National Institute for Health and Care Excellence
Social care of older people with multiple long-term conditions
Scope Consultation Table

Dates of consultation: 15 October-12 November 2013

Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
Action on hearing loss	27.01	General	Action on Hearing Loss welcomes the opportunity to provide comments on the 'Older people with long-term conditions' draft scope. Hearing loss is a long-term condition affecting over 10 million people in the UK – one in six of the population. As our society ages this number is set to grow and by 2031 there will be more than 14.5 million people with hearing loss in the UK. Hearing loss is the most widespread long-term condition among older people, experienced by almost three quarters (71%) of all people over 70 years. Hearing loss has significant personal and social costs and leads to high levels of social isolation and consequent mental ill health, and research shows it can increase the risk and impact of other long-term conditions such as depression and dementia. Many people with hearing loss are likely to have one or more other long-term conditions, and unaddressed hearing loss will cause issues for the management of other conditions, including problems with communication. In turn, effective diagnosis and management of hearing loss can minimise these impacts on peoples' lives, improving their quality of life, independence, and their ability to deal with any other long-term conditions.	Thank you for your comment and the information contained therein. People with sensory impairment are included within the population of interest, and flagged in the Equality Impact Assessment (published with the scope). That means that we will take particular steps, e.g. in identifying published evidence to support the guidance, to consider the impact of an individual's sensory impairment on their experience of service provision.

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			Our recently released evidence-based report 'Joining Up' (available at www.actiononhearingloss.org.uk/joiningup) showed how large cost savings and improvements to quality of life could be achieved from better provision of health and social care services to people who have hearing loss and also have other long-term conditions. Recent research has also identified particularly high levels of social isolation and communication difficulties for profoundly deaf British Sign Language (BSL) users in mainstream care. As they age and develop other long-term conditions, BSL users need culturally sensitive provision of care and particular interventions to ensure they can communicate independently and are not excluded. These include the proper provision of communication support such as BSL interpreters, and access to specialist diagnostic tools – interventions that are not usually available in mainstream care but which are essential for this group. As the largest UK charity working for people with hearing loss and deafness, including researching, campaigning and providing services, Action on Hearing Loss would like to offer our expertise and support in developing this social care guidance, in order to improve standards for people with hearing loss and other long-term conditions across the UK.	
Action on hearing loss	27.02	1	Hearing loss is the most widespread long-term condition among older people, experienced by almost three quarters (71%) of all people over 70 years, and it can lead to communication difficulties, social isolation, depression and dementia, as well as	Thank you for your comments. People with sensory impairment are included within the population of interest, and flagged in the Equality Impact Assessment (published with the scope). That means that we will take particular steps, e.g. in

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			causing problems for the management of other long-term conditions. Sight loss also has significant impacts on a person's quality of life and independence. Its prevalence also increases with age and it is very common in older people, affecting half of all people aged 90 and over. Given the prevalence and impact of hearing loss and sight loss, we feel that the guidance title should include the word 'sensory' as well as physical and mental, and that sensory loss should be included throughout.	identifying published evidence to support the guideline, to consider the impact of an individual's sensory impairment on their experience of service provision.
Action on hearing loss	27.03	3.1.3	Hearing loss is the most prevalent long-term condition, and its prevalence increases dramatically with age – it affects one in six of the general population, increasing to 41.7% of over 50 year olds and 71.1% of over 70 year olds. Unaddressed hearing loss has significant impacts on quality of life and on the management of other long-term conditions, which can be avoided if hearing loss itself is properly managed through better training for staff and the implementation of processes to ensure that hearing aids are used and working and that proper communication tactics are followed. We therefore strongly suggest that hearing loss should be included in this scope.	Thank you for your comments. People with sensory impairment are included within the population of interest, and flagged in the Equality Impact Assessment (published with the scope). That means that we will take particular steps, e.g. in identifying published evidence to support the guideline, to consider the impact of an individual's sensory impairment on their experience of service provision.
Action on hearing loss	27.04	3.1.5	There is now strong evidence that hearing loss, which is very common in older people, leads to other health conditions. In particular, hearing loss doubles the risk of depression, and severe hearing loss leads to a five times increase in the risk of developing dementia (mild hearing loss doubles the risk, and moderate hearing loss makes someone three times as likely to develop dementia). The impacts of hearing loss should therefore be included in this section. In particular, self-management of a physical	People with sensory impairment are included within the population of interest, and flagged in the Equality Impact Assessment (published with the scope). That means that we will take particular steps, e.g. in identifying published evidence to support the guideline, to consider the impact of an individual's sensory impairment on their experience of service provision, and on their mental health and ability to manage their conditions.

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			health condition is also often made more difficult by problems with communication resulting from hearing loss.	
Action on hearing loss	27.05	3.2.2	Despite the high prevalence and significant impacts of hearing loss, it often remains undiagnosed – there are currently four million people with unaddressed hearing loss in the UK, mostly older people, and on average people wait ten years before they seek help for their hearing loss. Our research has found that many do not get the support they need even when they do seek help. In one survey, 45% of people who were later diagnosed with hearing loss and given hearing aids had initially been turned away by their GP. Hearing loss is a common condition that is relatively easy to manage but is often not diagnosed or managed properly. Communication difficulties directly resulting from hearing loss can result in prolonged hospital stays for other conditions, and earlier admissions to care homes than if the person's hearing loss was properly managed. These easily avoidable outcomes reduce quality of life but they also cost more for our health and social care services. Our recent 'Joining Up' report (available at www.actiononhearingloss.org.uk/joiningup) estimated that at least £28 million could be saved in England by properly managing hearing loss in people with dementia and thus delaying admission to residential care.	Thank you for your comment. Older people with hearing loss and communication difficulties are within scope and are included within the population of interest, and flagged in the Equality Impact Assessment (published with the scope) as a group that are likely to be disadvantaged.
Action on hearing loss	27.06	3.2.3	Action on Hearing Loss has recently released a research report, 'Joining Up' (available at www.actiononhearingloss.org.uk/joiningup), which outlined the great need for better integration of services for the large numbers of people who have	Thank you for your comment. This guideline is motivated by the very problems which you identify. Integrated service models will certainly be important and are in the scope, as is working with people who have communication and

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			hearing loss and at least one other long-term condition. Currently, services too often assume someone has only one long-term condition, and patient pathways are not flexible enough to take more than one condition into account. With the increasing prevalence of long-term conditions, this system is currently failing older people. Services need to work together, professionals who specialise in one long-term condition need to have basic training in recognising and managing other long-term conditions, they need to be encouraged to cross-refer, share records, and put in place patient pathways for people with more than one long-term condition. Given that 71% of over 70 year olds have hearing loss, professionals managing the care for older people with other long-term conditions must be trained to recognise hearing loss and provide proper support and communication. This includes using proper communication tactics and technology before and after the individual is diagnosed, ensuring that individuals are referred for a diagnosis and hearing aid fitting or for support services such as repairs or new batteries for their hearing aids, support services such as lipreading classes, and/or access to counselling or other technologies that could help them. This shift in the way patients are cared for would improve communication, safety and care for the large numbers of older people who have hearing loss.	sensory difficulties. As part of guideline development, we will be making recommendations about 'what works' in integrated service delivery, based on the evidence reviews and the expert knowledge and experience of GDG members.
Action on hearing loss	27.07	3.2.5	Many people living in care homes will have two or more long-term conditions, given the high prevalence of conditions such as hearing loss, which affects 71% of people over 70. Only one in three people who	Thank you for your detailed comment and information, which we will share with the Guideline Development Group about the important area of hearing loss among care home residents, and how it

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			could benefit from hearing aids has accessed them, and people wait on average 10 years before they seek help for their hearing loss – many people wait so long that they then find it very difficult to adjust, for example when they are learning to wear hearing aids. Our research looking at hearing loss in care homes (entitled 'A World of Silence', available at http://www.actiononhearingloss.org.uk/aworldofsilence) showed that this is a particular problem in care homes - it found high levels of non-diagnosis of hearing loss, with inconsistent levels of management and staff training. Our research has found that proper diagnosis and management of hearing loss can significantly improve the management of other long-term conditions. Simple steps such as using assistive technologies (such as personal listeners) and proper communication tactics both before and after an individual is diagnosed, recognising hearing loss and referring people for hearing tests, recording and sharing information about communication preferences, ensuring there are places where background noise is kept to a minimum and people can read each other's lips, and putting in place processes for ensuring hearing aids are used and working in care homes, can make a huge difference to the communication, safety and care for people living with hearing loss.	might be recognised and addressed.
Action on hearing loss	27.08	3.3.3	The soon to be released Hearing Loss Action Plan, a cross-government strategy to tackle hearing loss, is a very relevant policy document that should be referenced here.	Thank you for your comment. The scope is a short summary of the topic area. Thank you for the additional reference which is useful context for the main phase of guideline development.
Action on hearing loss	27.09	3.4.3	Action on Hearing Loss has recently produced guidance on managing hearing loss in care settings (available at http://www.actiononhearingloss.org.uk/supporting-	Thank you for your comment and the information. We will pass them on to the Guideline Development Group.

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			you/care-and-support/proposed-standards-for-care-homes/diagnosis-of-hearing-loss.aspx) and on managing hearing loss alongside other conditions in a variety of care settings (available at www.actiononhearingloss.org.uk/joiningup) which should be included here.	
Action on hearing loss	27.10	4.3.1	Evidence from people with hearing loss and our research suggests other important ways that health and social care services can become more integrated, including the need for increased cross-referral between health and social care professionals, proper recording of patient information (such as communication preferences) and increased sharing of this information between professionals. Since hearing loss is the most common long-term condition, affecting 71% of people over 70 years old, training of staff should include recognising hearing loss and responding appropriately by referring individuals for a hearing test, deploying assistive technology such as personal listeners, ensuring hearing aids are used and working, creating a good environment for communication and utilising simple communication tactics such as reducing background noise, facing the person and checking they have understood. This should include all staff caring for older people with long-term conditions – including those working in care homes, community nurses, home carers and care agencies	Thank you for your comment. This important area will be considered by the Guideline Development Group.
Action on hearing loss	27.11	4.4	Our research suggests that other outcomes that may be useful here include delays in discharge from hospital (for example due to problems caused by communication difficulties). We support the inclusion of 'safety and adverse affects' as an outcome here – this should include unsafe situations created by miscommunication, for example misunderstanding of	Thank you for your comment. We have now included 'delayed discharge' as an adverse outcome in the scope.

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			medication or advice, misdiagnosis or a lack of informed consent, caused by an absence of communication support or improper management of a person's hearing loss.	
Action on hearing loss	27.12	4.5	As above, hearing loss is the most prevalent long-term condition among older people, affecting 71% of over 70 year olds, but it is very easy to manage. Hence it should be included here in the list of common conditions that staff should be trained to recognise and manage.	Thank you for your comment. Hearing loss is within the remit of the proposed review question (4.5, 5th bullet point) We have now removed the short list of examples provided and can discuss this further with the Guideline Development Group.
Action on hearing loss	27.13	4.6	There are a great many interventions that can save money by diagnosing and/or improving the management of a person's hearing loss, such as using assistive technologies (such as personal listeners) and communication tactics before and after an individual has a diagnosis, introducing hearing checks or hearing screening in GPs, pharmacies, care settings, community locations and at points of transition in care, referring individuals for a hearing test when staff recognise signs of hearing loss, providing proper communication support and training in communication methods, recording and sharing information about a person's hearing loss including their communication preferences, and ensuring processes are put in place and followed to ensure hearing aids are used and are working.	Thank you for your comment and the useful information, which will be considered by the Guideline Development Group. We will consider the areas that lend themselves to economic modelling in collaboration with the Guideline Development Group and then develop the economic plan accordingly.
Action on hearing loss	27.14	5.1.5	NICE has committed to producing a quality standard on hearing loss. As the most prevalent long-term condition among older people, affecting 71% of over 70s, the development of this guidance should be made a priority and it should be included on this list of relevant guidance.	Thank you for your comment. As this guideline topic has not yet been commissioned, it does not appear on the list of related NICE guidance.
Alzheimer's Society	18.01	General	Alzheimer's Society welcomes this draft scope guidance on social care for older people with long-term conditions. There are 800,000 people with	Thank you for your comment.

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			dementia in the UK today and the majority of these people are aged over 65. Many people with dementia also live with another long-term condition and the likelihood of living with more than one long-term condition increases with age.	
Alzheimer's Society	18.02	General	Research from Alzheimer's Society (Dementia 2013: The hidden voice of loneliness, 2013) found that the symptoms of a person's dementia can be exacerbated by another long-term condition. This could be because the person with dementia feels stressed or anxious about another long-term condition.	Thank you for your comment. This has been noted.
Alzheimer's Society	18.03	General	People with dementia often experience poor care for one long-term condition as the health or care professional does not understand dementia. Most health and care professionals will work with people with dementia, so it is essential that they have awareness of the needs of people with dementia.	Thank you for your comment. We agree that dementia is an important issue. We have not specified which conditions are of interest in the scope, because we do not intend to exclude any particular conditions, however, the role played by social care staff in recognising common conditions is in scope. While the number of people with one long-term condition is projected to be relatively stable, there is evidence to suggest that the number of people with multiple conditions will grow significantly.
Alzheimer's Society	18.04	4.1.1	Alzheimer's Society welcomes the inclusion of carers alongside older people living with long-term conditions in the groups covered. Carers play an important role in managing the long-term conditions of the person they care for. If carers are not supported, they struggle to fulfil their caring responsibilities.	Thank you for your comment. We do intend to consider the activities and needs of carers supporting people with long-term conditions.
Alzheimer's Society	18.05	4.1.2	Although Alzheimer's Society recognises that older people without social care needs are not included in the guidance, as local authorities face cuts, many are only funding care services for people assessed as	Thank you for your comment. Please note that the guideline will cover older people with social care needs who organise and/or fund their own care. We have not explicitly planned to

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			having substantial or critical needs. This means some people with dementia assessed with moderate needs, who are unable to fund their own care, do not receive any services and they would not be covered by this guidance. Furthermore, the Care Bill includes provision for national eligibility criteria, but the plan is to set this to set this to the current FACS criteria of substantial. Again, this could lead to some people with dementia not receiving any social care if they do not reach these criteria and do not have the means to fund their own care. Alzheimer's Society seeks clarification that people whose needs will not be met and their carers will also be covered by this guidance. It is also worth noting that every person with dementia will eventually need social care support as their condition progresses.	include only people who meet FACs thresholds, but we perceive a problem in finding evidence about people who have social care needs that are not considered eligible for statutory funding. However, we have not ruled them out.
Alzheimer's Society	18.06	4.3.1	Alzheimer's Society particularly welcomes the inclusion of the use of packages of care and support to promote social participation for older people with long term conditions. Social contact is important for people with dementia as conversations contain visual and other sensory clues for the person. These elements are an essential part of communication, particularly as dementia progresses. People with dementia interviewed for Dementia 2013 (Alzheimer's Society, 2013) described how they enjoyed visiting family or friends for Sunday lunch and this significantly improved their mental wellbeing. In order to maintain the mental wellbeing and independence of older people, Alzheimer's Society	Thank you for your comment. We recognise that social participation is important and have explicitly included voluntary and community sector services delivered formally as part of a package of care.

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			recommends that local authorities and other commissioners understand the needs of people with dementia within the context of living in the community and commission a wide-range of services to ensure that they are not socially isolated or lonely. Examples include: • Social groups, such as dementia cafes • Befriending services • Accessible transport. Social groups, like dementia cafes, also provide peer support for people with dementia. Alzheimer's Society has found that one of the greatest sources of support is having access to other people with dementia following diagnosis. To give another example, a year after the befriending service in Merseyside, West Lancashire and West Cheshire was set up, people with dementia living alone found visits from their volunteer befrienders to have a positive impact on their overall wellbeing. One person said that the service is important because it enables 'someone just to acknowledge you as a human being'.	
Alzheimer's Society	18.07	4.3.1	Alzheimer's Society welcomes the point that carers should receive support if they care for a person with social care needs and more than one long-term condition. There are currently 550,000 primary carers of people with dementia in England and they currently save the UK economy £7 billion a year (Prime Minister's challenge on dementia, 2012). Research from Alzheimer's Society (Support.Stay.Save, 2011) found that 52% of carers had insufficient support to	Thank you for your comment. We do intend to consider the activities and needs of carers supporting people with long-term conditions, including their views and experiences. Carers are referenced explicitly within 4.1.1. And 4.3.1.

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			carrying out their caring duties and this had a negative impact on their physical and mental health. This in turn exacerbates the needs of the person with dementia and leads to a greater need for intervention and a greater burden on the NHS, social services and individuals as they reach crisis point. If carers are supported, the person with dementia can live well with their condition, preventing the need for costly intervention measures.	
Alzheimer's Society	18.08	4.4	Alzheimer's Society welcomes the main outcomes in this guidance. The main outcomes are all important for the quality of life of people with dementia. Below are some of the reasons why the outcomes for this guidance are particularly important for people with dementia. Currently, many people with dementia say they have little choice about their day-to-day life. In a survey for Dementia 2013, 28% of respondents said they were not able to make choices. With regards to independence, nearly a quarter of respondents say they have had to stop doing things due to a lack of support. This shows that the current system of support does not allow people with dementia to remain independent. This also means that people with dementia are more likely to be lonely. In the survey for Dementia 2013, 38% of respondents reported feeling lonely, but among people with dementia living alone, this rose to 62%. Furthermore, without adequate support, people with dementia enter care homes earlier than expected, or	Thank you for your comment, and the information on people with dementia, which we will share with the Guideline Development Group.

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			are admitted to hospital in an emergency. For example, Support.Stay Save. (Alzheimer's Society, 2011) found that 19% of carers reported that the person with dementia was admitted to hospital when it could have been avoided and 22% said the person with dementia entered long-term care sooner than anticipated.	
Alzheimer's Society	18.09	4.6	Alzheimer's Society welcomes the economic aspects in the guidance, especially that NICE will consider interventions which reduce the negative consequences of living with dementia, their carers and families. Recent research on behalf of Alzheimer's Society has found a strong economic case for dementia-friendly communities. The principle behind is that if people with dementia are supported to remain independent in the community, it reduces the need for costly intervention measures, delays entry to care homes and reduces the likelihood of emergency hospital admissions.	Thank you for your comment, which we will pass on to the Guideline Development Group. We will consider the areas that lend themselves to economic modelling in collaboration with the Guideline Development Group and then develop the economic plan accordingly.
Bayer	25.01	4.1.1	**Groups that will be covered.** We are concerned that the focus of the guidance being on people with *'more than one'* long-term condition and their carers will exclude people who may have only one condition, but who have social care needs. It is acknowledged in section 3.1.5 that even one long term condition places people at greater risk of mental health problems. We suggest that all people with a long-term condition, particularly those who are elderly, could benefit from a joint health and social care assessment with a co-ordinated care plan.	Thank you for your comment. Our remit from the Department of Health was to look at Older People with more than one long-term condition and the scope emphasises the impact on people's lives. While the number of people with one long-term condition is projected to be relatively stable, there is evidence to suggest that the number of people with multiple conditions is likely to grow significantly over the next five years. Thank you for your comment. We have amended the scope to make clear that the guideline focuses on social care of older people with complex care needs and multiple long-term conditions.

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Bayer	25.02	5.1	Other related NICE guidance related to long-term conditions that occur most frequently in older people include: Atrial fibrillation. NICE clinical guideline 36 – update in progress	Thank you for your comment. We have not amended the scope, as the list is intended to provide examples, but the link to this condition will be highlighted in NICE pathways as appropriate when these are developed.
Bayer	25.03	5.2	Other related NICE guidance under development include: Macular degeneration. Publication expected July 2015.	Thank you for your comment. When we begin to identify and collate the research and guidance available to support this guideline, we will consider these additional resources.
Bladder & Bowel Foundation	4.01	General	The Bladder & Bowel Foundation are pleased to see that Continence is mentioned within the document. However as incontinence is cited as 'second only to dementia' as the reason for an individual being admitted to residential or nursing home.(Department of Health publication 'Good practice in continence services' 2000) the Bladder & Bowel Foundation would be keen to see this acknowledged more significantly within the guidance.	Thank you for your comment, which we will share with the Guideline Development Group. We have not specified conditions of interest in the scope, because we do not intend to exclude any particular conditions and also because specific conditions are the subject of clinical guidelines. This guideline aims to improve the way health and social care practitioners work together, focusing on the needs of the person and looking at them as individuals rather than a collection of symptoms.
Bladder & Bowel Foundation	4.02	3.1.2	The Bladder & Bowel Foundation would like to see Incontinence listed as an example of a long term condition. Commonly individuals with any of the listed long term conditions such as coronary heart disease, diabetes hypertension etc will also have continence problems. It is often a hidden long term condition but significantly affects quality of life, dignity and choice.	Thank you for your comment. We do recognise that continence services are important to many older people with multiple long-term conditions, and that social care staff need awareness and skills to handle this sensitively. We do plan to consider continence and other areas in the review questions (see 4.5 of the scope).
Bladder & Bowel Foundation	4.03	3.2.2	The final sentence of point 3.2.2 could be expanded to read: The regular assessment and review of care and support needs, carried out in the home setting where possible, by up skilled care teams directly supported by specialist clinicians (e.g dementia nurse, continence nurse employed to work with care teams) should help to maximise quality of life and make best use of resources.	Thank you for your comment. We will be searching for evidence on what works in respect of the assessment and review of care and support needs.

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Bladder & Bowel Foundation	4.04	4.6	Incontinence should be cited as a focus point for analysis Paragraph 3	Thank you for your comment. Incontinence is a common condition, and will be considered here, but the examples given in the economic plan are not intended to be exhaustive.
Bladder & Bowel Foundation	4.05	General	Suggestion for the reference list: http://www.appgcontinence.org.uk/pdfs/CommissioningGuideWEB.pdf	Thank you for your comment and the link to a valuable reference which will be considered as we identify material to support guideline development.
British Association for Counselling and Psychotherapy	29.01	General	BACP welcomes the development of guidance on social care of older people with long-term conditions and is grateful of the opportunity to comment upon the draft scope.	Thank you for your comment.
British Association for Counselling and Psychotherapy	29.02	4.1.1	By referring to older people with "more than one long-term condition" being in-scope, the draft scope has excluded those with only one (diagnosed) long-term condition. However, many of those with one currently-diagnosed long-term condition will go on to develop further diagnoses of other long-term conditions (and around 30% will develop a co-morbid mental health condition). Appropriate social care interventions for those with one diagnosed long term condition, including counselling, could be seen as a preventative intervention with respect to such future diagnoses, so the social care of this cohort should be included in the proposed guidance.	Thank you for your comment. Thank you for your comment. We have amended the scope to make clear that the guideline focuses on social care of older people with complex care needs and multiple long-term conditions. Our remit from the Department of Health was to look at older people with more than one long-term condition and the scope emphasises the impact on people's lives. While the number of people with one long-term condition is projected to be relatively stable, there is evidence to suggest that the number of people with multiple conditions will grow significantly. The prevalence of long-term conditions is linked to ageing and older people with long-term conditions are at risk of discrimination in terms of access to and experience of services. We include prevention as an outcome (4.4) and have suggested a review question aimed at understanding the role played by social care staff in recognising and referring to common problems such as depression.
British Geriatrics	9.01	4.1.1 & 4.1.2	There will doubtless be debate as to what is meant by 'older' and 'younger adults' and so the guidance	Thank you for your comment. We have deliberately not specified a younger age

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Society			should be clear as to what is meant by these terms – i.e. above and below what age? The alternative would be to make the scope adults with social care – this is tantamount to meaning frailty and protects against ageism.	limit as this may entrench existing service inequities. However, our remit is older people, and conditions which become more prevalent or more disabling with age are likely to be most prominent in the guideline.
British Geriatrics Society	9.02	General	The overall scope seems fine otherwise	Thank you for your comment.
Care & Repair England	13.01	General	Whilst the guidance is focused on social care many of the chronic health conditions experienced by older people have a link to or are exasperated by poor and inappropriate housing. There is a causal link between housing and the main long term conditions (heart disease, stroke, respiratory, arthritis) whilst risk of falls, a major cause of injury, hospital admission and demand for care and support amongst older people, is significantly affected by housing characteristics and the wider built environment. The majority of older people wish to live independently in mainstream housing, often in their existing home, for as long as possible, but also wish to have a range of supported housing options available to them should they need or wish to move to a more suitable home. 90% of older people live in mainstream housing i.e. homes not specially built for older people (6% in sheltered / retirement housing/ 4% nursing care or other.) In meeting the social care needs of older people with long term conditions their housing circumstances, needs, housing options and solutions should be assessed and addressed and the scoping document should acknowledge the role and impact of housing	Thank you for your comments and the useful information therein, which will be considered by the Guidance Development Group. The guidance will include these areas to the extent that they relate to coordinated (health and social) care around the individual.

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			and look at what good practice might look like where housing factors and solutions have been considered to provide good social care. Practical measures such as warm, safe, well designed housing, effective delivery of home adaptations, the provision of supported specialist housing, aids, equipment and assistive technologies all have quantifiable effects with regard to health, well-being and independent living. There is wide and expanding evidence base concerning the value of housing interventions to care and health planning and provision. This includes evidence of enablement, the impact of supported housing, home adaptations and other environmental interventions such as falls prevention all of which is strong and well documented. We would draw your attention to three reports that have summarised this evidence base which might be highlighted in sections in the scope. (Under 'Current Practice' at Item 3.2 for example) • Pathways to prevention. Hact. (2011) • Housing, prevention and early intervention work: a summary of the evidence base. Housing LIN (2011) • On the Pulse from the National Federation of Housing Associations (2011) Other examples of how housing solutions, particularly home adaptations, can impact on social care interventions are: - - Falls and accidents can be significantly	

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			reduced by simple adaptations such as handrails. Rapid low cost adaptations to homes, as delivered by handypersons services, make savings of £1.70 for every £1 (savings to health, social care and police) - Housing prevention and early intervention at work: a summary of the evidence base (2011) - For older people, common care packages involve providing level access showers and /or stair lifts, to help them undertake tasks of daily living with little or no formal care. The cost of an average adaptation package is £6,000 but delaying entry into residential care saves £26,000 each year (average). - Heywood and Turner, Better Outcomes, Lower Costs, 2007. - Reducing the need for daily visits and other home care costs through adaptations can make significant savings to community care packages – a high cost package can be £850 a week compared to a very low cost package of £82 a week. - Unit cost of health and social care, Lesley Curtis PSSRU 2011 - In 2010, at least 4 million households had someone with mobility problems. Four key features can maximise people's independence and mobility (level access and flush thresholds; sufficient door width; circulation space; toilet on ground / entry floor) but only 1 million homes have these (5%) and 6 million (26%) have none. English Housing Survey DGLG (2010) Housing considerations need to be an integral part of providing good social care, making best use of resources and contributing to the maintenance of	

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			physical and mental health and remaining independent. This means in various areas in the scoping document there needs to be greater reference to housing factors. (These are picked up in the specific comments made in this submission).	
Care & Repair England	13.02	General	The impact of housing on health and wellbeing has been well demonstrated and there are calls for greater integrated working between health, social care and housing. There is also an imperative to integrate services around people's needs. The Social Care White Paper for example is clear in its aim to promote high quality housing to support individual choices. *Caring for our Future - Reforming care and support DH (2012)* The Social Care Guidance Manual includes in scope 'the support the development of inter-agency and inter-professional working.' With the national integration agenda taking shape and at pace it would seem appropriate that this standard considers how, in delivering good social care, housing factors are assessed and addressed in order to develop a quality approach that improves outcomes for people. The aim should be to encourage that integration at both a strategic (commissioning) and individual (assessment and delivery) level.	Thank you for your comment. The scope includes these areas to the extent that they relate to coordinated (health and social) care around the individual.
Care & Repair England	13.03	3.1	Key facts and figures - Suggest a reference to housing as a social determinant of health in a new section and make reference to – *Department of Health Fair Society, Healthy Lives (2010)*	Thank you for your comment and the suggestion for the guideline.
Care & Repair England	13.04	3.2.4	Current practice - Widen this section to make reference to social care, primary and secondary healthcare services and housing and also add a further section as follows '*The majority of older people wish to live independently in mainstream*	Thank you for your comment. The purpose of the scope is to provide a short summary of the issues around social care for older people with multiple long-term conditions and is not intended to outline current practice comprehensively.

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			housing, often in their existing home, for as long as possible, but also wish to have a range of supported housing options available to them should they need or wish to move to a more suitable home. 90% of older people live in mainstream housing i.e. homes not specially built for older people (6% in sheltered / retirement housing/ 4% nursing care or other.) Practical measures that help those at home such as warm, safe, well designed housing and the effective delivery of home adaptations and assistive technologies are crucial to enabling people with long term conditions to live comfortably at home'. This section should also make reference to reports on housing's role in prevention as follows: - - *Pathways to prevention. Hact. (2011)* - *Housing, prevention and early intervention work: a summary of the evidence base. Housing LIN (2011)* - *On the Pulse from the National Federation of Housing Associations (2011)*	The Guideline Development Group will consider the impact of the setting for delivery of coordinated care in the home. One of the stated outcomes (4.4) concerns avoidance of hospital admissions.
Care & Repair England	13.05	3.3.3	Policy - Suggest adding - *Laying the Foundations – A Housing Strategy for England (Section on housing and ageing p48) (Nov 11)*	Thank you for your comment and the information. The scope is intended to be a brief summary of the topic area. Thank you for the additional reference, which we will note for the main phase of guideline development.
Care & Repair England	13.06	3.4.1	Legislation and Guidance – include a reference to the integration of housing in the reference to the Care Bill. In particular housing is included in the definition of wellbeing and housing is now explicitly referenced in local council's duty to promote the integration of health and care.	Thank you for your comment. The scope is a short summary of the topic area. Thank you for the additional reference which is useful context for the main phase of guideline development.
Care & Repair	13.07	3.4.3	Add Home Adaptations for Disabled People - Care &	Thank you for your comment. We will include

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England			Repair England on behalf of the Home Adaptations Consortium (2013)	information on housing adaptations with a focus on how they facilitate the delivery of coordinated, person-centred care, and on how people access and have information about these services. We will not be reviewing the effectiveness of housing aids and adaptations per se.
Care & Repair England	13.08	4.3.1	As the Social Care Guidance Manual includes in scope 'the support the development of inter-agency and inter-professional working' we would propose that this section includes a reference to housing in the paragraph on integrated health and social care for older people. This would fulfil and take forward the expectations of the Care Bill in relation to the role of housing in this integrated agenda and would ensure that people's housing needs and aspirations are included in the development of personalised and integrated care and support for older people and their carers.	Thank you for your comment. The scope is a summary document which cannot give an exhaustive account of what will be covered. The guideline will include aspects of housing services to the extent that they relate to coordinated (health and social) care around the individual.
Care & Repair England	13.09	4.4	To reflect the consideration of housing circumstances and needs an outcome specific to housing would ensure that this aspect is considered when assessing and delivering good social care. Outcome – older people with one or more long term condition are able to retain their independence and make informed decisions about their accommodation and their care needs.	Thank you for your comment. The extent to which packages of care support and promote independence is within scope for this topic.
Care & Repair England	13.10	4.5	Review questions – add housing to the first question about integration	Thank you for your comment. The guideline will include these areas to the extent that they related to coordinated (health and social) care around the individual.
College of Occupational Therapists	6.01	General	The College of Occupational Therapists welcomes the development of this social care guidance for older people with long-term conditions. National guidance in this topic area has important implications for the profession as OTs are key to promoting and	Thank you for your comment.

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			supporting independence, wellbeing and participation.	
College of Occupational Therapists	6.02	General	Having reviewed the comprehensive notes from the stakeholder scoping workshop, it is clear how decisions have been made as to the areas that should be covered in the guidance, and the appropriate terminology to use. The College agrees with the content of the scope and looks forward to further involvement in the development of this guidance.	Thank you for your comment and support for the scope.
Department of Health	10.01	General	I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.	Thank you.
Diabetes UK	2.01	1 3.2.2 4.1.1 4.4 4.3.1	Inconsistence in terminology: *One or more* long-term condition is preferable (section 1 refers to: "More than one...")	Thank you for your comment. Thank you for your comment. We have amended the scope to make clear that the guideline focuses on social care of older people with complex care needs and multiple long-term conditions. .
Diabetes UK	2.02	3.2.2	Seem to be using one sentence to describe fluctuation in care circumstances for both the person receiving care and family/carers providing care. This would be better expressed in two separate sentences.	Thank you for your comment. We have edited the sentence for clarity.
Diabetes UK	2.03	3.22 (top p.4)	Sentence finishing: "...when proactive approaches could have avoided that" is clumsy. Suggest instead, "..when this could be avoided with a proactive approach."	Thank you for your comment. This text has been written to fit with NICE house style which advises that we should ensure use of the active voice in our publications.
Diabetes UK	2.04	3.2.3	We welcome the focus on the need for better co-ordination of services. It might be helpful here to illustrate the point with a practical example, e.g: dietary needs are currently the responsibility of social care whereas blood glucose monitoring and insulin administration lie with 'health'. Two aspects which need to be vitally linked are contrarily often in	Thank you for your comment. We agree that this is a good example of the need for services to work in partnership. We have deliberately kept this reference broad rather than providing a specific example so as to maintain focus on the issue of integrated services, rather than on specific conditions.

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			opposition.	
Diabetes UK	2.05	3.2.4	This clearly states the status quo. The need for change to address this is implied, but would be better made explicit.	Thank you for your comment. This section is to outline (very briefly, in a short document) the status quo, but the core of the work is covered in the activities (section 4.3.1 of the scope). The role of the guideline in addressing problem areas is briefly described at section 2.
Diabetes UK	2.06	3.2.5 3.2.6	The results of the recent national Diabetes care Home audit by The institute of Diabetes for Older People also supports these sections, e.g.: "64.5 per cent of care homes had no policy on screening for diabetes." "17.3 per cent of homes had no system in place to examine whether those who self-medicate for diabetes have taken their medication."	Thank you for your comment. The role of social care staff in recognising common conditions and making appropriate referrals is within scope for this guideline topic.
Diabetes UK	2.07	4.1.2	It is stated: 'Younger adults' are excluded from the guidance but the scoping workshop identified there may be opportunities to signpost to services for this group. This would appear to be inconsistent	Thank you for your comment. The guideline focuses on the needs of older people with long-term conditions. However, some recommendations may be relevant to planning care for younger adults.
Diabetes UK	2.08	4.3.1	Given the prevalence of diabetes in this target group it would be pertinent to add hypoglycaemia to this short example list	Thank you for your comment. We agree, especially as this is one of many conditions which could be spotted by social care staff: the included list is not exhaustive and is only intended to provide examples.
Diabetes UK	2.09	4.6	Again, given the prevalence, could we add diabetes to bracketed list in 3rd paragraph	Thank you for your comment. Diabetes is a common condition, and will be considered here, but the examples given in the economic plan are not intended to be exhaustive.
Doncaster Council	8.01	General	The document is clearly written and quite straight forward and covers issues from all aspects and equality of opportunity, there are no amendments required and we feel there is nothing we would wish to add.	Thank you for your comment.

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East Riding of Yorkshire Council	22.01	General	Advice in this subject area is relevant for the on-going development and maintenance of care standards and influences contract content.	Thank you for your comment.
East Riding of Yorkshire Council	22.02	2	The increasing numbers of older clients with learning disabilities do not appear to be included.	Thank you for your comment. People with learning disabilities are included within the population of interest, and flagged in the Equality Impact Assessment (published with the scope). That means that we will take particular steps, e.g. in identifying published evidence to support the guideline, to consider the impact of an individual's learning disabilities on their experience of service provision.
East Riding of Yorkshire Council	22.03	3.1.2	Evidence for the increasing needs of the population have far reaching implications for the provision of services. Complex clients will place huge demands on social care.	Thank you for your comment. The request to produce a guideline on this topic derives from these concerns. Thank you for your comment. We have amended the scope to make clear that the guideline focuses on social care of older people with complex care needs and multiple long-term conditions.
East Riding of Yorkshire Council	22.04	3.1.3	Quality of life, independence, choice, dignity and control are valid principles but very difficult to measure. Guidance would be helpful in assessing how these principles should be supported.	Thank you for your comment. We will ask the Guideline Development Group to consider this important point.
East Riding of Yorkshire Council	22.05	3.2.5	Integrated working is vital to support Care Homes. A local initiative has reduced hospital admissions by 40% due to having regular contact with an allocated GP.	Thank you for your comment. The scope covers care homes, and we will seek evidence on this very important outcome (see 4.4 of scope).
East Riding of Yorkshire Council	22.06	3.3.1	Quality of life is highlighted as a key priority for people with long term conditions. Without central funding and support to local authorities and community initiatives many of the services to provide such value will be lost. Examples include day care, community lift, dementia café, libraries and dinner clubs.	Thank you for your comment. We acknowledge the financial pressures faced by local authorities and ensure that recommendations made by NICE are informed by evidence of effectiveness and cost-effectiveness. However, NICE cannot comment on existing funding structures
East Riding of Yorkshire	22.07	3.4.1	Mention is made of 'promotion of wellbeing', the problem areas remain in mental health care and the	Thank you for your comment. Both mental health care and support for carers are

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Council			needs of carers.	within scope (4.3.1).
East Riding of Yorkshire Council	22.08	4.3.2	Homecare guidance and provision for transitions is welcome	Thank you for your comment. The links between this topic and the NICE social care guideline on Transition between health and social care will be made explicit in NICE pathways.
East Riding of Yorkshire Council	22.09	4.3.2	The exclusions from advice are logical, however healthcare interventions remain relevant. Advice should suggest the appropriate means of seeking healthcare interventions if treatments are not effective. The holistic care of a person with long term conditions may include a variety of social and health interventions, whilst this guidance may not judge the healthcare interventions it would be a serious oversight to not acknowledge access to the service.	Thank you for your comment. The guideline is primarily about social care support, but the issues of coordinated and personalised care, and of partnership working between health and social care practitioners, around the needs of the person with complex needs or multiple long-term conditions, is central to the topic (4.3.1 and 4.5). Cross-referrals between health and social care are within scope.
East Riding of Yorkshire Council	22.10	4.4	Who will be responsible for measuring the main outcomes and where will they be published?	Thank you for your comment. Dissemination of the guideline is considered throughout the guideline development process. The guideline will also form the basis of Quality Standards and associated indicators. NICE guidance and quality standards are not mandatory and are intended to support local quality improvement. Quality standards provide associated measures which can be used locally to benchmark performance and progress by commissioners and providers, and where relevant, at a national level. The NICE Implementation Consultants gather examples of good practice and shared learning where possible which can help with putting guidance and quality standards into practice
East Riding of Yorkshire Council	22.11	5.1	The relevant published guidance is identified	Thank you for your comment.
East Riding of Yorkshire	22.12	7	The references listed have good variety and are recent. There are few from the voluntary sector such	Thank you for your comment.

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Council			as Age UK.	
Epilepsy Action	26.01	General	Epilepsy Action welcomes the scope. Responses given at the scoping workshop have clearly been incorporated into this draft of the scope.	Thank you
Epilepsy Action	26.02	1 and 4.1.1	Epilepsy Action strongly believe that the scope (and subsequent guidance) should not be limited to older people who have two or more LTC. Severity of impairment and level of social care support required is not determined by number of health conditions a person has. The impact of the condition or conditions is what's truly important, particularly in prevention work. The one conditional approach does not fit into the model of 'prevention' as promoted in the Care Bill. Providing social care to a person with care and support needs (despite having only one LTC) might prevent or delay the need for higher level support and/ or the development of additional conditions and comorbidities (such as depression).Unexplained epilepsy in an older person and occurring for the first time may be an early presentation of cerebrovascular disease (Hanandi K, 2003. Epilepsy. In : Fillit HM, Tallis RC et al 2003. Brocklehurst's textbook of Geriatric Medicine and Gerontology. Oxford: Churchill Livingstone). The one condition approach does not take into account that many older people might have several LTCs, either unbeknown to the individual or perhaps undiagnosed. Treating epilepsy in the elderly is difficult and comorbidities might wrongly be attributed to their epilepsy, or as a side effect of their medication.	Thank you for your comments. Our remit from the Department of Health was to look at Older People with more than one long-term condition and the scope has been updated to emphasise the impact on people's lives to include those with complex needs and multiple long-term conditions. We have not specified which conditions are of interest in the scope, because we do not intend to exclude any particular conditions and also because specific conditions are the subject of clinical guidelines. This guideline aims to improve the way health and social care practitioners work together, focusing on the needs of the person and looking at them as individuals rather than a collection of symptoms. The scope includes prevention as an outcome (4.4). We agree that other conditions may not be diagnosed, or may be attributed to a diagnosed condition and the scope does not exclude this.

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Epilepsy Action	26.03	3.1.2	We agree that prevalence of long-term conditions is strongly linked to ageing. Around 154,000 (one in 67) people over the age of 65 living in the UK have epilepsy (JEC. Epilepsy prevalence, incidence and other statistics. 2011). The incidence of epilepsy in people aged 65-69 is 90/100,000. After the age of 80 this rises to 150/100,000. Cerebrovascular disease and Alzheimer's disease also become more prevalent with increasing aged and both are associated with an increased incidence of epilepsy (Epilepsy in later life, 2011)	Thank you for your comment. This is useful information which will inform the guideline.
Epilepsy Action	26.04	3.1.3 & 3.1.4 & 3.3.1	We strongly agree with and support these statements.	Thank you for your comment.
Epilepsy Action	26.05	3.1.5	Again we agree strongly. Evidence suggests a reciprocal relationship between depression and epilepsy, and people whose seizures are not controlled by epilepsy medicines have a higher risk of experiencing depression, but depression can also make epilepsy worse. Some of the reasons suggested for this pattern, is that being depressed can disturb sleep patterns while lethargy / forgetfulness, may increase non-compliance with medication.	Thank you for your comment. The relationship between physical and mental health, and their impacts on each other, is one of the drivers for this guideline.
Epilepsy Action	26.06	3.2.3	We strongly agree. Coordination of care requires true integration, a clearer explanation of what care is free, and what needs to be paid for partially or in full. It should also include details of direct payments and sign posting to voluntary organisations and for independent financial advice. Our experience has also shown that people and families need one point of contact and a key worker to enable them to navigate the transition between health and social care effectively.	Thank you for your comment. As part of guideline development, we will be making recommendations about 'what works' in coordinated care, based on the evidence reviews and the expert knowledge and experience of GDG members.

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Epilepsy Action	26.07	3.4.2	We agree with the statement that older people may not receive the same standard of care as younger adults. Variations in the standard of healthcare also exist among people with epilepsy. Older people are particularly vulnerable due to chronic lack of geriatricians with a specialist interest in epilepsy. Over time this may lead to an increased burden on social care support.	Thank you, we agree.
Epilepsy Action	26.08	General	The draft scope gives mention to mental health but has little in terms of older people with learning difficulties. More than one in five people with epilepsy have learning or intellectual disabilities (JEC stats, 2011). Up to a quarter of people with epilepsy have learning disabilities and a half of people with learning disabilities have epilepsy. The prevalence of epilepsy is estimated to lie between 15 and 30 per cent among people with learning disabilities (primary care resource pack, 2012). Increasing age, learning difficulties and epilepsy represents a unique challenge for social care, particularly in how the service will meet the standards laid out in the Care Bill.	Thank you for your comments and the information therein. Older people with learning difficulties are included within the population of interest, and flagged in the Equality Impact Assessment (published with the scope). That means that we will take particular steps, e.g. in identifying published evidence to support the guideline, to consider the impact of an individual's learning difficulties on their experience of service provision.
Healthwatch Sheffield	3.01	General	In many ways the scope of the document covers the aspects we would expect, however we were unclear as to whether the scope would include people abusing alcohol or people with an acquired brain injury. We feel it is important to make the links between those areas in central and local government which are working to tackle discrimination and removing barriers and health, with a view of moving away from the individual at the centre of focus.	Thank you for your comment. People with acquired brain injury are included within the population of interest, and flagged in the Equality Impact Assessment (published with the scope). That means that we will take particular steps, e.g. in identifying published evidence to support the guideline, to consider the impact of an individual's learning difficulties on their experience of service provision.
Healthwatch	3.02	3.1.4	Although the document speaks broadly about long	Thank you for your comment.

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Sheffield			term conditions the only specific reference seems to be in relation to socio-economic status and prevalence	We have not specified which conditions are of interest in the scope, because we do not intend to exclude any particular conditions and also because specific conditions are the subject of clinical guidelines. This guideline aims to improve the way health and social care practitioners work together, focusing on the needs of the person and looking at them as individuals rather than a collection of symptoms.
Healthwatch Sheffield	3.03	3.1.5	It states that older people are more depressed than are treated/understood but we do not know within this whether the other factors such as gender have an impact upon these rates.	Thank you for your comment. The scope is a short summary of the issues around social care for older people with multiple long-term conditions
Healthwatch Sheffield	3.04	3.2.4	We feel that configuration of mental and physical health services is important for all users, including children, as often mental health and social services are in a different trust and people with a physical disability can find it more difficult to access mental health services.	Thank you for your comment. This has been noted.
Healthwatch Sheffield	3.05	4.3.1	We would like to see this being more specific around access to information. We are aware that people find it incredibly difficult to manage their condition without intervention if the available options are not clearly understood.	Thank you for your comment. We agree that access to information is essential, and we believe this to be covered in 'access to information' and in 'support to self-manage' (4.3.1).
Housing Learning and Improvement Network (LIN)	1.01	General	a) There is no definition of social care in the document. Does it only include the needs of those who meet local authority FACS critical and substantial thresholds or is the term used more generally? b) There is insufficient recognition of the importance of dementia as a long-term condition which co-exists with many physical LTCs and sensory impairments. It finally gets included with depression on p 12. c) There is no mention at all of sensory impairments, which, whether defined as long-term conditions or	Thank you for your comments. a) Please note that the guideline will cover older people with social care needs who organise and/or fund their own care. We have not explicitly planned to include only people who meet FACs thresholds, but we perceive a problem in finding evidence about people who have social care needs that are not considered eligible for statutory funding. We have not ruled them out. Likewise, our definition of social care is flexible.

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			not, interact with other conditions to compound the problems faced. d) We are pleased to see the inclusion of sheltered and extra care housing as settings (para 4.2.1, see below), but the housing sector is not mentioned in the context of integration, interface with health and social care agencies, and in supporting improved outcomes for those living in their own homes with long-term conditions. The Housing LIN "healthwatch" webpages provide a dedicated section on housing and long term conditions at: http://www.housinglin.org.uk/Topics/browse/HealthandHousing/ We would welcome signposting to this in future. e) There is no mention of telecare and/or telehealth, although there is evidence of how this can play a significant contribution in caring for people with long term conditions at home. In the specific points below we identify where we consider the elements (in b-e) warranted being explicitly mentioned.	b) We are including dementia, but the scope does not list individual conditions, as this could result in some failing to be acknowledged. c) People with sensory impairments are considered with the Equality Impact Assessment (published with the scope). d) and e) the guideline will include these areas to the extent that they relate to an integrated and coordinated (health and social) care package around the individual's needs. Telecare is included in the scope for the guideline on home care
Housing Learning and Improvement Network (LIN)	1.02	3.1.3	No mention here of mental health LTCs or sensory impairments. Mental health conditions are mentioned in 3.1.5, but only in relation to depression. Given the point in 3.2.5 about the evidence of mental health needs not being addressed, this document needs to give mental health needs and dementia as well as depression more prominence.	Thank you for your comment. Older people with dementia and other long-term conditions are included in the scope. We have not specified which conditions are of interest in the scope, because we do not intend to exclude any particular conditions. We have used depression (e.g. at 3.1.5, and in the review questions, 4.5) as an example of a mental health condition because it is common and linked to long-term conditions. People with dementia, people with sensory impairment and people with severe mental illness are included within the population of interest, and flagged in the Equality

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				Impact Assessment (published with the scope). That means that we will take particular steps, e.g. in identifying published evidence to support the guideline, to consider the impact of these conditions.
Housing Learning and Improvement Network (LIN)	1.03	3.2.2	Same applies. No mention of dementia or sensory impairments.	Thank you for your comment. We have not specified which conditions are of interest in the scope, because we do not intend to exclude any particular conditions.
Housing Learning and Improvement Network (LIN)	1.04	3.3.2	Again, no mention of dementia despite the inclusion of the Dementia Strategy in the document list in 3.3.3	Thank you for your comment. Dementia is in scope, but we have not specified which conditions are of interest in the scope, because we do not intend to exclude any particular conditions.
Housing Learning and Improvement Network (LIN)	1.05	3.4.1	Is now referred to as the Care Bill	Thank you for your comment. We have altered the reference in the scope.
Housing Learning and Improvement Network (LIN)	1.06	3.4.3	Document reference to the Bill needs updating	Thank you for your comment.
Housing Learning and Improvement Network (LIN)	1.07	4.3.1	Mention of integration and interfaces should include the housing sector, for example extra care and sheltered scheme managers, housing-related support staff, providers of assistive technology devices (including telecare/telehealth), and care call services. Interface with the voluntary/community sector which provides social support may also be seen as relevant.	Thank you for your comment. The guideline will include these areas to the extent that they relate to coordinated (health and social) care around the individual. We have included (4.3.1; 4.5) reference to voluntary/community sector care which promotes social participation.
Housing Learning and Improvement Network (LIN)	1.08	4.3.2 last bullet point	We appreciate that this point covers what is excluded from the scope. However, when the scope for transitions is drawn up, the transition to housing settings, in particular extra care housing should be included.	Thank you for your comment, which we will share with the project team managing the NICE social caret guideline on Transition between health and social care.

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Housing Learning and Improvement Network (LIN)	1.09	4.5	On the integration theme, sometimes it is integrating social care and housing that is needed, e.g. adaptations to a property for someone with mobility problems, installation of assistive technology for someone with dementia, so this needs to be included in the first question, where relevant. Dementia needs to be added to bullet point 5 along with reference to safeguarding	Thank you for your comment. We will include information on housing adaptations that emerge with a focus on how they facilitate the delivery of coordinated, person-centred care, and on how people access and have information about these services. We will not be reviewing the effectiveness of housing aids and adaptations per se.
Leonard Cheshire Disability	12.01	General	We welcome the development of guidance on older people with long term conditions. We hope this will support people to live longer and healthier lives and reduce variations in health outcomes for this group. This guidance has an important role to play in supporting the development and delivery of personalised social care services for older people which respond to individual needs and focus on achieving outcomes. In particular, it is important that this guidance focuses on improving people's quality of life through the delivery of integrated, person-centred services which reflect individual needs and desired outcomes. To this extent it is important that this guidance focuses on the *impact* of long term conditions and how people can achieve improved outcomes rather than simply focusing on the conditions themselves and the processes put in place to manage them. It is important to gather qualitative evidence from people using services and their carers to supplement quantitative data in the development of this guidance.	Thank you for your comments. We agree with the points made and the approaches suggested: social care guidelines are particularly concerned with improving the life of the person as a unique individual.
Leonard Cheshire Disability	12.02	General	**Terminology** It is vital that people are treated as equal partners in the planning of their care and support and that	Thank you for your comment about the use of language and the need to consider care which is holistic, person-centred and tailored to the

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			practitioners take a holistic person-centred approach to working with people with social care needs. To support this, it is important that the right language is used when referring to people receiving social care support. In particular, it is important to avoid using the term 'patient' to refer to people using social care services as this reflects an overly medicalised approach to care and support. In addition, it is preferable to avoid using the term 'service user' and instead to talk about 'a person' or 'people' where possible. Referring to people as 'service users' can imply a 'one size fits all' approach to service delivery and is not reflective of person-centred approaches which focus on individual needs, preferences and strengths and put people at the centre of decisions about their care and support.	individual's expressed needs and desires.
Leonard Cheshire Disability	12.03	4.1.1	**Groups that will be covered** We feel that the scope of this guidance should be extended to include people with a single long term condition (LTC) in order to promote equality of support, and access to services, in relation to disability. 58% of people over 60 have at least one LTC and it is important that they can benefit equally from this guidance alongside the 25% of people over 60 who have two or more LTCs.[1] Older people with a single LTC are at increased risk of developing additional LTCs and therefore it is particularly important that that they are supported to access and benefit from preventative and early intervention services to help prevent, postpone or delay the onset of additional needs. This is not only beneficial for individuals, supporting them to live	Thank you for your comment. We have amended the scope to make clear the focus is on those with complex care needs and multiple long-term conditions, which need support from social care. .. Our remit from Department of Health was to look at Older People with more than one long-term condition and the scope emphasises the impact on people's lives. Thank you. Care which delivers delays or slows the progression of long-term conditions is in scope (4.4).

[1] Department of Health, *Long Term Conditions Compendium of Information*, (2012).

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			longer, healthier lives, but is also economically beneficial for health and social care services. In addition, focusing only on people with two or more LTCs will exclude people with a single LTC who may need a high level of care and support from multiple health and social care teams. People with complex support needs will benefit most significantly from increased integration of health and social care services and therefore it is important that they are able to benefit from guidance on integrated health and social care. **Age group** From a regulatory perspective, we would appreciate some further clarification on the exact age group that this guidance will be applicable to. However, we hope that there will be a degree of flexibility around this to ensure that people can access the services and support that most fully meets their needs and are not moved between teams and services simply as a result of their age.	Thank you. We have deliberately not specified a younger age limit to provide a degree of flexibility.
Leonard Cheshire Disability	12.04	4.2.2	**Settings that will not be covered** We would appreciate clarification on whether 'care provided in NHS settings' includes people funded by NHS Continuing Healthcare in social care settings. A large proportion of older people with long-term complex health needs living in care homes with nursing are funded through Continuing Healthcare and it is important that they are able to benefit from this guidance.	Thank you for your comment. We are not excluding people funded by NHS Continuing Healthcare, provided that they are in receipt of social care (in the community or in care homes). We have made this clear in the scope (see section 4.1.5).
Leonard Cheshire Disability	12.05	4.3	**Integration** More effective integration between health and social care services is essential to ensure smoother	Thank you for your comment. We intend to cover all these areas in the guideline.

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			transitions for people with complex needs moving between hospital and community settings. Person-centred coordinated care is essential to ensure that people are receiving the care and support that it most appropriate for them and that, where possible, they can remain in community settings (either in their own home or in residential care). This will require more collaborative working between NHS and local authority commissioners and providers of health and social care services. In addition, people will benefit from multi-disciplinary case management, systematic follow-up, and more integrated working between professionals– for example between mental and physical health professionals and health and social care professionals.	
Leonard Cheshire Disability	12.06	4.4	**Main outcomes** We would like to see the inclusion of 'wellbeing' as a specific outcome of care and support. While we appreciate that this outcome is partly encompassed by guidance on promoting preventative approaches and looking at how people can be supported to participate actively in their communities, we feel that it would be useful to include this concept more fully. The concept of wellbeing is central to the Care Bill and is an essential part of looking at the whole person and considering how to most effectively support them. Therefore it is important that this concept is promoted effectively in this guidance.	Thank you for your comment. We have included 'mental wellbeing' in the scope (see outcomes, 4.4) and also recognise that many of the outcomes listed in scope are also likely to contribute to broad wellbeing outcomes.
Marie Curie Cancer Care	20.01	General	Many older people with long term conditions will be imminently facing the end of life, whether because they develop a terminal condition or because one of their long term conditions enters a terminal phase. We ask that NICE ensures that end of life care is	Thank you for your comment. End of life care is referenced in the Equality Impact Assessment, (published with the scope). That means that we will take particular steps, e.g. in identifying published evidence to support the guidance, to

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			reflected in the final older people with long-term conditions guidance. Research by the Nuffield Trust (Social Care and Hospital Use at the End of Life, 2010) has shown that the more long term conditions a person has at the end of life, the more hospital care they consume. Further research by the Nuffield Trust (Understanding Patterns of Health and Social Care at the End of Life, 2012) showed a link between use of local authority funded social care and reduced hospital costs. We know from our experience as a provider of palliative and end of life care that where people have access to high quality social care, they are less likely to experience inappropriate emergency admissions and therefore less likely to die in hospital. For this reason, social care is an essential part of ensuring that people at the end of life, with long term conditions, are able to be cared for and die in the place of their choice. Our patients and their families do repeatedly experience issues with social care, however, primarily around access. The current system of applying for local-authority funded social care does not work well for people who are terminally ill. It is not uncommon to hear of terminally ill people waiting 30 or more days to hear about whether they are entitled to local-authority funded social care. Often they will be in hospital while they wait to hear the outcome of their application. We know of cases where people have died while waiting for a local authority to come to a decision. The Government recently amended the Care Bill to	consider the needs of this group. We will also consider access issues, as this is of huge consequence to people at the end of life. Thank you for your offer, which we will pass on to the Guideline Development Group.

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			make clear, on the face of the Bill, that local authorities have the power to treat terminally ill people as urgent cases (ie, to fast-track their applications for care and put a care package in as soon as possible). We ask that NICE reflects this in their older people with long-term conditions guidance as best practice in situations where someone with multiple conditions reaches a terminal phase. We know also from our experience that not all homecare staff feel adequately trained or prepared to work with people in a palliative phase. Research in 2010 found that around two thirds of homecare workers had no training in palliative care and just over half felt the need for further training in palliative care. (Devlin, McIlfatrick. Providing Palliative and End of Life Care in the Community: the role of the home-care worker. 2010). We would ask that NICE highlight this particular area when looking at the training needs of social care workers who provide care to older people with long term conditions, who will need to be prepared for when the people they care for reach a palliative phase. If required, we would be pleased to provide further feedback and evidence to the Review.	
MND Association	14.01	3.1.1	We are concerned that the draft scope's definition of a long-term condition could lead to people with a diagnosis of motor neurone disease (MND) being excluded from the guidance. It cannot accurately be said that MND can be 'managed by use of medication or other therapies'.	Thank you for your comment. The definition of a long-term condition at 3.1.1 of the scope ('one that cannot currently be cured but can be managed...') is certainly intended to include MND. We have not specified which conditions are of interest in the scope, because we do not intend to exclude any particular conditions.

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			MND is terminal and progressive, and cannot be made stable – the the best that can be done is to delay progression somewhat and maximise quality of life that can be achieved under the circumstances. We do not believe that excluding a rapidly progressive condition such as MND from this guidance is appropriate. We believe that if MND is not to be covered by the guidance on long term conditions, then it will likely fall entirely outside the scope of all NICE guidance. We believe that this would be an unacceptable failing, and that this section must therefore be amended to make clear that degenerative neurological conditions are included within the scope.	The aims of social care as described in the scope are consistent with a focus on quality of life and preventing or slowing progression (see the outcomes section of the scope, 4.4).
MND Association	14.02	4.1.1	The Association does not believe that there is good reason for limiting the scope of the guidance solely to people with more than one long-term condition. We are concerned that limiting the scope to people with a single diagnosed long-term condition will lead to many of the people who would benefit the most from this guidance being excluded. We foresee a number of issues with this limitation that could impact on the number of people likely to be included within the scope of this guidance. Firstly, limiting the scope to people with more than one long term condition will create an anomaly for those people who are living with a single but complex issue, with several symptoms, multiple and different care and support needs. A person living with MND is likely to have several distinctive care needs, covering communication, mobility, nutrition, and others. We do not believe it would be uncommon for a person living	Thank you for your comment. Thank you for your comment. We have amended the scope to make clear that the guideline focuses on social care of older people with complex care needs and multiple long-term conditions. Our remit from the Department of Health was to look at Older People with more than one long-term condition and the scope emphasises the impact on people's lives. We have not specified which conditions are of interest in the scope, because we do not intend to exclude any particular conditions. The guideline development work will consider the impact of the more common conditions which are not diagnosed, or are wrongly attributed to the 'primary' condition. The guideline will be concerned with how social care staff can be assisted to recognise the

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			with MND to have more complex social care needs than people with multiple conditions. Likewise, we are concerned at the possibility that people with undiagnosed secondary long term conditions will be erroneously left outwith the scope of the guidance. In many cases, the effects of MND will be of such an extent that they would overwhelm the impact of other long-term conditions that a person may have. We fully agree with the points made at the stakeholder workshop surrounding the number of older people with one major long term condition who will also be living with one or more other conditions that, because of the impact of their primary diagnosis, remain undetected. For these reasons, we strongly believe that the scope should be amended to include all people with one or more long term conditions.	likelihood of other long term conditions and support needs.
MND Association	14.03	4.1.1	We welcome the inclusion of carers in the scope for the guidance.	Thank you for your comment.
MND Association	14.04	4.1.2	Although the Association understands the explained rationale for limiting the scope of this guidance to 'older people' we are nevertheless concerned about the possible implications. MND largely affects an older population; however there is a sizeable minority of people with the condition who are of working age. If younger adults are not to included within the scope of this guidance, we question what will cover social care for working age adults. We do not believe that a sufficient case has been made as to why their care needs should not be covered by this guidance.	Thank you for your comment. The scope focuses on the needs of older people with multiple long-term conditions, which was the remit from Department of Health. While we recognise that younger adults can also have complex care needs, the link between ageing and long-term conditions and the discrimination that older people can experience provides the rationale for focusing the guideline in this way. However, the guideline may be of interest to providers of services to younger people, and we will consider this when disseminating the guideline.
MND	14.05	4.3.1	We particularly welcome the inclusion of integrated	Thank you for your comment. The guideline is

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Association			health and social care. MND is a diagnosis that has heavily medical care needs; many of the social care demands for a person living with MND cannot easily be separated from the health care that they are receiving. We believe it is vital that this integration in services is properly recognised by new guidance as it is developed.	focused on the delivery of person-centred services that focus on the individual, rather than a collection of symptoms.
National Voices	7.01	General	Overall, National Voices welcomes the recognition of the need for a more joined up approach for older people with health and social care needs. We would, however, like to question the decision to limit the scope to those with more than one diagnosed long term condition. We believe that this goes against the Government's intended focus on wellbeing and prevention (e.g. Clauses 1 and 2 of the Care Bill – as recognised under 3.4.1 of the draft scope) and commitment to more person-centred approaches that can support earlier identification and better management of risk factors (e.g. the Mandate, the participation guidance for CCGs). Much of the evidence included in the draft equally applies to those with one or more long term conditions, with the key distinctions focusing on the stability of the numbers and the costs imposed. As recognised in the document itself under 3.1.5, having one or more long term condition places a person at greater risk of mental health problems, just as older people who have had a long term mental health problem have poorer physical health outcomes: a two-way causality. As you recognise in 3.2, the approach set out in this scope document would go some way to addressing some of the current challenges relating to uncoordinated care and support for people with one or more long term conditions and encourage a more	Thank you for your comment. Thank you for your comment. We have amended the scope to make clear that the guideline focuses on social care of older people with complex care needs and multiple long-term conditions. Our remit from the Department of Health was to look at Older People with more than one long-term condition and the scope emphasises the impact on people's lives. We also recognise that many conditions are undiagnosed, and we propose to consider how social care practitioners may be able to recognise and respond, by referral or signposting, to common conditions (section 4.5).

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			proactive approach towards regular review, maximising quality of life and enabling a person to stay and live well. Excluding people with a single diagnosed condition would seem to risk increasing the number of, and therefore costs associated with, people with multiple long term conditions further, due to a lack of proactive support following the diagnosis of the first condition. There is also an argument in relation to patient outcomes. Under 3.2.2, it's noted that many people with long term conditions have other conditions too, including depression, which have not been recognised or treated. Junger et al (2005), for example, found that patients with chronic heart failure are eight times more likely to die within 30 months if they have depression. There is also evidence to indicate that co-morbid mental health problems can reduce a person's ability to actively manage their own physical condition, and are associated with unhealthy behaviours such as smoking. If people with one diagnosed condition are excluded from the scope of this guidance, the chances of picking up on these issues through active case finding and putting the relevant support in place to prevent the development of additional conditions are significantly reduced.	
National Voices	7.02	3.3.3	This section should also make a link to National Voices' 'Narrative for coordinated care'. This can be found here: http://www.england.nhs.uk/wp-content/uploads/2013/05/nv-narrative-cc.pdf We would also recommend making a link to TLAP's Making it Real Initiative. More information can be found here: http://www.thinklocalactpersonal.org.uk/Browse/mir/?	Thank you for your comment. The scope is intended to be a brief summary of the topic area. Thank you for the additional information, which we will share with the Guideline Development Group.
National Voices	7.03	4.3.1	National Voices welcomes the recognition of the	Thank you for your comments, and the extensive

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			importance of personalised care and support to improve quality of life, maintain independence and ensure that carers are adequately supported. In collaboration with our members and partners, National Voices has created some Principles of Care and Support Planning. More information on this project can be found here: http://www.nationalvoices.org.uk/principles-care-support-planning These aim to encourage a common understanding of what care and support planning should look like across health and social care – enabling people to have a conversation with a professional about what they would like to do, and what sort of care, support and independent actions could help them get there. The approach we set out encourages professionals to start from the perspective of the person, breaking down the artificial silos of health and social care and consider how shared decision making, prevention (living and staying well) and support for self management are all built into the approach, alongside consideration of care and support options (including the local VCS offer). The approach also spells out a role for a 'facilitator' who would: • support the person in identifying what they want to achieve; • connect them to what is available locally; • work with other professionals to ensure that the person gets best treatment, care and support and specialist advice where required; • and make sure that the package of care and support can be delivered and happens as agreed.	references to National Voices resources. We will be considering different models of organisation, integration and personalisation in care.

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			This approach encourages professionals to look at a person's physical and mental health as a whole and advocates more multi-disciplinary and inter-professional working to ensure they are supported as effectively as possible. In health, various documents - including the Mandate and the recent participation guidance to CCGs - commit to ensuring that everyone with a long term condition should have a care plan that reflects their preferences and agreed decisions, and helps them develop the skills knowledge and confidence to manage their own health. As highlighted above, this stresses the importance of people with a single long term condition being included within the scope. National Voices has also created a Narrative, which sets out what person-centred, coordinated care would feel like to a person experiencing it. More information on this can be found here: http://www.nationalvoices.org.uk/defining-integrated-care	
National Voices	7.04	4.4	We welcome the focus on evidence in relation to preventive effects, such as delaying the onset of, and slowing the progression of, long term conditions. However, we believe that this should focus on those with a single diagnosed condition too.	Thank you for your comment. Thank you for your comment. We have amended the scope to make clear that the guideline focuses on social care of older people with complex care needs and multiple long-term conditions. Our remit from the Department of Health was to look at Older People with more than one long-term condition and the scope emphasises the impact on people's lives. We have not specified single conditions within the scope, because we do not intend to exclude any particular conditions. In addition, specific conditions

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				are the subject of clinical guidelines. This guideline aims to improve the way health and social care practitioners work together, focusing on the needs of the person and looking at them as individuals rather than a collection of symptoms. Furthermore, while the number of people with one long-term condition is projected to be relatively stable, there is evidence to suggest that the number of people with multiple conditions will grow significantly.
National Voices	7.05	4.6	We believe that this section should also consider the potential preventative effective of voluntary and community services, in addition to the formal social care offer. It is important for professionals to consider when and how it might be useful to signpost the people they work with to alternative forms of support, which, for example may mitigate the social impacts of medical issues (e.g. buddying schemes, peer to peer support etc.).	Thank you for your comment. The impact of voluntary and community services on social participation is within scope. We will consider the areas that lend themselves to economic modelling in collaboration with the Guideline Development Group and then develop the economic plan accordingly.
Royal College of Nursing	24.01	General	The Royal College of Nursing welcomes proposals to develop this social care guidance. It is timely. The draft scope seems comprehensive.	Thank you for your comment.
Royal College of Nursing	24.02	2	*Proposed exclusions:* As raised in the workshop, we strongly believe there needs to be careful consideration and inclusion of those people who develop neuro-degenerative conditions at an earlier age in this scope. This group often present with more than one long term condition and/or mental health needs and as such they often have similar care/ nursing needs, e.g. those with Parkinson's Disease, multiple sclerosis and early onset dementia. To exclude them would run the risk	Thank you for your comment. Our remit is to focus specifically on older people. However, the guideline may be of interest to providers of services to younger people, and we will consider this when disseminating the guideline. Older people with conditions which developed at an earlier age are within the population of interest.

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			of services not being aware of their needs and not being made available.	
Royal College of Nursing	24.03	4.3.1	We would ask for some reference to malnutrition in older people and refer the developers to the work that the Malnutrition Taskforce has undertaken www.malnutritiontaskforce.org.uk/	Thank you for your comment. Malnutrition is within the remit of the proposed review question (4.5, 5th bullet point) which gives examples of need which social care staff may identify and refer on.
Royal College of Nursing	24.04	4.3.1	The guidance should also make some reference to nurses working in care homes and link to specialist nurses working in the community caring for the older person i.e. district nurses, community matrons, care home liaison teams, dementia specialist nurses. The draft seems to reference care workers only.	Thank you for your comment. The guideline is primarily about social care support, but the issues of coordinated and personalised care, and of partnership working between health and social care practitioners, around the needs of the person with long-term conditions, is central to the topic (4.3.1 and 4.5).
Royal College of Nursing	24.05	General	The term residential care is used several times in the document - can this be changed to care homes to ensure that it is inclusive and follows the terminology used by the regulator?	Thank you for your comment. We have made this change in the scope.
Royal College of Nursing	24.06	Page 2	See 'Falling/wandering'- It is not helpful to use the term 'wandering' as this is not an indication of frailty and is not meaningful as it may have multiple causes. Immobility, delirium, incontinence, dementia/ delirium, polypharmacy and end of life are more accurate indicators for frailty.	Thank you for your comment, which we understand refers to the stakeholder workshop report. It is agreed that this is not an indication of frailty
Royal College of Nursing	24.07	Page 3	'Whose impact necessitates high involvement with social care' – add 'or potential involvement'	Thank you for your comment.
Royal College of Nursing	24.08	Page 4	'The delivery of care to older people'- perhaps use a different terminology? To differentiate between delivery of items such as milk and papers...? Would a better term be 'care and support'?	Thank you for your comment. We have amended the scope so that the 'Areas that will be covered' (4.3.1) refer to 'care and support'.
Royal College of Nursing	24.09	Page 4	Personal budgets not mentioned in full – there is no mention of choice and flexibility determined by the older person.	Thank you for your comment. Personal budgets are in scope, as are self-funders.
Royal College of Nursing	24.10	Page 4	Housing with care has no real feature here as an option for older people.	Thank you for your comment. The guideline will include housing support only to the extent that it

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				relates to coordinated (health and social) care around the individual.
Royal College of Nursing	24.11	Page 4	'Care and support' – prefer this terminology	Thank you for your comment.
Royal College of Nursing	24.12	Page 9	Community nurses - not mentioned in the list	Thank you for your comment. We agree that community nurses are a vital aspect of healthcare support for older people, and did not mean to exclude them.
Royal College of Nursing	24.13	Page 9	Residential care - can this be changed to Care Homes the term used by the regulator?	Thank you for your comment. We have made this change.
Royal College of Physicians	15.01	General	Please take this email as confirmation that the RCP wishes to endorse the response submitted by the British Geriatrics Society on the above draft scope	Thank you for your comment.
Royal College of Psychiatrists	23.01	General	In terms of the NICE Equality Impact Assessment scoping exercise informing this draft social care guidance for older people with long term conditions, the reasons for not setting an age threshold of 65 are clearly articulated. The scoping states that there is no wish to promote a view that adults of a particular age should have different services and standards of care.	Thank you for your comments.
Royal College of Psychiatrists	23.02	3.3.2	The National Mental Health strategy referenced in the scoping in 3.3.2 expects services to be age appropriate and non discriminatory.	Thank you for your comment. The guideline will reflect these values and the scope should be read in conjunction with the Equality Impact Assessment.
Royal College of Psychiatrists	23.03	General	Current evidence strongly suggests specialist old age mental health services staffed and managed by professionals who have expertise in meeting the complex mix of psychological, cognitive, behavioural, physical, functional and social problems relating to ageing.	Thank you for your comment.
Royal College of Psychiatrists	23.04	General	There has been a very worrying replacement of old age services with 'ageless 'or age inclusive' services in some parts of the UK with a split between these	Thank you for your comment. Although we have not set a lower age limit for this guideline, we are committed to exploring the experiences of older

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			services and 'dementia only' old age services created .These emerging models do not reflect the multi morbidity articulated earlier in the scoping document and are unlikely to provide the sort of joined up holistic care for patients with complex multiple long term conditions which can include dementia	people, and how these might be improved.
Royal College of Psychiatrists	23.05	3.2.3	In 3.2.3 and 4 the scope articulates the need for joined and coordinated services. The Old age faculty would support the specific inclusion of the words 'mental health services' in addition to secondary care as this split of services is the most significant one in terms of under recognition and treatment of mental health problems in older people	Thank you for your comment. Integration between service levels, and between physical and mental healthcare are central to the remit and scope for the guideline. We have edited 3.2.4 to make clear that mental health services are included.
Royal College of Psychiatrists	23.06	3.2.1	In 3.2.1 some of the inequalities and discrimination when resources are addressed are related to a lack of parity of esteem and training opportunity in Post graduate medical training in exposing all doctors in training in psychiatry to enable the future medical workforce across primary and secondary care to recognise and treat mental health problems .These challenges are articulated in HEE ' Better Training Better Care' and Shape of Training; specific recognition of what specialist training in Old age psychiatry to the care of patients in an ageing population cannot be understated. HEE will have a role in the training of multi professional workforce; all doctors require a strong skill set in the delivery of care and treatment to patients with mental health problems to contribute to patient care and the training of other professionals	Thank you for your comment. Healthcare services are not in scope for this guideline, although integrated care services, and coordination and liaison between different providers, is in scope.
Royal College of Psychiatrists	23.07	General	Generally the scope has considered the equality issues related to all protected characteristics. I have written below two points worth considering within the scope of the document	Thank you for your comment.

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Royal College of Psychiatrists	23.08	4.1.1	In relation to the 4.1.1 Groups that will be covered 1. Older people with long term conditions and caring role (caring for an individual with Intellectual disability for example) could place particular difficulty in accessing services even with one long term condition. 2. Older people with disability (E.g.: ID) may have difficulty even with one long term condition.	Thank you for your comment. We have not specified which conditions are of interest in the scope, because we do not intend to exclude any particular conditions. People with intellectual and physical disability are in scope.
Royal College of Psychiatrists	23.09	General	The overall the scope is quite thorough and covers all relevant areas.	Thank you for your comment.
Royal College of Psychiatrists	23.10	General	There are several current NIHR funded programmes which focus upon the psychosocial aspects of LTCs. Most of these programmes involve the study of people with multi-morbidity. In addition to reviewing the literature the consultation should seek to incorporate findings from current ongoing research which can be fast tracked into clinical services. This is a direct aim of NIHR.	Thank you for your comment. When we begin to identify evidence to set against the review questions, we will certainly consider NIHR programmes of research in progress.
Royal College of Psychiatrists	23.11	General	The link between multimorbidity depression and social deprivation in older people needs to be highlighted, with a focus upon delivering integrated care which addresses physical, psychological and social needs.	Thank you for your comment.
Royal College of Psychiatrists	23.12	General	The guidelines should consider the inclusion of both old age psychiatry and liaison psychiatry experts to provide expert opinion regarding the care of older people with LTCS, both in primary care and the general hospital, and other settings.	Thank you for your comment. The guideline is on social care specifically, but certainly will cover how it is integrated with psychiatry and other clinical specialisms. Your point about liaison psychiatry experts appears important.
Royal College of Psychiatrists	23.13	General	The guidance should think specifically about information sharing systems and linking different sources of information about patients and how best to disseminate assessments and patient contacts. What is the evidence is for the use of shared IT	Thank you for your comment. Information sharing is a vital part of integration, which we will consider within the guideline.

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			systems in co-ordinated care models.	
Royal College of Psychiatrists	23.14	General	Care planning is mentioned in the scope. It would be good to examine this more closely. What exactly does this mean? What is the best model for care planning? How does care planning affect outcomes? What are the best systems for effective care planning? It is very easy to get this wrong or for care plans to be filled in and then thoroughly ignored by all concerned because they have no practical use in patients' care. How are psychological and social services integrated into physical health.	Thank you for your comment on the questions for review.
Royal College of Psychiatrists	23.15	General	People with chronic severe mental illness are very likely to be disadvantaged and should be examined closely in the guidance so we are pleased this group are mentioned specifically.	Thank you for your comment, with which we agree.
Royal Pharmaceutical Society	28.01	General	The Royal Pharmaceutical Society welcomes NICE Social Care Guidance for Older People with Long-Term Conditions. We recognise that management of long term conditions is a core business of the NHS and is set to be more so as the number of patients living with a long-term condition continues to rise. The recently published RPS *Now or Never: Shaping pharmacy for the future* report (http://www.rpharms.com/models-of-care/report.asp) recommends that "joint working needs to be built around a shared commitment towards improving ultimate outcomes for patients". Pharmacy, as the third largest health profession, with universally available and accessible community service, has a central role to play in assuring the safe and consistent use of medicines and as a provider of wider care, in primary, social and acute care.	Thank you for your comments and the information contained therein.
Royal	28.02	General	We agree with the proposals for the scope and look	Thank you for your comment.

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Pharmaceutical Society			forward to viewing and commenting on the draft guidance.	
Royal Pharmaceutical Society	28.03	4.3.2	We support the development of guidance for transition between hospital and community or care settings, although it is not within the scope of this guidance. We agree that it is necessary to cross reference to this guidance as necessary. Recommendations will need to be aligned as some healthcare professionals involved in providing services to patients in social care, such as pharmacists, are also involved in providing care to those transferring between care settings.	Thank you for your comment. The links between this topic and the NICE social care guideline project on Transitions between health and social care will be made explicit in NICE pathways.
Royal Pharmaceutical Society	28.04	7	Some additional guidance from the RPS that might be of relevance: *Now or Never: Shaping pharmacy for the future. Future Models of Care delivered through pharmacy.* http://www.rpharms.com/leading-on-nhs-reforms-for-pharmacy/models-of-care.asp *Keeping patients safe when they transfer between care providers – getting the medicines right.* http://www.rpharms.com/medicines-safety/getting-the-medicines-right.asp *Medicines Optimisation: Helping patients to make the most of medicines.* http://www.rpharms.com/promoting-pharmacy-pdfs/helping-patients-make-the-most-of-their-medicines.pdf	Thank you for your comment, and the references to safe management of medicines. We will refer these on to the Guideline Development Group.
Self management UK	5.01	4.4	No reference to self-management programmes such as Self-Management for Life Patients or the evaluation tool for self-reported behavioural change Health Education Impact Questionnaire	Thank you for your comment. Self-management is in scope, to the extent that it is part of a wider package of social care support.
Self	5.02	4.5	Self-Management for Life for Patients offers tools,	Thank you for your comments, and the information

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management UK			skills for people with long-term conditions to self manage and feel more in empowered, confident and in control. The programme reduces isolation as face to face and if part of a wider offering such as local groups, coffee morning's isolation is further reduced. Self-Management for Life Carers offers tools and skills for people who care for people with long-term conditions. Self-management is no 1 on the Kings Fund Report – 10 priorities – Transforming our health care system – April 2013. Self-Management for Life for care professionals in how the support people to self-manage. Self management uk are able to support organisations to devised the most appropriate offering for self-management for people with long-term conditions and their carers. As well as providing training in supporting self-management for care home staff. All evaluated using Health Education Impact Questionnaire for behavioural change. As stated by the Kings Fund that '70-80% of people can self-manage.' Kings Fund Report – 10 priorities – Transforming our health care system – April 2013. Self management uk, offers a range of interventions and courses that support people to stay well and live independently. This could be part of the long-term care package – in a co-production to ensure that individual's needs are met in an equal and reciprocal relationship - supporting personalisation and	contained therein. Support to self-manage as part of a wider package of social care support is in scope (4.3.1).

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			reducing isolation. The tools of self-care/management are helpful in making the right decisions for support and also to help one's self. The programme reduces isolation as people attend the course and continue to meet up after the course end. Self management uk has developed a web portal to further support the self-management community for all who have attended a course so that they can continue to gain the benefits of the course, maybe through a refresher session. The carers self-management programme is helpful for those who care for a loved one. The main benefits for carers are to learn skills to support/cope with the caring situation, develop confidence to take more control of their own lives, develop a supportive relationship with the health care team, tools and knowledge to lead a fuller life. The programme increases a sense of health and wellbeing and this supports them in their caring role. The tools learnt are relaxation tools, adjustment, maybe 'saying no' to things, so that more social activities, meeting with friends, being part of networks can be formed. A sense of empowerment and general wellbeing of maybe starting a new hobby or returning to an old one.	
Self management UK	5.03	4.5	There needs to be a more integrated approach to services such as self-management programmes plus other social interactions such as coffee mornings and so on. As this provides social interaction and reduces isolation. The patient programme encourages people to care for their own health and to make the right health choices, as well as using local resources, tools and	Thank you for your comments, and the information contained therein. Support to self-manage as part of a wider package of social care support is in scope (4.3.1). The use of packages to promote social participation is also in scope.

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			skills in areas of eating healthy, fitness, looking after one's self to name a few, all of which has shown to encourage people to make healthy choices and care for their health better. Research has shown that those who attend a course, data from approximately 1000 course questionnaires (Jan 2003 – Jan 2005) has revealed that, four to six months after completing the course: • A&E attendances decreased by 16% • Outpatient visits decreased by 10% • GP consultations decreased by • 7% Pharmacy visits increased by 18%. In addition, key research findings from a randomised trial carried out by the National Primary Care Research and Development Centre (Rogers A; Bower P; Gardner H; Gravelle H; Kennedy A; Reeves D – 2007) found course participants have: • Improved partnerships with doctors • Increased confidence to manage their condition • Improved quality of life and psychological wellbeing • Increased energy • A high satisfaction with the course. The benefits for those attending a course are: • Increase confidence, optimism, energy and self-esteem • Reduce attendances at A&E and outpatient visits • Improve relationships with family, friends and work colleagues	

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			• Improve communication with health care professionals • Increase social inclusion • Reduce pain, tiredness, depression and isolation • Re-introduce structure into daily life • Improve quality of life • Provide opportunities for volunteering • Identify shared experiences with others in a similar situation • Provide the potential for further support through contact with others with self-management experience and access to a wider network.	
Sing for your Life Ltd	19.01	General	I consider that the Social Care Guidance Scope fairly represents the comments and suggestions made at the meeting on 19th September	Thank you.
St Mungo's	21.01	General	**Adult social care often excludes homeless people and rough sleepers. There is a lack of expertise within adult social care services about the barriers to health and social care faced by homeless people, particularly those who are living in hostels or rough sleeping. Guidance should highlight these barriers and enable social care staff to provide appropriate support.** St Mungo's is one of Britain's largest charities supporting people who are at risk of homelessness. We manage more than 200 housing, health and work projects and provide a bed and more for around 1900 people each night. Our 2013 Client Needs Survey showed that 11% of our clients are aged 55-64, and 5% are aged over 65. Many homeless people face multiple and chronic	Thank you for your comment. People without a home are referenced in the Equality Impact Assessment, (published with the scope). That means that we will take particular steps, e.g. in identifying published evidence to support the guidance, to consider the needs of this group. We will also consider access issues.

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			health problems which can include physical health problems, mental health problems, problems associated with old age, and alcohol and drug use. 67% of our clients have a physical health need, 45% a significant medical problem. 14% experience memory loss problems, 9% are vision impaired and 5% have mobility problems. 38% are known to have a disability. Many homeless people, particularly those with a long history of rough sleeping, have long-term conditions. Older homeless people are at particular risk of multiple and complex health problems. These complex and multiple needs may create a need for social care. Living in temporary and insecure housing may make it more difficult to access, or engage fully, with social care services, and often means there is no-one available to provide informal care. This leaves homeless people at risk of developing more serious conditions and requiring more intensive care: homeless people use 4 times as many acute health services, and 8 times as many inpatient services as the general public. Social care guidance should recognise that some older people who require social care will be homeless, and should enable staff to understand the implications of this. Social care staff should be made aware of the needs of homeless older people, so that they can provide appropriate and flexible support. Our experience of working with people who are homeless has shown they often find it hard to access social care assessments at all. The social care	

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			guidance should aim to raise awareness of the long term health needs of homeless people, and provide social care staff with the information necessary to meet these needs.	
St Mungo's	21.02	General	**Housing and homelessness needs should be explored at the point of assessment and support built into personalised plans.** Social care providers should ensure that they have strong links with housing and homelessness agencies, so that individuals needing both housing support and social care can receive appropriate assistance. The guidance should include a recommendation to social care providers to develop and maintain links with housing and homelessness agencies	Thank you for your comment. The scope includes housing support to the extent that it relates to coordinated (health and social) care around the individual.
St Mungo's	21.03	General	**Individual needs may fall below 'critical' criteria, but complex needs should be taken into account, as has been done with Disability Living Allowance.** The existence of multiple needs magnifies the impact of each need. Guidance which does not allow complex needs to be considered jointly may leave homeless people and rough sleepers without access to the care they need to avoid developing more serious problems. This is particularly important for rough sleepers, as our experience shows that when their assessments are carried out in hostels or other temporary shelter, the full extent of their social care needs can be obscured. St Mungo's believes that rough sleeping should be a needs category in itself, rather than a description of a population. The multiple and complex needs experienced by	Thank you for your comment. The scope includes integration, and coordination between different services, to address multiple needs.

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			many homeless people are not easily met by separate services. This can result in them being passed from service to service, making it more difficult to access appropriate care and support. **Social care guidance should highlight the need for integration, and coordination between different services, and tailored packages of support which address multiple needs.**	
St Mungo's	21.04	General	**Personal budgets have been shown to work for rough sleepers** (http://www.communitycare.co.uk/2010/05/21/personal-budgets-help-rough-sleepers-into-accommodation/). Despite this, experience shows that people are often excluded from having a personal budget which could be effective in managing complex needs because they are homeless. In 2011, no St Mungo's clients had a personal budget. **Social care guidance should promote the use of personal budgets for homeless people, particularly those who are sleeping rough.**	Thank you for your comment.
The Lesbian and Gay Foundation	16.01	3.1.5	As lesbian, gay, bisexual and trans (LGB&T) people are already at higher risk of depression and other mental health problems than the general population it is likely that older LGB&T people with 2 or more long-term conditions are particularly vulnerable.	Thank you for your comment. We recognise the importance of ensuring the guideline addresses people who are likely to suffer from discrimination or who are disproportionately affected by long term conditions. The Equality Impact Assessment notes the potential for stigma and discrimination associated with some groups, and the need to provide personalised care which is appropriate for the individual's needs. That means that we will take particular steps, e.g. in identifying published evidence to support the guideline, to

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				consider the impact of an individual's identity on their experience of service provision.
The Lesbian and Gay Foundation	16.02	4.3.1	We commend the focus on integrated health and social care provision for all customer groups including those covered by this guidance.	Thank you.
The Lesbian and Gay Foundation	16.03	4.4	We agree that "choice, control and dignity for service users" is paramount. Guidance should reflect particular circumstances of LGB&T people who may face homophobia and transphobia in the provision of social care services and see their dignity undermined as a result. Social care providers contracted by local authorities should be held accountable to the public sector equality duty and all should adopt best practice in terms of LGB&T inclusion including sexual orientation monitoring. Similar arguments can be made regarding black and minority ethnic communities.	Thank you for your comment. People who identify as LGB&T and those suffering stigma and discrimination are included within the population of interest, and flagged in the Equality Impact Assessment (published with the scope). That means that we will take particular steps, e.g. in identifying published evidence to support the guideline, to consider the impact of equalities issues on an individual's experience of service provision.
The Lesbian and Gay Foundation	16.04	General	It is important that HIV and Aids are treated as long-term conditions and that the specific needs of those affected are addressed. Since a significant proportion of people living with HIV/Aids are men who have sex with men this needs to be understood as an equality issue, too.	Thank you for your comment. People with HIV and Aids are included within the population of interest, and flagged in the Equality Impact Assessment (published with the scope). That means that we will take particular steps, e.g. in identifying published evidence to support the guideline, to consider the impact of their HIV status on their experience of service provision.
The Lesbian and Gay Foundation	16.05	General	In relation to HIV/Aids we need to bear in mind that this is still a very stigmatising condition, which is likely to impact on how health and social care professionals deal with those affected.	Thank you for your comment. People living with HIV and Aids are flagged as a group experiencing stigma and discrimination in the Equality Impact Assessment. We will be looking for evidence of where equalities issues affect individual care.
The Lesbian and Gay Foundation	16.06	General	Often advice on particular conditions or for particular groups of people is provided by voluntary and community sector (VCS) groups and organisations. However, health and social care services in general	Thank you for your comment. The scope specifically considers the use of packages of support (including those provided by the voluntary and community sector) to promote social participation (4.3.1) and

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			do not engage with these organisations or signpost service users to them. The guidance should recommend this.	your comment has highlighted the need to consider services for this population.
The Lesbian and Gay Foundation	16.07	General	Older LGB people are more likely than both their heterosexual peers and younger generations of LGB people to be single and live alone, and are less likely to have children. They are therefore likely to have a greater need of formal care and support. [Ward, R, et al. 'Don't look back? Improving health and social care service delivery for older LGB users', Equality and Human Rights Commission, 2010.]	Thank you for your comment. We will consider the range of people included under 'carers', and how these might vary for different populations.
The Lesbian and Gay Foundation	16.08	General	Informal care and support is organised differently in LGB&T population: Older LGB people identified that they are more likely to rely on partners to provide care in times of illness, and on partners and healthcare professionals for care in old age. Friendships can also be an unexpected source of care. Few expected family members to provide care and few had actually made plans for care in health crises or old age. [Heaphy, B., Yip, A.K.T. & Thompson, D. "Ageing in a Non-Heterosexual Context", Ageing and Society, 2004.]	Thank you for your comment. We will consider the range of people included under 'carers', and how these might vary for different populations.
The Lesbian and Gay Foundation	16.09	General	Older LGB couples are often dynamic relationships where the role of carer and cared-for are blurred, showing the often interdependent nature of LGB caring relationships. [Cronin, A. & King, A., "A Queer Kind of Care: Some preliminary notes and observations", in R.L. Jones & R. Ward (eds) 'LGBT Issues: Looking beyond categories', 2010]	Thank you for your comment. We will consider the range of people included under 'carers', and how these might vary for different populations.
The Lesbian and Gay Foundation	16.10	General	Older LGB&T people are more likely to be socially isolated than the general population: 1 in 5 older LGB&T people have no one to contact in times of crisis (as much as ten times the number in the general population). ['Opening the doors to the needs of older lesbians, gay men and bisexuals',	Thank you for your comment. The scope specifically considers the use of packages of support (including those provided by the voluntary and community sector) to promote social participation (4.3.1) and your comment has highlighted the need to consider services for this population.

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			Age Concern, 2002, p. 12]	
The Lesbian and Gay Foundation	16.11	General	Often advice on particular conditions or for particular groups of people is provided by voluntary and community sector (VCS) groups and organisations. However, health and social care services in general do not engage with these organisations or signpost service users to them. The guidance should recommend this.	Thank you for your comment. The scope specifically considers the use of packages of support (including those provided by the voluntary and community sector) to promote social participation (4.3.1) and your comment has highlighted the need to consider services for this population.
The Lesbian and Gay Foundation	16.12	General	Older LGB&T people are more likely to turn towards health rather than social care services in times of crisis: 8% of lesbian, gay and bisexual people over 55 say they would have to rely on GP services if they were ill and needed help around the home, compared to 10% of heterosexual people over 55. 2% of lesbian, gay and bisexual people over 55 say they would turn to social services if they were ill and needed help around the home, compared to 13% of heterosexual people over 55. [Guasp, April. 'Lesbian, Gay & Bisexual People in Later Life', London, Stonewall, 2011]	Thank you for your comment and the information it provides.
The Lesbian and Gay Foundation	16.13	Equality Impact Assessment > Mental health of people from BME backgrounds	Similar points can be made about LGB&T people who also face an increased risk of mental health problems coupled with problems in accessing services, judgemental attitudes of professionals, the assumption that mental health problems are automatically related to sexual orientation, the fairly recent removal of homosexuality from the Diagnostic Statistical Manual, the proliferation of reparative or conversion therapy, etc. If the mental health of people from BME backgrounds is separately explored so should the mental health of LGB&T people.	Thank you for your comment. Although the Equality Impact Assessment is a summary rather than a comprehensive document, we will aim to address this area of disadvantage within a framework of personalised care.
The National LGB&T Partnership	11.01	3.1.5	As lesbian, gay, bisexual and trans (LGB&T) people are already at higher risk of depression and other mental health problems than the general population it	Thank you for your comment. We recognise the importance of ensuring the guideline addresses people who are likely to suffer from discrimination or

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			is likely that older LGB&T people with 2 or more long-term conditions are particularly vulnerable.	who are disproportionately affected by LTCs. The Equality Impact Assessment notes the potential for stigma and discrimination associated with some groups, and the need to provide personalised care which is appropriate for the individual's needs. That means that we will take particular steps, e.g. in identifying published evidence to support the guideline, to consider the impact of equalities issues on an individual's experience of service provision.
The National LGB&T Partnership	11.02	4.3.1	We commend the focus on integrated health and social care provision for all customer groups including those covered by this guidance.	Thank you for your comment.
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The National LGB&T Partnership	11.04	General	It is important that HIV and Aids are treated as long-term conditions and that the specific needs of those affected are addressed. Since a significant proportion of people living with HIV/Aids are men who have sex with men this needs to be understood as an equality issue, too.	Thank you for your comment. People with HIV or Aids are within the scope, and are highlighted within the Equality Impact Assessment (published with the scope). That means that we will take particular steps, e.g. in identifying published evidence to support the guideline, to consider the needs of this group.
The National LGB&T Partnership	11.05	General	In relation to HIV/Aids we need to bear in mind that this is still a very stigmatising condition, which is likely to impact on how health and social care professionals deal with those affected.	Thank you for your comment. People with HIV or Aids are within the scope, and are highlighted within the Equality Impact Assessment (published with the scope). That means

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The National LGB&T Partnership	11.07	General	Older LGB people are more likely than both their heterosexual peers and younger generations of LGB people to be single and live alone, and are less likely to have children. They are therefore likely to have a greater need of formal care and support. [Ward, R, et al. 'Don't look back? Improving health and social care service delivery for older LGB users', Equality and Human Rights Commission, 2010.]	Thank you for your comment. We will consider the range of people included under 'carers', and how these might vary for different populations.
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