to 71% of people aged 71 to 80iii • hearing loss is one of the most	Thank you for your comment. We have separated out the previous reference to 'sensory loss' to read 'hearing and sight loss' to make clear that these are distinct issues and to emphasise the importance of each element.

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					common long-term conditions in older people - NB over 8.4 million people in England have a hearing loss (c.90% are aged 55 and over) iv and 3.8 million people in England have unmet hearing needsv • in England, adult hearing loss is the 6th leading cause of years lived with disabilityvi • unsupported age-related hearing loss can create significant barriers to implementing this guideline – e.g. unsupported adult hearing loss increases the risk of depressionvii, social isolationviii, lonelinessix, cognitive declinex, early retirementxi and reduced quality of lifexii - i.e. the very things this guideline aims to tackle. Hearing needs therefore need to be part and parcel of this guideline, and including a hearing needs assessment for this cohort will make the recommendations more specific to older people with long-term conditions.	
National Community	3	General	General	General	Question 4: "What should practitioners be doing, or doing better, to care for this	Thank you for your comment. We have separated out the previous reference to

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Hearing Association (NCHA)					population that is not already covered in this guideline?" Age-related hearing loss in older people is a major public health challenge – NB in March 2015 Sir Bruce Keogh, Medical Director of NHS England acknowledged "the growing problems of hearing loss [have] significant economic, social and personal consequences including unemployment and feelings of isolation, exclusion and even depression"xiii. Yet despite • NICE stating the importance of hearing tests for people living in care homesxiv • NHS England recognising unsupported hearing loss as 1 of 11 risk factors associated with functional decline in older peoplexv and recommending older people to have their hearing tested without delayxvi and • Monitor noting that early intervention can also reduce pressure on health and social servicesxvii 76% of older people in England with a	'sensory loss' to read 'hearing and sight loss' to make clear that these are distinct issues and to emphasise the importance of each element. The issue of communication needs was discussed at the most recent meeting of the Guideline Committee (July 2015). It was agreed that the guideline would reference the NHS England Accessible Information Standard, which it now does. We have also expanded recommendation 1.7.2 to make clear that practitioners need to 'consider the impact of' and 'respond to' a range of common conditions – including hearing and sight loss - rather than simply be able to identify them. This would include referring to other specialists, as appropriate, and the need to ensure links with specialist support is also covered in recommendation 1.7.3.

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					hearing loss still have unmet hearing needsxviii. This unsupported hearing loss can have a significant impact on the effectiveness of the social care older people with complex and long-term conditions receive. For example research has shown • 28% of people with hearing loss were unclear about their diagnosis, 26% had been unclear about health advice they were provided with and 19% had been unclear about their medicationxix. If people with unsupported hearing loss misunderstand advice then they are at greater risks of worse outcomes than people without hearing loss or with supported hearing loss. The current guideline helpfully mentions sensory needs on two occasions, but we feel it needs to go further. Practitioners need to better understand the communication needs of older people and help them access the hearing care and support that they are entitled to – this is not happening as of July 2015. Another challenge to implementation is	

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					that often only sight is checked when assessing sensory needs. This is despite the fact that hearing impairment is more prevalent than sight impairment in older people and has a greater impact on quality of life at a population level – e.g. adult hearing loss, not sight loss, is noted in the top 10 causes of years lived with disability in Englandxx. Unfortunately past NICE guidelines might have encouraged this bias towards sight rather than hearing assessments – e.g. the NICE guideline on hearing and sight tests for people living in care homes only recommends measuring sight tests as an outcomexxi. In our view, more needs to be done to raise awareness about age-related hearing loss. Early hearing intervention and ongoing support can improve quality of life by reducing the psychological and social effects associated with age-related hearing lossxxii. NHS England and the Department of Health (2015) have started this process by publishing their Action Plan on Hearing Lossxxiii and we feel it is important this guideline nudges practitioners to specifically include a hearing needs assessment in older people with multiple	

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					long-term conditions and complex needs.	
National Community Hearing Association (NCHA)	4	General	General	General	Question 5: "Does the guideline cover all the challenges in caring for this group'?" 76% of older people with hearing loss (3.8 million people) are still without the support they would benefit fromxxiv. More could be done to explain the importance of hearing needs and the barriers that unsupported hearing loss might create to caring effectively for this group (see comments 2 and 3).	Thank you for your comment. We have separated out the previous reference to 'sensory loss' to read 'hearing and sight loss' to make clear that these are distinct issues and to emphasise the importance of each element.
National Community Hearing Association (NCHA)	5	General	General	General	Question 6: "The intention of the guideline is that all recommendations should be considered in conjunction with the person and taking into account their views. Does the guideline make this clear? Are there ways in which this could be made clearer in the guideline?" Yes, but a person's right to be treated fairly should be made clearer. Specifically that age is a protected characteristic in the Equality Act 2010 and that people should not be treated differently because of their age. For example we fully support ensuring that people have "choice and control" (1.2.2. p 9) because research shows that co-management of long-term conditions leads	Thank you for your comment. The Guideline Committee discussed equalities issues throughout scoping and development period and, in particular, noted that evidence (and their experience) indicates that people can experience discrimination in resource allocation based on age. All of the recommendations are founded on a need to consider people's needs and preferences as priority, and to maximise choice and control. This is referenced particularly in the introduction, and in recommendation 1.1.3, 1.2.2 and 1.2.5. Further information on specific protected

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					to better outcomes. This is also true in hearing care where older people that are given a choice report that they feel in control of their carexxv. Unfortunately, people might be denied a choice based on their age – e.g. research commissioned by Monitor, the sector regulator, has shown that people over the age of 80 while valuing choice of hearing care provider were less likely to be offered this choicexxvi.	characteristics can be found in the Equality Impact Assessment
National Community Hearing Association (NCHA)	6	NICE	7	1.1.3	(See evidence provided in comments 2-5) Hearing loss is often overlooked and may not be well understood by front-line staff, we recommend clarifying that sensory loss refers to hearing and vision loss.	Thank you for your comment. We have separated out the previous reference to 'sensory loss' to read 'hearing and sight loss' to make clear that these are distinct issues.
National Community Hearing Association (NCHA)	7	NICE	8	1.1.6-7	(See evidence provided in comments 2-5) Undiagnosed and unsupported hearing loss is a common long-term condition in older people. This might act as a barrier to using telecare. People should have the right to choose how they receive their support – NB cost-effectiveness research of telecare interventions is prone to methodological challenges and users that do not want to, or cannot, access support in this way might be less cost-effective to support by means of	Thank you for your comment. The Guideline Committee agreed that choice and control are paramount and these have been referenced throughout the guideline. In particular, the telecare recommendations are included within the section on assessment to emphasise that people need information and advice about their options in this respect early on.

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					telecare than those that opt to use the technology. That said, provided their sight ability is taken into account, telecare services that convert speech to text might support people with hearing loss to access care.	
National Community Hearing Association (NCHA)	8	NICE	9	1.2.2	(See evidence provided in comments 2-4, and comment 5) We support ensuring that people have "choice and control". We recommend adding information on the Equality Act 2010 and reminding readers that age is a protected characteristicxxvii and that older people have the same rights to 'choice and control' as others.	Thank you for your comment. The Guideline Committee discussed equalities issues throughout scoping and development period and, in particular, noted that evidence (and their experience) indicates that people can experience discrimination in choice of resource allocation based on age. All of the recommendations are founded on a need to consider people's needs and preferences as priority, and to maximise choice and control. This is referenced particularly in the introduction, and in recommendation 1.1.3, 1.2.2 and 1.2.5. Further information on specific protected characteristics can be found in the Equality Impact Assessment
National	9	NICE	9	1.2.2	(See evidence provided in comments 2-5)	We have separated out the previous

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Community Hearing Association (NCHA)					Hearing loss is often overlooked and may not be well understood by front line staff, we recommend clarifying that sensory loss refers to hearing and vision loss.	reference to 'sensory loss' to read 'hearing and sight loss' to make clear that these are distinct issues.
National Community Hearing Association (NCHA)	10	NICE	9	1.2.4	Section 1.2.4 notes care plans include medicines management. We feel this should also include information about medical devices – e.g. hearing aids. This is because • hearing aid batteries need replacing once a week on average and it is important that, especially in care homes where 80% of the population has a hearing loss, this is done – otherwise people are less likely to understand instructions about medicine. Example: o a patient survey in England found that 26% people with hearing loss were unclear about health advice they were provided with and 19% had been unclear about their medicationxxviii • NHS England and the Department	Thank you for your comment. Specific interventions were not within scope for this guideline, however 1.2.5 does now make reference to the importance of considering sight, hearing and communication needs.

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					of Health note "that by 2032, there will be around 620,000 older people living in care homes in England and of these, almost 500,000 will have a hearing loss and will need support to maximise their independence and wellbeing. People with unmanaged hearing loss and either dementia or mental health problems are more likely to go straight to expensive care packages, such as a care home, than would be the case if their hearing loss were effectively managed. Overall, the personal, societal and economic costs of hearing loss will continue to rise as the incidence and prevalence of hearing loss increases with an ageing population"xxix	
National Community Hearing Association (NCHA)	11	NICE	10	1.2.7	We think that a bullet point should be added to this section to clarify that personal budgets need not be spent where other entitlements apply, such as eye tests and hearing correction under NHS. A further bullet point might read 'ensuring that people are aware of and have access to any NHS and social services to which they are also entitled.'	This recommendation has been edited following Guideline Committee 12 and the most recent editorial review.

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National Community Hearing Association (NCHA)	12	NICE	10	1.2.9	(Please see comment 10, and evidence provided comments 2-5) We feel that the list should include "using medical devices –e.g. hearing aids".	Thank you for your comment. Effectiveness of medical devices was not in scope for this guideline.
National Community Hearing Association (NCHA)	13	NICE	12	1.4.2	(See evidence provided in comments 2- 5) One reason that hearing loss is underdiagnosed and remains a public health challenge is that hearing tests, unlike sight tests, are not normalised. We therefore recommend adding "community audiologist (hearing aid dispensers)" to this list.	Thank you for your comment. We did not look for effectiveness evidence on condition-specific medical interventions and therefore did not find evidence on community audiologists as part of our reviews. We recognise, however, the importance of hearing loss and this is now referenced explicitly in the guideline.
National Community Hearing Association (NCHA)	14	NICE	13	1.5.4	(See evidence provided in comments 2- 5) We support • encouraging social contact • reducing background noise • using hearing loops These are all important to support the older people stay healthy and mitigate the risk of social isolation and functional decline. Unfortunately, people do not always benefit	We have also expanded recommendation 1.7.2 to make clear that practitioners need to 'consider the impact of' and 'respond to' a range of common conditions – including hearing and sight loss - rather than simply be able to identify them. This would include referring to other specialists, as appropriate, and the need to ensure links with specialist support is also covered in recommendation 1.7.3.

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					from hearing loops because • carers and/or users are not aware how to make the best use of them (e.g. some hearing aids have to be 'activated' to benefit from the loop, this might include flicking a switch on the hearing aid itself) • not all hearing aids are compatible with loops (but in such cases people can be refitted with NHS hearing aids that are) • hearing loops – if used incorrectly – might result in confusion, e.g. Age UK notes the risk that "in some situations i.e. nursing homes, where several rooms have loops installed, other digital hearing aid users can listen in to their neighbours' rooms"xxx. This is why care teams should consult experts in hearing care for advice and support. This is readily available in areas where the NHS commissions community-based adult hearing care (often for lower costs and to higher standards than in areas without choicexxxi, an example of how heatlh and social care can support older people with	

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					long-term and complex conditions in a cost-effective way). We appreciate that this guideline can only give an overview of care in care homes, but given over 80% of this population is likely to have a hearing loss, we recommend a specific section on ensuring older people in care homes have their hearing assessed (this would also be consistent with the NICE guideline for the mental wellbeing of people in care homesxxxii).	
National Community Hearing Association (NCHA)	15	NICE	14	1.5.10	(As per comment 10) Include "medical devices – e.g. hearing aids".	Thank you for your comment. Effectiveness of medical devices was not in scope for this guideline. The importance of accessibility was discussed at Guideline Committee meeting 12 (July 2015). It was agreed that the guideline would reference the NHS England Accessible Information Standard, which it now does.
National Community Hearing Association (NCHA)	16	NICE	15	1.5.14	Stylistic: Change to "Health and social care providers should give information and advice about continence to older people. Make a range of continence products available, paying full attention to people's rights to dignity and respect".	Recommendations have been reviewed at Guideline Committee 12 and subsequently by NICE Editors.

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National Community Hearing Association (NCHA)	17	NICE	15	1.5.19	We are aware of numerous instances in which people's essential functional aids, such as hearing aids and spectacles, are left behind in the event of a health emergency or other crisis. We therefore recommend including a statement to mitigate the risk of this occurring in the future, we propose introducing the wording: "that older people or their carers take essential functional aids, like spectacles and hearing aids, with them in the event of a crisis as the loss of these aids may have an adverse effect on people's ability to communicate with care givers and vice versa". Given NHS England has now published its communication standard (3 July 2015) we feel that statements like this should become common in NICE guidelines.	Thank you for your comment. We have expanded recommendation 1.7.2 to make clear that practitioners need to 'consider the impact of' and 'respond to' a range of common conditions – including hearing and sight loss - rather than simply be able to identify them. This would include responding appropriately in the event of the person needing to move from place to place or in a crisis.
National Community Hearing Association (NCHA)	18	NICE	17	1.7.1	(As per comment 10) Change to "Medicines and medical devices".	Thank you for your comment. Medical devices were not within scope for this guideline, however 1.2.5 does now make reference to the importance of considering sight, hearing and communication needs.
National Community Hearing Association (NCHA)	19	NICE	18	2	Older people with complex care needs require specialised and joined-up care. The number and range of interventions is not easy to memorise and there are risks of both error and omission. To ensure	Thank you for your comment. This was discussed at Guideline Committee meeting 12 (July 2015). It was agreed that it would not be appropriate to include an assessment checklist as this would not be

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					continuous quality improvement, we would recommend the use of a checklist to support people deliver whole person care. We would like to see 'hearing and sight care needs assessed' as separate tick items on the checklist under the heading "sensory needs assessment" for all people in care homes and those at risk of cognitive decline and/or social isolation.	aligned with the person-centred focus of the Care Act, nor did we review any evidence on effectiveness of structured tools in assessment.
National Osteoporosis Society	1	NICE	17	general	In the section on "Training health and social care practitioners", 1.7.2, we would like to see included reference to falls and fractures risk. Falls and fractures have an enormous impact on a growing frail and elderly population and can take place at home or in a care setting. Health and social care practitioners need to be able to identify those potentially at high risk of falls and fractures and refer them where appropriate for, say, a bone health or falls assessment.	Thank you for your comment. We have now included a reference to falls in recommendation 1.7.2.
National Osteoporosis Society	2	Full	161	general	Related NICE guidance should include reference to the NICE Quality Standard for Falls (QS86) and NICE Clinical Guideline, Osteoporosis: Assessing the Risk of Fragility Fracture (CG146)	Thank you for your comment. This has now been included.
National Osteoporosis	3	Full	3, 8,	65-68 205-208	The draft guidelines makes significant reference to the Long term conditions	Thank you for your comment. The Long-term Conditions Compendium is published

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Society			155	2882-2883	compendium of information third edition. We note with concern that osteoporosis is not mentioned as a long terms condition at any point in the Compendium and fear that this omission (particularly from the table of other long term condition in the QOF on page 5) may hamper the implementation of these guidelines. We recommend that the Compendium is updated so that osteoporosis is clearly recognised alongside other long-term conditions to ensure that the care of older people living with osteoporosis are considered in light of these guidelines.	by the Department of Health, not NICE or the NCCSC. Within the Scope for this guideline (linked below) we have used the Royal College of Physicians 2011 definition of long-term conditions. We did not list all possible conditions which may fall underneath this umbrella term. http://www.nice.org.uk/guidance/GID-SCWAVE0715/documents/social-care-of-older-people-with-multiple-longterm-conditions-final-scope3 The specific conditions referenced in the final guideline – for example, in recommendation 1.7.2 - are examples only and the Guideline Committee recognise the older people who are the target population of this guideline may experience many other conditions.
National Osteoporosis Society	4	General	General	General	Please read the checklist for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly. 1. How will you use the recommendations in the guideline?	Thank you for your comment and your support for the guideline. Case studies are not normally included within NICE guidelines however the Guideline Committee agreed these may be useful and should be considered as part of

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					The National Osteoporosis Society will refer health and social care professionals to the guideline as and when appropriate. 2. Which recommendations do you think are the most important? And why? All of the recommendations are important and in particular "Integrating health and social care planning" and "Training health and social care practitioners." 3. In what ways can the recommendations be made more specific to the care of older people with long-term conditions? It might be helpful to illustrate the recommendations with case studies of some of the more common long-term conditions and associated complications. 4. What should practitioners be doing, or doing better, to care for this population that is not already covered in this guideline? 4. Does the guideline cover all the challenges in caring for this group'? Yes, it covers them in general. 6. The intention of the guideline is that all	implementation work.

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					recommendations should be considered in conjunction with the person and taking into account their views. Does the guideline make this clear? Are there ways in which this could be made clearer in the guideline? No	
NHS England: Patient Safety Domain, Nursing Directorate.	1	Full	General	General	We would ask that NICE considers the inclusion of osteoporosis in this guideline as a long term condition. We note that osteoporosis was not listed in the original scope however we would suggest that as a condition it fits well within in the definitions. Osteoporosis affects 1in 3 women and 1 in 5 men, risk increases with age and the risk of occurrence and morbidity associated with fracture increases. Studies have demonstrated that only 25% of women age 75 and over with fragility fracture had evidence of treatment for osteoporosis. Existent NICE guidance and HTA's identify that this condition remains under-recognised and undertreated indicating a significant health inequality gap. https://www.nice.org.uk/Guidance/CG146 Hippisley-Cox J, Bayly J, Potter J et al. Evaluation of standards of care for	Thank you for your comment. Within the Scope for this guideline (linked below) we have used the Royal College of Physicians 2011 definition of long-term conditions. We did not list all possible conditions which may fall underneath this umbrella term. http://www.nice.org.uk/guidance/GID-SCWAVE0715/documents/social-care-of-older-people-with-multiple-longterm-conditions-final-scope3 The specific conditions referenced in the final guideline – for example, in recommendation 1.7.2 - are examples only and the Guideline Committee recognise the older people who are the target population of this guideline may experience many other conditions. The treatment and management of specific conditions e.g. Osteoporosis are covered in clinical guidelines. NICE have also produced

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					osteoporosis and falls in primary care. 2007. QRESEARCH and NHS: The Information Centre for health and social care	a guideline on multimorbidity.
NHS England: Patient Safety Domain, Nursing Directorate.	2	Full	General	General	We would ask NICE to consider linking this guideline with both the falls CG 161 and QS 86. Falls are a known artefact of many Long Term Conditions and there is significant evidence via national audit to demonstrate considerable variance in treatments and services offered to affected persons. The linking of current NICE guidance would demonstrate commitment to appropriate and person- centric assessments encouraging equal and appropriate access to falls prevention assessments and interventions. http://www.nice.org.uk/Guidance/cg161 http://www.nice.org.uk/Guidance/QS86 https://www.rcplondon.ac.uk/resources/national-audit-falls-and-bone-health-older-people	Thank you for your comment. We have responded to this by included a reference to falls within recommendation 1.7.2, recognising, as you highlight, that this is common care need of older people with multiple long-term conditions.
NHS England: Patient Safety Domain,	3	Full	17	1.7.2	We would ask that NICE consider the inclusion of the recognition of risks of falls and the associated risks of poor bone heath	Thank you for your comment. We have now included a reference to falls in recommendation 1.7.2.

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Nursing Directorate.					in this section directed at health and social care practitioners.	
Optical Confederation and College of Optometrists	1	NICE	general	general	The importance of communication and awareness of sensory impairment is helpfully noted throughout this guidance. Communication is largely dependent on sensory functioning – at a minimum through either vision or hearing, though ideally through both – and as such we particularly welcome this guideline's inclusion of sensory loss and impairment as a key feature of supporting older people with multiple long-term conditions. The consideration given to emotional and psychological support in the document could be strengthened. People with multiple, complex and degenerative health conditions, such as impending sight loss, will inevitably have high emotional support needs.	Thank you for your comment and your support for the guideline. The Guideline Committee agreed on the importance of emotional and psychological support and this is referenced explicitly in recommendations 1.1.3 and 1.2.5, and as well as indirectly in 1.2.12 (in relation to building confidence).
Optical Confederation and College of Optometrists	1	NICE	General	General	We fully agree with this identification of the most important and challenging areas of the draft guideline for implementation.	Thank you for your comment and your support.
Optical Confederation and College of Optometrists	2	NICE	General	General	With regard to empowering older people and carers to choose and manage their own support, we suggest consideration be given to the increased risk of social isolation and	Thank you for your comment, which will be considered as part of our implementation work.

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					additional barriers to community participation experienced by people with sensory loss, particularly those who are registered as blind or partially sighted. As a result, people with sensory impairment may be less confident than their peers to try new activities or travel outside the home. For example, sight loss has major adverse impacts on mental health and wellbeing with over one-third of older people with sight loss suffering from depression, which puts them at greater risk of social isolation. People with sight loss are also at a substantially increased risk of falls and hip fractures; between 40 and 50 per cent of older people with sight loss fear falling to the extent that they reduce their own levels of activity.	The Guideline Committee discussed and recognised the barriers faced by people with different kinds of sensory loss which is why hearing and sight loss are now referenced explicitly in the guideline, following discussion on this topic at Guideline Committee 12.
Optical Confederation and College of Optometrists	2	NICE	7	1.1.3	As sight loss is often overlooked and may not be well understood by front line staff, we recommend clarifying in plain language that sensory loss refers to vision and hearing when this term is first used in the text.	Thank you for your comment. We have separated out the previous reference to 'sensory loss' to read 'hearing and sight loss' to make clear that these are distinct issues.
Optical Confederation and College of Optometrists	3	NICE	General	General	With regard to empowering and valuing practitioners so they can deliver person-centred care, we recognise that many front line health and social care staff will need	Thank you for your comment, which will be considered as part of our implementation work.

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					extra support and training to recognise sensory loss, and that this will need to be carried out in layman's language.	
Optical Confederation and College of Optometrists	3	NICE	8	1.1.6-7	In recognition of the mounting evidence that telecare is not a universal panacea – and indeed is often prescribed without full understanding of a person's desire and ability to utilise the technology and therefore not well utilised – we suggest that the guideline make explicit the need to account for the person's level of sensory and other abilities, which may inhibit their befitting from telecare. Undiagnosed hearing or sight loss, common in older people, may act as a barrier to using assistive technologies such as telecare. Older people who have a visual impairment may also have lower than average digital literacy others in their age group, and this should be taken into account when considering suitable telecare equipment. A further issue is that not all parts of the country or all individual homes have access to good broadband and telephone lines.	Thank you for your comment. While it was not within the scope of this guideline to search for and review the effectiveness evidence on specific telecare interventions for older people with multiple long-term conditions, the Guideline Committee highlighted a number of examples of how telecare can be used to support people to live independently. On this basis, they agreed that the recommendations should include a reference to telecare, specifically focused on ensuring people have sufficient information to be able to consider their options and make decisions accordingly. While there was no effectiveness evidence on specific telecare interventions for older people with multiple long-term conditions, the Guideline Committee highlighted a number of examples of how telecare can be used to support people to live independently. On this basis, they agreed that the recommendations should include a reference to telecare, specifically focused on ensuring people have sufficient

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						information to be able to consider their options and make decisions accordingly. They also considered how best to support people to access telecare. The recommendation makes reference to potential benefits, risks and costs (which may include barriers to use).
Optical Confederation and College of Optometrists	4	NICE	8-9	1.2	Training in the use of medical devices and assistive equipment, such as low vision aids, should also be included in this section, as part of information to be included in the care plan.	Thank you for your comment. The effectiveness of specific interventions was out of scope for this guideline.
Optical Confederation and College of Optometrists	5	NICE	9	1.2.2	We note that this guideline does not explicitly remind health and social care practitioners of good practice around providing people with a copy of their care plan for their reference. Because adherence to this good practice can be quite variable on the front line, we would suggest adding a bullet point to this section to that effect and further reminding care coordinators that they may need to provide the copy of the care plan in an accessible format.	Thank you for your comment. This has now been included in recommendation 1.2.3.
Optical Confederation and College of Optometrists	6	NICE	9	1.2.4	We have some concern that ophthalmic prescriptions, which may not be issued by a pharmacist but must nonetheless be taken regularly to avoid serious complications (e.g. glaucoma drops), may be overlooked	Thank you for your comment. We have expanded recommendation 1.7.2 to make clear that practitioners need to 'consider the impact of' and 'respond to' a range of common conditions – including hearing and

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					in standard medicines management. We therefore recommend that this be highlighted in the guideline for the benefit of front line staff who are less familiar with supporting people with sensory loss.	sight loss - rather than simply be able to identify them. This would include providing (or ensuring the provision of) specialist medical support (which is also covered in recommendation 1.7.3). The recommendations on medicines management relate specifically to the need for health and social care practitioners to communicate effectively. There is already NICE guidance on the following topics which provide greater specificity on the practicalities of medicines management: - Medicines adherence http://www.nice.org.uk/guidance/cg76 - Managing medicines in care homes http://www.nice.org.uk/guidance/sc1 - Medicines optimisation http://www.nice.org.uk/guidance/ng5
Optical Confederation and College of Optometrists	7	NICE	10	1.2.7	We would suggest adding a bullet point to this section to clarify that personal budgets need not be spent where other entitlements apply, such as eye tests under GOS. A further bullet point might read 'ensuring that people are aware of and have access to any NHS and social services to	Thank you for your comment. We have now included a bullet within recommendation 1.2.10 noting that people should be offered information about benefits entitlement (which potentially would cover a wide range of financial support).

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					which they are also entitled.'	
Optical Confederation and College of Optometrists	8	NICE	12	1.4.2	Given the significant number of older people who are at risk of visual impairment – 1 in 5 of those aged 75 and older and 1 in 2 of those over 90 – we suggest that community optometrists, dispensing opticians and low vision specialists be included in the list of health and social care practitioners who might be involved in a multidisciplinary support team.	Thank you for your comment. The example practitioners listed were those suggested and agreed by Guideline Committee members. They recognised, however, that this is illustrative rather than comprehensive and that a large number of conditions will require support from specialist practitioners who may also be part of this team.
Optical Confederation and College of Optometrists	9	NICE	13	1.5.4 – sub point 1	Consideration of provision for suitable lighting should be strengthened here. This is a very important issue for people who are often bed-bound. A minor point but lighting cannot be accessible, we would suggest rephrasing to 'accessible signage and good lighting.'	Thank you for your comment. We agree this is important and the wording of the recommendation 'acceessible signage and lighting' was intended to reflect the need for both to be appropriate.
Optical Confederation and College of Optometrists	10	NICE	15	1.5.14	There seems to be a word missing in this sentence – we suggest rephrasing to 'paying full attention to people's rights to dignity and respect.'	Thank you for your comment. This has been reworded following review at Guideline Committee 12 and subsequently by NICE Editors.
Optical Confederation and College of Optometrists	11	NICE	15	1.5.19	We are aware of numerous instances in which people's essential functional aids, such as spectacles and hearing aids, are left behind in the event of a health emergency or other crisis. We therefore suggest including a prompt to this effect as the 3rd sub point in this section. We propose:	Thank you for your comment. We have expanded recommendation 1.7.2 to make clear that practitioners need to 'consider the impact of' and 'respond to' a range of common conditions – including hearing and sight loss - rather than simply be able to identify them. This would include

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					'double checking that older people or their carers take essential functional aids, like spectacles and hearing aids, with them in the event of a crisis as the loss of these aids may have an adverse effect on people's ability to communicate'	responding appropriately in the event of the person needing to move from place to place or in a crisis.
Optical Confederation and College of Optometrists	12	General	General	General	1. How will you use the recommendations in the guideline? We believe they will be useful for all those engaged in care planning with older people with complex care needs and multiple long-term conditions. 2. Which recommendations do you think are the most important? And why? We particularly value the attention given to sensory impairments and communication throughout this guideline as these factors are often overlooked. 3. In what ways can the recommendations be made more specific to the care of older people with long-term conditions? 4. What should practitioners be doing, or doing better, to care for this population that is not already covered in this guideline? Being aware that sensory impairments – vision and hearing – and essential functional aids are often forgotten in the event of a health emergency or other crisis.	Thank you for your comments and your support for the guideline. The effectiveness of specific interventions for hearing loss were not in scope for this guideline. We have, however, expanded recommendation 1.7.2 to make clear that practitioners need to 'consider the impact of' and 'respond to' a range of common conditions – including hearing and sight loss - rather than simply be able to identify them.

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					5. Does the guideline cover all the challenges in caring for this group'? Yes 6. The intention of the guideline is that all recommendations should be considered in conjunction with the person and taking into account their views. Does the guideline make this clear? Are there ways in which this could be made clearer in the guideline? Yes, the guideline makes this clear	
Parkinson's UK	1	Full	11	88-89	We are disappointed that the guideline only defines 'older people' in contrast to 'younger adults'. It is not clear if 'younger adults' refers to children and teenagers, or adults below retirement age. Some of the recommendations made in the body of the guidance are not of relevance to either of these groups (see comment three). We therefore recommend that NICE explicitly defines the terms 'older' and 'younger people' in this context.	Thank you for your comment. The focus on older adults is explained in the Equality Impact Assessment. http://www.nice.org.uk/guidance/gid-scwave0715/resources/social-care-of-older-people-with-multiple-longterm-conditions-draft-equality-impact-assessment2 We deliberately avoided an age threshold for older adults recognising that this can be defined differently in different studies.
Parkinson's UK	1	NICE	General	General	We agree that the areas identified will be challenging to implement. Requirements to 'empower' people with care needs are commendable, but are difficult to implement consistently.	Thank you for your comment. The issue of capacity was discussed by the Guideline Committee and is now referenced in the introduction.

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					Although we welcome the ambition that people with Parkinson's are empowered to choose and manage their support wherever possible and appropriate, this will not be practical in all circumstances. Practitioners therefore need to recognise that for people with Parkinson's who may have mental capacity issues, it may be preferable for support to be arranged by a loved one, for example.	
Parkinson's UK	2	Full	11	261	We strongly support the recommendation that there should be greater referrals between health and social care to identify and offer needs assessments. However, we are disappointed that the recommendation merely asks health and social care practitioners to 'consider' this. We recommend that the wording is amended so that it reads 'Health and social care practitioners must refer older people with multiple long-term conditions to the local authority for a needs assessment as soon as it is identified that they may need social care and support' The section on recommended wording on page 10 notes that NICE recommendations only employ such a phrase when 'the quality of the evidence is poorer, or where	Thank you for your comment. Within NICE guidance, 'must' denotes a legal obligation and therefore cannot be used in this instance. As you highlight, the use of 'consider' reflects the fact the evidence was weaker. In NICE guidance 'should' recommendations are used where there is strong evidence. While we recognise your point that there is research in this area, our exclusion criteria meant that studies were excluded where they were not explicitly about people with multiple long-term conditions, given the focus of this guideline.

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					there is a closer balance between benefits and risks.' Parkinson's UK would also dispute the notion that timely referrals for social care assessments may reflect an uncertain balance between 'benefit and risk' or lack evidence of positive impact. Research commissioned by Parkinson's UK* found that people with Parkinson's are often unaware of social care and how to access it, until they reach crisis point and require immediate help. A person with Parkinson's explains: "I liken it to a pinball machine that you sort of hit against this or that or, you know, you get your information by happenchance and bumping into people and speaking to people." *McDonnell, A et al (2014), 'Putting people with Parkinson's in control: exploring the impact of quality social care' Sheffield Hallam University Centre for Health and Social Care Research, available at: http://shura.shu.ac.uk/7965/	

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Parkinson's UK	2	NICE	General	General	Parkinson's UK welcomes the goal of empowering and valuing practitioners to deliver person-centred care. We have developed the UK Parkinson's Excellence Network* which aims to equip professionals concerned with Parkinson's to work together, this may provide a useful resource for further professional collaboration. *http://www.parkinsons.org.uk/professionals	Thank you for your comment and your support for the guideline. Thank you for signposting to the resource which we can consider as part of implementation work.
Parkinson's UK	3	Full	11	265-66	Parkinson's UK would caution against automatically referring all 'older people' to a geriatrician or old-age psychiatrist in the first instance. Such referrals would not be appropriate for people with conditions such as early-onset Parkinson's, where symptoms can appear in people under 40, for example*. We recommend that the clinical guideline therefore explicitly defines 'older' and 'younger' people in order to provide age-appropriate referral pathways. *NHS Choices, Parkinson's http://www.nhs.uk/Conditions/Parkinsons-disease/Pages/Introduction.aspx	Thank you for your comment. The guideline focuses on older people only, though we recognise that many older people with multiple long-term conditions will have had these conditions, or experienced symptoms, as younger adults. We deliberately avoided an age threshold for older adults recognising that this can be defined differently in different studies

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Parkinson's UK	4	Full	12	280-1	Although we strongly support the recommendation around including all relevant practitioners in a person's care, it is important to emphasise that carers are often friends or family members who have a deep understanding of a person's condition and how it impacts them, and are well placed to make decisions with or on behalf of a person with Parkinson's. A carer of a person with Parkinson's explains: 'Health and social care professionals often don't recognise you have the expertise to share with them – Parkinson's is such an individual and complex condition and I know my wife better than anyone! Carers need to be treated as equal partners by professionals as we are there for the person 24/7.' We therefore recommend that if a person with care needs and their carer is not able to attend an assessment together, the meeting is rescheduled to allow them to participate.	Thank you for your comment. There was extensive discussion about the important role played by family and friends who care for older people with multiple long-term conditions throughout guidance development. The importance of ensuring carer involvement, as appropriate, is already captured in the recommendations in the wording of 1.1.3 which refers to the need to 'always involve the person and, if appropriate, their carer' in assessment and also to make alternative arrangements (which may include rescheduling the meeting) if either party cannot attend a scheduled meeting.
Parkinson's UK	5	Full	12	286-88	Parkinson's UK strongly supports the acknowledgement that carers who have specific needs of their own should be referred for assessment. However, the	Thank you for your comment. The focus of 1.1.4 is on ensuring practitioners are vigilant to the needs of the carer as well as to the person being cared for, in order that

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					wording of the recommendation suggests that it is only carers with established social care needs that should receive assessments. We do not believe that this goes far enough to fully support carers in their essential role and conflicts with the statement in section 1.1.5 which calls for assessments of anyone with caring responsibilities. Carers of people with Parkinson's are frequently friends and family members. A Parkinson's UK membership survey, conducted by YouGov25 found that a quarter of family members or carers surveyed were in full-time employment, with nearly six in ten not working at all. The survey also found that nearly a quarter of those in paid employment have had to reduce their working hours in order to look after someone with Parkinson's, and around 23% of those who were not working had to give up work to care for a person with Parkinson's.	they can make an appropriate referral if needs be. This stemmed from Guideline Committee discussions that highlighted, in some cases, carers may not recognise, or may be reluctant to highlight their own needs. The recommendations seek to complement the requirements of the Care Act 2014. In addition, the focus of the guideline is on supporting people with social care needs and multiple long-term conditions (i.e. general support to all carers is out of scope); this is why the wording of 1.1.4 and the separation of 1.1.4 and 1.1.5 remain unchanged.

[25] Parkinson's UK, *Survey of people with Parkinson's and their friends, family and carers*, 2013

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					Research* has also found that increases in stress-related symptoms in those caring for a person with Parkinson's were associated with the number of tasks required of a carer. Caring impacted on their own health conditions and their financial status. A carer of a person with Parkinson's explains: 'When someone is living with advanced Parkinson's your focus is on them and not yourself. In hindsight I now know my own health suffered, and I needed more support but didn't want to admit it. I'd really encourage people to get the support they need.' Given the significant emotional and psychological impact on carers, we feel that all carers should have assessments of their needs and that local authorities should be proactive in offering assessments, in order to prevent carers of people with Parkinson's from developing care needs themselves. We therefore recommend that recommendations 1.1.4 and 1.1.5 are combined, to emphasise that all carers must be offered assessments of their needs and that this must not be conditional.	

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					*Drutyte, G et al (2014) 'What impacts on the stress symptoms of Parkinson's carers? Results from the Parkinson's UK members' survey' in Disability and Rehabilitation 6(3):199-204 available at: http://www.ncbi.nlm.nih.gov/pubmed/23586667	
Parkinson's UK	6	Full	12 - 13	302	Parkinson's UK strongly supports all of the recommendations made under this section, including the involvement of the named care coordinator in the assessment process. We are particularly supportive of the requirement in point 1.2.4 to 'write any medicines management requirements into a care plan' including the importance of timings and implications of non-adherence as timely medicine administration is crucial to control Parkinson's symptoms. However, we recommend that the wording goes further, to note the impact of missed or delayed doses as well. When someone with Parkinson's doesn't get their medication at the time prescribed for them their symptoms become uncontrolled – increasing their care needs considerably. A person may not be able to move, get out of	Thank you for your comment and your support for the guideline. Thank you for your comment. The recommendations on medicines management relate specifically to the need for health and social care practitioners to communicate effectively. There is already NICE guidance on: - Medicines adherence http://www.nice.org.uk/guidance/cg76 - Managing medicines in care homes http://www.nice.org.uk/guidance/sc1 - Medicines optimisation http://www.nice.org.uk/guidance/ng5 NICE are also developing a guideline on Managing medicines for people receiving

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					bed or walk down the corridor. Once this balance of chemicals has been upset it may take hours, days or even weeks for a person's Parkinson's to stabilise. A person with Parkinson's who did not receive their medication on time while in hospital explains: 'A nurse witnessed me 'freezing' in the corridor. I had seized up and was completely unable to move. She was horrified. She thought I'd had a heart attack.' Given the importance of timely access to medication for people with Parkinson's, we also recommend that the wording of the recommendation is updated, so it reads – 'The importance of timing and implications of non-adherence and late or missed doses.'	social care in the community. http://www.nice.org.uk/guidance/indevelopment/gid-managingmedicinescommunitysocialcare The recommendation was worded to ensure consistency with the Home care guideline in which this issue was also discussed.
Parkinson's UK	7	Full	15	370	Although we welcome recommendation 1.2.10 which calls for care plans to 'include ordinary activities outside the home', it is important to recognise that this will not be appropriate in all cases, particularly for people with advanced Parkinson's who may struggle to mobilise. We urge that such recommendations are used only in agreement with a person with care needs.	Thank you for your comment. The Guideline Committee and the NCCSC are in absolute agreement that care should be coproduced with the person using support services. To this end, the focus on ensuring the person using services has choice and control is at the heart of all the recommendations. This is reflected throughout including, for example, in the introduction, and in

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						particular in recommendations 1.1.3, 1.1.6, 1.2.2, 1.2.3 and 1.2.5.
Parkinson's UK	8	Full	16	397	Parkinson's strongly supports greater access for carers to carer breaks and respite care. However, we are disappointed that this should only be 'considered'. A critical element of the Care Act is a requirement to promote 'wellbeing', which is broadly defined in the guidance to local authorities across a number of areas, including 'control by the individual over day-to-day life (including over care and support provided and the way it is provided) including participation in work, education, training or recreation and social and economic wellbeing'* Given the importance to participation in recreation and wellbeing noted in the Care Act guidance, we feel that access to carers breaks and respite care should be compulsory. *Department of Health, Care and Support Statutory Guidance: Issued under the Care Act 2014, available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/3661	Thank you for your comment. We recognise the importance of carer wellbeing. 'Consider' is used to denote a recommendation where the evidence was weaker. This recommendation came from Guideline Committee consensus only; we did not find effectiveness evidence on different types of intervention for carers of people with multiple long-term conditions.

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					04/43380_23902777_Care_Act_Book.pdf	
Parkinson's UK	9	Full	18	460	We welcome recommendations contained within this section around notifying the named care coordinator if there are issues relating to medicines management. As mentioned in point six above, timely access to medicines is of critical importance for people with Parkinson's. However, we are disappointed that there is not a parallel procedure for notifying social care professionals if a person's care needs appear to have increased, in order to instigate a review of a person's care needs. Given the progressive nature of Parkinson's, it's vitally important that people with the condition have their needs reviewed regularly, to ensure they are being fully supported.	Thank you for your comment. Recommendation 1.2.4 emphasises the need to review and update care plans regularly.
Parkinson's UK	10	General	General	General	in recommendation 1.2.4 and signpost readers to the Parkinson's guidance for further information. 4. What should practitioners be doing, or doing better, to care for this population that is not already covered in this guideline? Care practitioners should ensure that they seek the views of people with care needs wherever possible, as part of the care	Thank you for your comment. All of the recommendations are founded on a need to seek people's views, involve people in the process of planning and delivering their care and maximise choice and control. This is referenced particularly in the introduction, and inrecommendation 1.1.3, 1.2.2 and 1.2.5.

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					planning process. Practitioners should also recognise that carers of people with Parkinson's have an essential role in supporting people with the condition and have a valuable insight, and should be involved in decision-making wherever possible A carer of a person with Parkinson's explains: 'Throughout the many years I have been my husband's full-time carer, the progression in severity and complexity of his various health conditions, (in which Parkinson's is a major player), has meant my caring role has had to alter and adapt to his ever increasing needs. All aspects of Ray's wellbeing and safety rest squarely with me.' 5. Does the guideline cover all the challenges in caring for this group'? To a large extent. However, the guideline fails to acknowledge the fact that many conditions prevalent in older age, such as Parkinson's or dementia, are progressive. The progressive nature of such conditions provides additional challenges in delivering social care for people with multiple long-term conditions and already complex needs,	The Guideline Committee agreed the role of carers is vital and there was extensive discussion about this throughout guidance development. The importance of ensuring carer involvement, as appropriate, is already captured in the recommendations in the wording of 1.1.3 which refers to the need to 'always involve the person and, if appropriate, their carer' in assessment and also to make alternative arrangements (which may include rescheduling the meeting) if either party cannot attend a scheduled meeting. There was extensive discussion about the wording in the recommendation about involving carers. The term 'if appropriate' was chosen to reflect the fact that some people may not want their carers involved in discussions. It may also be that carers are involved in some discussions but not others. There may also be issues of capacity to consider. The wording is intended, therefore, to allow flexibility. The Guideline Committee recognised the progressive nature of many long-term conditions and this is now reflected

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					and preventing exacerbation of those needs. Care Act guidance to local authorities makes specific requirements to 'ensure the integration of care and support provision, including prevention with health and health-related services, which include housing. This responsibility includes in particular a focus on integrating with partners to prevent, reduce or delay needs for care and support'* The recommendations in the guideline make no specific mention of progressive conditions as a key component of 'complex care needs' nor how preventative social care should be approached in this context. Therefore we strongly believe this should be reflected in the guideline. *Care and Support Statutory Guidance: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/366104/43380_23902777_Care_Act_Book.pdf 6. The intention of the guideline is that all recommendations should be considered in conjunction with the person and taking into account their views. Does the guideline make this clear? Are there ways in which	explicitly in the recommendations in 1.2.4. and 1.4.2.

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					this could be made clearer in the guideline? Yes, we welcome recommendation 1.1.13 which calls on practitioners to always involve the person and their carer. However, we are disappointed that it is stated only 'if appropriate' instead of 'whenever possible'.	
RNIB	1	NICE	General	General	About the RNIB: Royal National Institute of Blind People (RNIB) is the UK's leading charity providing information, advice and support to almost two million people with sight loss. We are a membership organization with over 13,000 members throughout the UK and 80 percent of our Trustees and Assembly members are blind or partially sighted. We encourage members to get involved in our work and regularly consult them on matters relating to Government policy and ideas for change. As a campaigning organisation we act or speak for the rights of people with sight loss in each of the four nations of the UK. We also disseminate expertise to the public sector and business through consultancy on products, technology, services and	Thank you for your comments.

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					improving the accessibility of the built environment. RNIB is pleased to have the opportunity to respond to this consultation	
RNIB	2	NICE	General	General	Equalities Act 2010: We believe that all NICE work should reflect the duties of public bodies under the Equalities Act 2010, not just in relation to communication and accessible information, but in relation to non-discriminatory treatment. We would expect NICE to take steps to meet their legal obligations. This not only requires public bodies to have due regard for the need to promote disability equality in everything they do - including the provision of information to the public - but also requires such bodies to make reasonable adjustments for individual disabled people where existing arrangements place them at a substantial disadvantage.	Thank you for your comment. An Equality Impact Assessment has been completed to accompany the guideline and ensure NICE is fulfilling its duties under the Equality Act 2010. This can be found here: http://www.nice.org.uk/guidance/indevelopment/gid-scwave0715/documents
RNIB	3	NICE	General	General	Accessible information: We believe this guideline should be culturally appropriate. It should also be	Thank you for your comment. The issue of communication needs was discussed at the most recent meeting of the Guideline Committee (July 2015). It was agreed that

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					accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English." The Equality Act expressly includes a duty to provide accessible information as part of the reasonable adjustment duty. Online information on websites should conform to the W3C's Web Accessibility Initiative Web Content Accessibility Guidelines (WCAG) 1.0, level AA, as required by the NHS Brand Guidelines and the Central Office of Information. With regard to the accessibility of print materials, including downloadable content such as PDF files, we would request that wherever possible they comply with our "See it Right" guidelines: http://www.rnib.org.uk/professionals/accessibleinformation/Pages/see_it_right.aspx	the guideline would reference the NHS England Accessible Information Standard, which it now does.
RNIB	4	NICE	11	265	The language of 'substantial' and 'critical' is old terminology. Local authorities have to meet people that have 'significant' care needs. This assessment of needs takes into consideration the wider consideration of	Thank you for your comment. This text has now been amended so it is aligned with the wording of the Care Act.

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					the impact of 'wellbeing'. Eligibility guidance has moved away from a system in which personal care needs are prioritised. NICE guideline should reflect recent policy language.	
RNIB	5	NICE	14	359	RNIB welcome the list pertaining to aspects of daily. However we feel this should also include managing and maintaining relationships and shopping. Shopping is considered an important day-to –day living task and an absence can lead to social isolation for many. Relations for some are considered an important factor for emotional and psychological wellbeing.	Thank you for your comment. Shopping is now referenced in 1.1.13. Addressing social needs and maintaining social relationships is referenced in recommendations 1.1.3, 1.2.5, 1.2.11, 1.2.121.5.5, 1.5.18, 1.6.2 and 1.6.4.
RNIB	6	NICE	17	420	RNIB produced a report entitled 'Seeing it from their side' which sets out information to ensure that people with a visual impairment living in a care home have optimal support and care. Link to report: https://www.rnib.org.uk/sites/default/files/Seeing_it_from_their_side_care_home_guide.pdf Link to support services https://www.rnib.org.uk/sites/default/files/	Thank you for your comment and for highlighting this report which may be useful contextual information for implementation work.

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RNIB	7	NICE	20	523	RNIB welcome section 1.6.3. However, older people with sight loss experience more difficulty getting out and about (McManus et al., 2012) and may experience negative outcomes in relation to health, economic wellbeing and social and civic participation (Nazroo and Zimdars, 2010; Gjonca and Nazroo, 2005). References • McManus S and Lord C, 2012. Circumstances of people with sight loss: Secondary analysis of Understanding Society the Life Opportunities Survey. Natcen and RNIB. • Nazroo J and Zimdars A, 2010. Social inclusion, social circumstances and the quality of life of visually impaired older people. Thomas Pocklington Trust. • Hodge S, Barr W and Knox P, 2010. Evaluation of emotional support	Thank you for your comment. We have expanded recommendation 1.7.2 to make clear that practitioners need to 'consider the impact of' and 'respond to' a range of common conditions – which would include sight loss - rather than simply be able to identify them. This would include referring to other specialists, as appropriate, and the need to ensure links with specialist support is also covered in recommendation 1.7.3. In addition, please see further information about protected characteristics within the Equality Impact Assessment https://www.nice.org.uk/guidance/GID-SCWAVE0715/documents/social-care-of-older-people-with-complex-care-needs-and-multiple-longterm-conditions-equality-impact-assessment2

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					and counselling within an integrated low vision service. Liverpool University. • Gjonca E and Nazroo J, 2005. An investigation of the circumstances of older people with sight loss: An analysis of the English Longitudinal Study of Ageing. Thomas Pocklington Trust.	
RNIB	8	NICE	21	540	RNIB welcome the list detailed in section 1.7.2 particularly sensory loss.	Thank you for your comment and your support for the recommendations.
Royal College of Nursing	1	General	General	General	The Royal College of Nursing welcomes proposals to develop this social care guideline. It is timely and well needed.	Thank you for your comment and your support for the guideline.
Royal College of Nursing	2	NICE	General	General	We are surprised and disappointed that there does not appear to be a nurse on the guideline committee.	Thank you for your comment. We are limited to 12-14 Guideline Committee members. There was, however, due consideration paid to health sector interests throughout development and representation on the Committee from a pharmacist and an Occupational Therapist.
Royal College of Nursing	3	NICE	7	1.1.2	The recognition of the need for comprehensive clinical assessment based on the principles of comprehensive geriatric assessment (CGA) would be a helpful inclusion. There should be recognition that	Thank you for your comment. The recommendation wording reflected the evidence we reviewed and GC consensus.

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					CGA does not need to be performed by a medical practitioner and can be carried out by appropriately trained and competent nurses.	
Royal College of Nursing	4	NICE	7	1.1.3	There is no recognition of spiritual or sexual health needs throughout the document and this should be addressed as approximately 605 of those over 80 maintain some sexual activity.	Thank you for your comment. This has now been added to recommendation 1.1.3.
Royal College of Nursing	5	NICE	7	1.1.3	If the person is unable to attend meetings, it should be encouraged that health and social care professionals meet in a venue of the person's choice.	Thank you for your comment. The importance of ensuring people are involved in meetings and discussions about their care was discussed by the Guideline Committee who agreed this is important. This was reflected in the wording of 1.1.3 which refers to the need to 'always involve the person and, if appropriate, their carer' in assessment and also to make alternative arrangements (which may include rescheduling the meeting) if either party cannot attend a scheduled meeting.
Royal College of Nursing	6	NICE	9	1.2.2	Whilst continence is important to everybody it seems an unusual area to highlight, skin, pain, dementia care might all be highlighted.	Thank you for your comment. The review found specific evidence on continence care and the Guideline Committee thought this was a particular area where care and support could be improved to make a significant difference to the lives of people with multiple long-term conditions. Skin

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						integrity, pain and dementia care are also all explicitly referenced within recommendation 1.7.2.
Royal College of Nursing	7	NICE	9	1.2.2	The inclusion of end of life wishes, CPR and other advanced directives that the person would wish known. Who holds Lasting Power of Attorney (LPA)?	Thank you for your comment. Recommendation 1.2.5 makes specific reference to both palliative and end-of-life needs, recognising, as you identify, that these are important areas of support to address.
Royal College of Nursing	8	NICE	11	1.2.9	To ensure care plans are accessible to all agencies and ideally patient held.	Thank you for your comment. The issue of accessibility was discussed at the most recent meeting of the Guideline Committee (July 2015). It was agreed that the guideline would reference the NHS England Accessible Information Standard, which it now does. Following discussion at Guideline Committee 12, recommendation 1.2.3 was worded to ensure care plans are 'jointly owned' recognising the person should coproduce and own their care and support, but agencies also have a legal responsibility to hold, review and update the plans.
Royal College of Nursing	9	NICE	12	1.3.4	Please change 'consider' to 'ensure' in relation to carer support	Thank you for your comment. Use of the word 'consider' reflects the strength of the recommendation, using NICE house style terminology. 'Consider' indicates a weaker recommendation, while 'should' indicates a

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						stronger recommendation and 'must' indicates a recommendation is a legal requirement.
Royal College of Nursing	10	NICE	12	1.4	Addition of single point of access would be helpful	Thank you for your comment. We did not find effectiveness evidence on single point of access for older people with multiple long-term conditions.
Royal College of Nursing	11	NICE	13	1.5.4	Please include – access to learning, rehabilitation, exercise, sunlight and the natural world.	Thank you for your comment. We have included reference to 'opportunities for movement' in recommendation 1.5.17. We have also included reference to exercise and dance in recommendation 1.5.5 and a reference to 'visiting public spaces' in 1.2.12 (which could include parks and gardens but could also be much broader depending on people's preferences).
Royal College of Nursing	12	NICE	13	Genral	Inclusion of access to all NHS services that people living "none care home" settings enjoy	Thank you for your comment. We have expanded recommendation 1.7.2 to make clear that practitioners need to 'consider the impact of' and 'respond to' a range of common conditions rather than simply be able to identify them. This would include referring to NHS practitioners, as appropriate. The need to ensure links with specialist support is also covered in recommendation 1.7.3.

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Royal College of Nursing	13	NICE	14	15.11	It is difficult for social care practitioner to know if it is the medicines that are affecting a persons condition, we should be aiming for regular review by healthcare practitioners, such as community matrons, admiral nurses, specialist nurses etc.	Thank you for your comment. The frequency of medical review and the roles that should undertake medical review were not in scope for this guideline.
Royal College of Nursing	14	NICE	15	1.5.14	Again it appears unusual that continence is particularly highlighted here	Thank you for your comment. The review found specific evidence on continence care and the Guideline Committee thought this was a particular area where care and support could be improved to make a significant difference to the lives of people with multiple long-term conditions.
Royal College of Nursing	15	NICE	16	General	Participation in research should also be included, particularly people who are living with dementia.	Thank you for your comment. The need to gather more data from people with multiple long-term conditions on their views and experiences was thought to be extremely important. This is the subject of a stand-alone research recommendation.
Royal College of Nursing	16	NICE	17	General	Actively seeking of feedback on care should be embedded throughout the document.	Thank you for your comment. The Guideline Committee agree the need to review care and support with the person – and reflect changing needs and preferences - is important and this is reflected within recommendations 1.2.2, 1.2.4 and 1.5.1.
Royal College of Nursing	17	NICE	18	1.5.19	Plans toward end of life should also be included	Thank you for your comment. We have added a reference to addressing both palliative and end-of-life care needs within

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						recommendation 1.2.5.
Royal College of Nursing	18	NICE	19	General	People should be invited to share their skills and knowledge in a meaningful way.	Thank you for your comment. The importance of ensuring practitioners are appropriately skilled and knowledgeable underpins a number of the recommendations, most notably 1.7.2 and 1.7.3.
Royal College of Nursing	19	NICE	20	1.6.2	There seems to be little consideration of the funding implications of this.	
Royal College of Nursing	20	NICE	21	1.7.1	The need for training in comprehensive old age assessment (CGA) should be acknowledged here. Specialist older people's care/education should be included in this section	Thank you for your comment. We searched for, but did not find, evidence on the impact of training on outcomes for older people with multiple long-term conditions. We have expanded recommendation 1.7.2 to make clear that practitioners need to 'consider the impact of' and 'respond to' a range of common conditions – including hearing and sight loss - rather than simply be able to identify them. This would include referring to other specialists, as appropriate, and the need to ensure links with specialist support is also covered in recommendation 1.7.3.
Royal College of Nursing	21	NICE	21	1.7.1	Mental Capacity Act training is required.	Thank you for your comment. The Guideline Committee agreed capacity is an important issue and this is now referenced within the

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						introduction.
Royal College of Physicians	1	Full	General	General	The RCP is grateful for the opportunity to respond to this consultation. In doing so, we wish to endorse the response submitted by the British Geriatrics Society (BGS) and to make the following comments.	Thank you for your comment.
Royal College of Physicians	2	Full	3	62-64	We do not recognise the use of the term 'life limiting condition' to refer to long term conditions and we believe this description might be confusing.	Thank you for your comment. This has been deleted.
Royal College of Physicians	3	Full	7	173-188	We recognise the workforce challenges being referred to. We believe the guidance would be strengthened by an explicit reference to the role which physicians (specifically geriatricians) can play by providing in-reach services into care homes. They can support care home staff with the medical care of patients and can hopefully achieve the goal of reducing hospital admissions.	Thank you for your comment. We did not find evidence on the effectiveness of in-reach services provided by physicians for this specific population.
Royal College of Physicians	4	Full	16	406-411	Once again, we feel this section would be strengthened by a reference to the positive role which physicians can play by working as part of community teams delivering services in community settings (ie outside the traditional setting for hospital care).	Thank you for your comment. We did not find evidence on effectiveness of in-reach models provided by physicians for this particular population.
Royal College of Physicians	5	Full	17-18	420-452	This section (on care needs of care home residents) could expand in greater detail on	Thank you for your comment. The medical interventions provided to care home

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					the medical care needed by patients who are resident in care homes, eg medicines management.	residents was not in scope for this guideline. There is, however, a NICE guideline on Medicines management in care homes.
Royal College of Physicians	6	Full	21	534-546	We agree with the central point regarding training of the workforce to meet the needs of caring for frail elderly patients and we believe this point should be emphasised more prominently. From the RCP's census of consultant physicians we know that Trusts are showing a very high demand for geriatricians, but that most of these posts go unfilled.	Thank you for your comment and your support.
Royal College of Physicians	7	General	General	General	Please read the checklist for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly. 1. How will you use the recommendations in the guideline? The Royal College of Physicians (RCP) will not use this guidance directly, however, the guidance may be used by our members and fellows or may have implications for our members and fellows' ways of working. The RCP represents 30,000 members worldwide working in hospitals and the community across 30 different medical specialties (including geriatric medicine),	Thank you for your comment and your support for the guideline. We did not find effectiveness evidence on specialist geriatric in-reach for this population, or the models of assessment you have specified. The Committee members recognised, however, the importance of providing 'joined-up' assessment, care and support for people and a number of the recommendations are focused on collaborative working and involvement of health professionals.

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					diagnosing and treating millions of patients with a huge range of medical conditions. We have a number of projects which are focussed on improving the medical care delivered to frail elderly patients. 2. Which recommendations do you think are the most important? And why? Of greatest interest and relevance to the RCP are the recommendations in sections 1.4 Integrating Health and Social Care Planning and 1.5 Delivering Care. We believe these sections are important because they relate most directly to the medical care of frail older patients (though of course other aspects of social care are also relevant). Frail older people (especially those with complex needs or long term conditions) are a particular focus for the RCP because they account for a large majority (70%) of hospital bed days and represent a growing section of demand for hospital care (65% increase in secondary care episodes for over 75s in the previous 10 years). 3. In what ways can the recommendations be made more specific to the care of older people with long-term conditions? Within sections we would urge you to	

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					consider more explicitly the contribution which can be made by secondary care specialists (eg geriatricians) and to consider the interaction between social care and acute care. We were pleased to see reference to the involvement of geriatricians in advanced care planning (lines 265-267). We have explicitly supported the principle of comprehensive geriatric assessment for improving the medical care of frail older patients in acute settings (see Acute Care Toolkit 3: Acute Medical Care for Frail Older People, RCP London, March 2012). We also support physicians working in community settings, in collaboration with multi-disciplinary teams. There exists evidence from a number of pilot projects which show that better care can be achieved through increased geriatric support into care homes (for further details see British Geriatric Society report: A Quest for Quality - An Inquiry into the Quality of Healthcare Support for Older People in Care Homes 4. What should practitioners be doing, or doing better, to care for this population that is not already covered in this guideline? We believe it is vital to have specialist	

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					geriatric in-reach to provide medical support to frail older people living in care homes to ensure the medical needs of this group are met. It is also essential that there is co-ordination between the providers of acute care and community services, eg the provision of ambulatory emergency care to prevent hospital admissions requires coordination between acute and community services to ensure patients can be discharged with ongoing care and support packages in place. 5. Does the guideline cover all the challenges in caring for this group'? We believe the guideline in its current form is fairly comprehensive, however, it could be strengthened by clearer reference to the case for comprehensive geriatric assessment, the step-up/step-down provisions required between acute and community care, and the importance of recognising patients with frailty indicators. The guideline could also be strengthened by including stronger recommendations in relation to the use of IT infrastructure and improved record sharing to support integrated care across acute and community settings. These issues are summarised in lines 863-879, but should	

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					also be translated into the recommendations section. 6. The intention of the guideline is that all recommendations should be considered in conjunction with the person and taking into account their views. Does the guideline make this clear? Are there ways in which this could be made clearer in the guideline? We believe the guideline does make this clear. We strongly support the explicit references to involving patients in their care, shared decision making and support for self-management. See section 3.9 of Developing NICE guidance: how to get involved for suggestions of general points to think about when commenting.	
Sense	1	General	General	General	We agree that these are the right three priorities for implementation.	Thank you for your comment and your support for the guideline.
Sense	1	NICE	7	1.1.3	We welcome the recommendation of including variety of practitioners, to address all of the persons needs. We expecially welcome the inclusion of sensory and communication needs alongside other health needs. The Chief Medical officers report (2012) found that 69% of those reporting a dual sensory loss have two or more additional long term conditions, it	Thank you for your comment and your support for the guideline. We will note the comment on specialist practitioner involvement for the work on guideline implementation.

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					also found that only 64% of people with dual sensory loss feel confident in managing their own health. This is likely to be do with difficulties in communicating with health care professionals and accessing information about there conditions. As such it is crucial that practitioners who understand the unique needs of someone with dual sensory loss are included in assessment and care planning.	
Sense	2	NICE	9	1.2.2	We welcome the recommendation that individuals are given the opportunity to have a range of needs addressed, not just health needs, in care plans and that sensory loss has been identified as a particular area for consideration. It is crucial that people with sensory loss get the right social care support to meet their sensory needs, as well as any support received for healthcare support. Assessments for those with dual sensory loss must be carried out by a professional who is suitably qualified, this is stipulated in the Care Act.	Thank you for your comment and the support for this recommendation.
Sense	3	NICE	13	1.5.4	We welcome the recognition of the importance of providing individuals with social opportunities, and in particular that these opportunities must be provided in	Thank you for your comment and your support for the recommendations.

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					such a way that maximises opportunities for communication and reduces difficulties people might be having with their sight and vision. This is crucial when we have an increasing population of people with sensory loss; over 50% of people over 60 have a hearing loss (Age UK), 1.8million of the 2million people with sight loss in the UK are older people and there are also 250000 older people with dual sensory loss. As such it is important that these needs are recognised in provision of services.	
Sense	4	NICE	17	1.7.2	We welcome the fact that sensory loss is included as a condition that health and social care practitioners should be able to recognise. All too often sensory loss is seen as a 'normal' part of ageing, however it can cause huge difficutlies for people in accessing information, communicatining and reaching their communities. It can also have a significant effect on their health related quality of life (Chief Medical Officers Report).	Thank you for your comment and your support for the guideline.
The Royal College of General Practitioners	1	NICE	General	General	This is a thoughtful and inclusive document, reviewing the literature and commenting appropriately. The resource implications of its implementation are considerable, the evidence base is weak and there is a need	Thank you for your comment and your support for the work we have done. We recognise that the notion of 'need' is complex and this was discussed during

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					to prioritise the recommendations. It is written as a professional document identifying "need" as perceived by a professional - this may be less appropriate in examining the "needs" of older people who do not necessarily accept this model. Where people have the money and freedom to arrange their own care it is with an emphasis on choice, risk taking, not always being the recipient but having the dignity to still serve and care for others. General Practitioners appreciate the support provided by our care of older people colleagues. However there are pressures in the system, and when a timely needs assessment is required the dependency is time from referral to assessment, which if prolonged, could lead to the need for crisis intervention. The use of intermediate teams based in the community seem to have diminished through the loss of community matrons and district nurses as a result of workforce shortfalls through reduced recruitment and retention. This clearly needs to be factored in by commissioners.	development, along with the pressures in the system. Funding and commissioning are not in scope for the guideline but commissioning can be considered as part of the work on implementation. In addition, economic analysis was undertaken for the guideline, the Guideline Committee considered costs when making all recommendations and a costing statement will be published alongside the final guideline. We are limited to 12-14 Guideline Committee members. There was, however, due consideration paid to health sector interests throughout development and representation on the Committee from a pharmacist and an Occupational Therapist. The importance of recognising people's religious and cultural needs and preferences was recognised as important by the Guideline Committee which informed recommendation 1.2.5 (which has since been updated to include reference to people's 'spiritual' needs). The Guideline Committee recognised the importance of supported people in the

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					It might have been helpful if there had been some medical input into the working group and in particular psychiatry, care of the elderly and general practice, and also representation from Age Concern and community based religious leaders to cover ethnicity and diversity. The family is not mentioned or only as carer but providing for family access, family support is important e.g. free telephone, help with travel, discussion of the tricky questions around inheritance versus nursing home fees and power of attorney, subsidised/free legal advice. Highlighting exemplars of charitable organisations that promote independent living and promoting the chance to learn new skills would have been helpful, but this is locally dependent and commissioners of social care services will have local engagement. The need for dignity in death and freedom to choose the timing of one's death is fraught, but it is now on the agenda and needs to be considered in discussing living wills and last wishes.	context of their family and friends, which informed recommendations 1.2.11, 1.2.12, 1.6.2 and 1.6.3. We have also added in a reference to the need to support people in understanding benefits entitlement (1.2.10). Dignity in death is another important issue that was discussed. Both palliative and end-of-life care is now referenced in recommendation 1.2.5. For further information on protected characteristics, please see the Equality Impact Assessment: https://www.nice.org.uk/guidance/GID-SCWAVE0715/documents/social-care-of-older-people-with-complex-care-needs-and-multiple-longterm-conditions-equality-impact-assessment2

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					The wide differences in outlook and expectation are determined by income, social class, race, religion, support networks and personal idiosyncrasy, and make for difficult policy.	
Thomas Pocklington Trust	1	Full	11	265 - 267	1.1.2 – Why is this a one time assessment? We know from research we have funded that people's changing needs are not recognised or acted in and that a one time assessment will not catch change.	Thank you for your comment. This recommendation is aimed at ensuring that assessment of healthcare needs is considered alongside social care needs assessment (as we understand that in some cases health and social care needs assessments are not 'joined up'). This recommendation does not rule out additional, follow-up health assessments or interventions. We have included a definition of 'one time assessment' in the section on 'Key terms'.
Thomas Pocklington Trust	2	Full	11	275	Please could you include the word aspirations here	Thank you for your comment. This has been included.
Thomas Pocklington Trust	3	Full	13	324 – 326	As well as medicines management within care plans, care plans should also record what aids and adaptations are required, for example, spectacles, magnifiers, task lighting, etc	Thank you for your comment. Aids and adaptations were not within the scope of this guideline.
Thomas	4	Full	14	337 –	1.2.7 – it may be relevant to include	Thank you for your comment. We have

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Pocklington Trust				340	Attendance Allowance here: https://www.gov.uk/attendance-allowance/overview	expanded 1.2.10 to include offering information about benefits entitlement which would cover a range of options for financial support, including attendance allowance.
Thomas Pocklington Trust	5	Full	16	406 - 411	1.4.2 should include rehabilitation officers for people with a vision impairment. We mention this because this profession can often be overlooked so it is useful to explicitly list them.	Thank you for your comment. We could not, within the scope of this guideline, examine evidence on effectiveness of specific interventions visual impairment.
Thomas Pocklington Trust	6	Full	17-18	420 - 452	Staff require training to recognise that different long term conditions will have different requirements. The worry is a 'one size fits all' policy could be adopted which may not respond to the needs of people with sight loss and other specific conditions. As a charity for people with sight loss we are keen to ensure that the needs and aspirations of people with sight loss and other conditions are met. The NICE QS 50: Quality Statement 4 with regards mental wellbeing of older people in care homes details the need for staff training and the recognition of sensory impairment: http://publications.nice.org.uk/mental-	Thank you for your comment. The issue of sensory loss was discussed at the most recent meeting of the Guideline Committee (July 2015). We have separated out the previous reference to 'sensory loss' to read 'hearing and sight loss' to make clear that these are distinct issues. We have also expanded recommendation 1.7.2 to make clear that practitioners need to 'consider the impact of' and 'respond to' a range of common conditions – including hearing and sight loss - rather than simply be able to identify them. This would include referring to other specialists, as

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					wellbeing-of-older-people-in-care-homes-qs50/quality-statement-4-recognition-of-sensory-impairment The discussion paper 'How can care homes "look out" for eye health?, Sue Cooper, University of London, 2013' funded by Thomas Pocklington Trust discusses a pilot study to test the value of ambassadors delivering sight loss training directly to care home staff: http://www.pocklington-trust.org.uk/researchandknowledge/publications/rdp13.htm	appropriate, and the need to ensure links with specialist support is also covered in recommendation 1.7.3.
Thomas Pocklington Trust	7	Full	17-18	420 - 452	Please can this section include accessibility when looking at the care home environment and layout. Good colour contrasting, clear and trip hazard free routes along with other simple changes can greatly improve the care home environment. Guidance can be found from: 1) Greasley-Adams, Bowes, Dawson and McCabe, University of Stirling, Thomas Pocklington Trust, 2014, Good practice in the design of homes and living spaces for people with dementia and sight loss http://dementia.stir.ac.uk/design/g	Thank you for your comment. We did not review the evidence on effectiveness of specific interventions to improve accessibility of the care home environment because this was not in scope, hence use of the umbrella terms 'accessible signage and lighting' and 'a range of technologies' with some examples provided.

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					ood-practice-guidelines	
Thomas Pocklington Trust	8	Full	17	424 - 427	1.5.1 Where choices of snacks are made available during the day, it must be made clear to an individual with sight loss that those snacks are present in the room.	Thank you for your comment. Accessibility – and accessibly information about the support or services on offer - was discussed at Guideline Committee meeting 12 and reference to this features in the introduction.
Thomas Pocklington Trust	9	Full	17	430 - 431	1.5.3Adaptations may need to be made to premises to allow control of heating by the individual. RICA have produced a useful guide to heating controls with support from Thomas Pocklington Trust. This guide can be found here: http://www.rica.org.uk/content/saving-energy 1.5.3 There should also be mention of control over lighting using measures such as dimmer switches, blinds to control glare from daylight, etc. There are numerous resources available on our website: http://www.pocklington-trust.org.uk/researchandknowledge/publications/Lighting+and+Design	Thank you for your comment and for reference to this guide which we will consider as part of our implementation work. The specific technologies cited in 1.5.17 are only examples and we recognise there are others, such as those you have highlighted.
Thomas Pocklington	10	Full	17	432 - 441	1.5.4 Please could you add: 'Making physical activities accessible to all'? Some	Thank you for your comment. We have added to 1.5.18 a bullet point that

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Trust					physical social activities like gentle exercise either inside or outside the premises are not always accessible to all. 1.5.4. Please could you include audio description being enabled on televisions? This is a simple, no cost solution for those with sight loss wishing to watch television and is something a lot of people are unaware of.	indicates providers should 'offer opportunities for movement' recognising that this may vary from individual to individual The specific technologies cited in 1.5.17 are only examples and we recognise there are others, such as those you have highlighted.
Thomas Pocklington Trust	11	Full	18	450 - 451	1.5.7 Please can you mention links with local voluntary organisations and community groups	Thank you for your comment. Recommendation 1.5.18 now references voluntary and community sector organisations.
Thomas Pocklington Trust	12	Full	18	456	Please can you include people in similar circumstances not only similar conditions	Thank you for your comment. This has been updated.
Thomas Pocklington Trust	13	Full	16	401 - 405	1.4.1 There needs to be a process whereby integration of care is monitored beyond the initial service specification. Building 'seamless referrals between practitioners' into specifications is vital but there needs to be a mechanism to make sure it is delivered in reality and this mechanism needs to sit at a central point. This should likely sit with the named care coordinator.	Thank you for your comment. We have updated recommendation 1.2.1 to highlight that named care coordinators should operate 'within local arrangements'. This was following discussion at Guideline Committee meeting 12 (July 2015) about the consultation comments on ensuring accountability.
Thomas	14	Full	18-19	460-488	When discussing medicines, if individuals	Thank you for your comment. Effectiveness

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Pocklington Trust					are managing their own medicine intake then medicine details, and instructions on how to take them and how regularly, should be provided in the preferred format for that individual (for example, large print, Braille, etc). Also, support to use mediation devices and use of suitable devices, such as audio blood glucose monitors, audio scales as well as support to use eye drops.	of medical devices was not in scope for this guideline. The importance of ensuring information is provided in preferred format was discussed at Guideline Committee meeting 12 (July 2015). It was agreed that the guideline would reference the NHS England Accessible Information Standard, which it now does. NICE is currently developing a guideline on Managing medicines for people receiving social care in the community.
Thomas Pocklington Trust	15	Full	19	490-496	Please could this section be more explicit about the need for different communication needs of people when receiving information. For example, sign language, audio format or EasyRead, etc and including support to meet other people with similar conditions. There should be an annual review to identify any changes in communication needs over time as a result of changes in health such as sight loss. Please can this section be explicit about acting on what is identified through review.	Thank you for your comment. The issue of communication needs was discussed at the most recent meeting of the Guideline Committee (July 2015). It was agreed that the guideline would reference the NHS England Accessible Information Standard, which it now does.
Thomas Pocklington	16	Full	20	502 – 504	It is also important that the worker is aware of the person's needs rather than being a	Thank you for your comment.

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Trust					familiar face. A worker can be well known by the person but not providing the support for their needs.	
Thomas Pocklington Trust	17	Full	20	521	Please could you add 'and / or care homes that offer specialist support suited to their needs and aspirations'.	Thank you for your comment. The overall emphasis of this recommendation is on enabling the individual (and their carers, as appropriate) to have enough information to exercise choice and control. This may include, as you identify, understanding what specialist support is available. All of the recommendations are founded on a need to consider people's needs and preferences and this is referenced particularly in the introduction, and in recommendation 1.1.3, 1.2.2 and 1.2.5.
Thomas Pocklington Trust	18	Full	20	522 - 524	1.6.3 – this advice should include mobility and transport to maintain or make new contacts and the use of IT, for example with social media.	Thank you for your comment. The need to consider mobility and transport requirements is addressed in recommendation 1.2.5.
Thomas Pocklington Trust	19	Full	20	525 – 528	1.6.4 – this should include reference to commissioners to consider funding voluntary sector organisations as well as community enterprises.	Thank you for your comment. Commissioning is not in scope for NICE guidance however the role of commissioners in implementation will be considered as part of implementation.
Thomas	20	Full	20	529 –	1.6.5 – there is a need to be conscious not	Thank you for your comment.

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Pocklington Trust				532	to replace well functioning 'old ways' with new ways of working.	
Thomas Pocklington Trust	21	Full	21	539	As well as being able to recognise conditions, practitioners should know how to act appropriately to meet the needs of the individual once the condition is identified.	Thank you for your comment. We have expanded recommendation 1.7.2 to make clear that practitioners need to 'consider the impact of' and 'respond to' a range of common conditions. The need to ensure links with specialist support is also covered in recommendation 1.7.3.
Thomas Pocklington Trust	22	Full	22	571	This research funded by the National Institute for Health Research (NIHR) provides good detail about dementia and sight loss with regards service delivery models: https://www.york.ac.uk/media/chp/documents/2015/RF45.pdf	Thank you for your comment and the reference.
Thomas Pocklington Trust	23	Full	23	591	Please could this be described as 'Reablement and rehabilitation'. Vision rehabilitation is the term used to describe a specialist service for people with sight loss. It is recognised by the Association of Directors of Adult Social Services (http://www.adass.org.uk/position-statement-on-visual-impairment-rehabilitation-in-the-context-of-personalisation/) and used in the Care Act 2014.	Thank you for your comment. We have since received (and scoped) the topic of reablement as a separate guideline referral and therefore this has been removed as a research recommendation here. Details about the NICE guideline on Intermediate care including reablement can be found here: https://www.nice.org.uk/guidance/indevelopment/gid-scwave0709

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Thomas Pocklington Trust	24	Full	23	591	Thomas Pocklington Trust commissioned the Social Policy Research Unit, University of York to undertake a review of the evidence base for vision rehabilitation services, and to supplement this with new quantitative and qualitative research about impact. Their findings are summarised at http://www.pocklington-trust.org.uk/Resources/Thomas%20Pocklington/Documents/PDF/Research%20Publications/rf-46-vision-rehab.pdf and highlight that 'though the existing evidence base for community-based vision rehabilitation services is under-developed. However, there are strong indications of the potential for these services, in particular group-based interventions, to have a positive impact on people's daily life and emotional wellbeing.	Thank you for your comment and for the link.
Thomas Pocklington Trust	25	Full	General	General	Please read the checklist for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly. 1. How will you use the recommendations in the guideline? As a charity for people with sight loss, Thomas Pocklington Trust will use the recommendations to promote good practice to commissioners, providers and others. We feel that sight loss should be	Thank you for your comment and your support for the guideline and its implementation.

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					recognised and defined by the NHS and social care as a long term condition (LTC). Sight loss should not be accepted as an inevitable part of ageing. Activity needs to be designed to address this both in terms of identification of sight loss and in supporting people who are blind or partially sighted. One in five people aged 75 or over and one in two people aged 90 or over will be living with sight loss. People aged over 75 will have at least three health conditions. We will also use the guidelines to inform our research and development activity, with the aim of supporting implementation of the guideline for people with sight loss. 2. Which recommendations do you think are the most important? And why? We think all the recommendations are important to people with sight loss. If we prioritise, the following are most important to people with sight loss: referral for needs assessment as soon as need identified (1.1.1); always involving the person and their carer (1.1.3); a named care coordinator (1.2); the integration of health and social care planning (1.4). Individuals should always be at the centre of their care planning and their voice heard and acted on. Meeting an individual's needs	

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					can fail due to lack of coordination between services. A care coordinator would ensure services join up for the individual and would be able to recommend further assessments as an individual's needs change over time. Having integration built into systems from the start is vital for the individual and improves the ability of the care coordinator's to undertake their role and the effectiveness of services. 3. In what ways can the recommendations be made more specific to the care of older people with long-term conditions? Recommendations to provide regular sight and hearing assessments for older people with complex care needs and multiple LTC are required. All too often sight and hearing loss is overlooked (1) when another LTC is diagnosed. This may prevent action to treat or correct sight or hearing loss or make the most of those senses. Lack of action makes it harder for people with sight or hearing loss, and those who care for them, to manage other health conditions, and vice versa. (1) J. Watson and S-M Bamford, ILC-UK, Thomas Pocklington Trust, 2012, Undetected sight loss in care homes: an evidence review, www.pocklington-trust.org.uk/Resources/Thomas%20Pockling	

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					ton/Documents/PDF/Research%20Publications/ILC%20UK%20Undetected%20sight%20loss%20in%20care%20homes.pdf 4. What should practitioners be doing, or doing better, to care for this population that is not already covered in this guideline? Practitioners should be looking out for signs of sight loss and signposting those who need an eye examination to an optometrist. Practitioners should be thinking about the impact of sight loss on activities of daily living, how to modify the environment to make the most of useable (including use of assistive technology). For example, people aged 65 or over need three times the light to see the same as someone in their 20s. All information that relates to a person's sight, or other condition, is documented in all care records. Practitioners should understand local external infrastructures which might reduce any individual's independence such as location and accessibility of local public or community transport. Working with the local voluntary sector is a good way to use condition specific expertise which connects with a wider network.	We have separated out the previous reference to 'sensory loss' to read 'hearing and sight loss' to make clear that these are distinct issues. We agree these are important conditions to consider, however we could not, within the scope of this guideline, examine evidence on specific interventions for hearing and sight loss. We have expanded recommendation 1.7.2 to make clear that practitioners need to 'consider the impact of' and 'respond to' a range of common conditions – including hearing and sight loss - rather than simply be able to identify them. This would include referring to other specialists, as appropriate, and the need to ensure links with specialist support is also covered in

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					5. Does the guideline cover all the challenges in caring for this group'? There should be more explicit mention of the importance of communicating in an accessible manner. It is implied in places but needs to be more readily brought to the fore. The NHS England Accessible Information Standard places legal requirements on health and adult social care providers to provide information in an accessible manner and should be used as a benchmark: www.hscic.gov.uk/isce/publication/scci1605. There is a need for health and social care practitioners to be aware that when someone has multiple conditions, one condition may mask another; for example, dementia and sensory loss. Recognising the secondary conditions can improve quality of life 6. The intention of the guideline is that all recommendations should be considered in conjunction with the person and taking into account their views. Does the guideline make this clear? Are there ways in which this could be made clearer in the guideline?	recommendation 1.7.3. We note your comments on emphasising accessible communication and this was also discussed at the most recent meeting of the Guideline Committee (July 2015). It was agreed that the guideline would reference the Accessible Information Standard, which it now does.

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					It makes it clear in planning care but there does not appear to be a recommendation with regards individuals challenging the quality of care they are receiving. You recommend, and we endorse, reviewing care plans to account for changing needs. It would be useful to recommend that the quality of care being provided is reviewed and in particular whether it meets the individual's needs and aspirations. That may be the intention of 1.2.12 (page 15) but it needs to be more explicitly stated.	We have included a recommendation (1.2.4) on the need to review and update care plans regularly and also noted that people should be involved in planning their support (1.2.2), jointly own it and sign to indicate they agree with it (1.2.3).

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[i] Monitor (2015) NHS adult hearing services in England: exploring how choice is working for patients

[ii] Chisolm, T. et al. 2007. A Systematic Review of Health-Related Quality of Life and Hearing Aids: Final Report of the American Academy of Audiology Task Force on the Health-Related Quality of Life Benefits of Amplification in Adults. *Journal of the American Audiology*, 18(2), pp. 151-183; Barker, F. et al, 2014. Interventions to improve hearing aid use in adult auditory rehabilitation (Protocol). Cochrane Database of Systematic Reviews: Reviews 2014; Issue 7 and most recently see NHS England and Department of Health, 2015, Action Plan on Hearing Loss http://www.england.nhs.uk/wp-content/uploads/2015/03/act-plan-hearing-loss-upd.pdf page 12-13

[iii] Davis, A. 1989. The Prevalence of Hearing Impairment and reported Hearing Disability among Adults in Great Britain. *International Journal of Epidemiology,* 18(4), pp. 911-917
Davis, A. 1995. *Hearing in Adults*. London: Whurr

[iv] Population data source Office for National Statistics Mid-2011 Population Estimates for Clinical Commissioning Groups in England by Single Year of Age based on 2011 Census[iv]. Prevalence calculated for the following cohorts: 0-16 years (0.33%), 17-30 (1.8%), 31-40 (2.8%), 41-50 (8.2%), 51-60 (18.9%), 61-

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70 (36.8%), 71-80 (60.2%), >80 years old (93.4%). Notes: Estimates from 0-16 are not available in the literature, so are based on 35,000 children in England having a hearing loss[iv] and the population of people aged ≤16 being 10,673,755[iv] (0.33%). Prevalence data for 17 to 80 year is taken from Davis (1989)[iv] and for adults aged 80 and over from Davis (1995) [iv]. Davis, A. 1989. The Prevalence of Hearing Impairment and reported Hearing Disability among Adults in Great Britain. *International Journal of Epidemiology,* 18(4), pp. 911-917.Davis, A. 1995. *Hearing in Adults*. London: Whurr

[v] Davis and Smith 2013, Adult Hearing Screening: Health Policy Issues—What Happens Next?, http://aja.pubs.asha.org/article.aspx?articleid=1809402

[vi] Vos, T et al (2015), Global, regional, and national incidence, prevalence, and years lived with disability for 301 acute and chronic diseases and injuries in 188 countries 1990-2013: a systematic analysis for the Global Burden of Disease Study 2013. T he Lancet

[vii] Acar, B. et al. 2011. Effects of hearing aids on cognitive functions and depressive signs in elderly people. *Archives of Gerontology and Geriatrics*, 52(3), pp. 250-252.

[viii] Hidalgo, J. L. et al. 2009. Functional status of elderly people with hearing loss. *Archives of Gerontology and Geriatrics,* 49(1), pp. 88-92

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[xii] Appollonio, I. et al. 1996. Effects of Sensory Aids on the Quality of Life and Mortality of Elderly People: A Multivariate Analysis. *Age and Aging*, 25(2), pp. 89-96.
[xiii] http://www.england.nhs.uk/2015/03/23/hearing-loss/ accessed 30 June 2015

[xiv] NICE, 2013. Mental wellbeing of older people in care homes. NICE Quality Standard 50. pp. 28-31.
https://www.nice.org.uk/guidance/qs50/resources/guidance-mental-wellbeing-of-older-people-in-care-homes-pdf Accessed 1 February 2015

[xv] NHS England, 2015. Evidence base for the practical guide to healthy ageing. http://www.england.nhs.uk/resources/resources-for-ccgs/out-frwrk/dom-2/healthy-ageing/ Accessed 1 February 2015

[xvi] NHS England and Age UK, 2015. A practical guide to healthy ageing. p.14 http://www.england.nhs.uk/wp-content/uploads/2015/01/pract-guid-hlthy-age.pdf Accessed 1 February 2015

[xvii] Monitor, 2015. NHS adult hearing services in England: exploring how choice is working for patients.

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[xviii] Davis and Smith 2013, Adult Hearing Screening: Health Policy Issues—What Happens Next?, http://aja.pubs.asha.org/article.aspx?articleid=1809402

[xix] Research cited in NHS England and Department of Health, 2015, Action Plan on Hearing Loss http://www.england.nhs.uk/wp-content/uploads/2015/03/act-plan-hearing-loss-upd.pdf

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[xxv] Monitor (2015) NHS adult hearing services in England: exploring how choice is working for patients

[xxvi] Monitor (2015) NHS adult hearing services in England: exploring how choice is working for patients

[xxvii] Equality Act 2010, Section 5 http://www.legislation.gov.uk/ukpga/2010/15/section/5

[xxviii] Research cited in NHS England and Department of Health, 2015, Action Plan on Hearing Loss http://www.england.nhs.uk/wp-content/uploads/2015/03/act-plan-hearing-loss-upd.pdf

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