

People's experience in adult social care services: improving the experience of care for people using adult social care services
Consultation on draft scope
Stakeholder comments table

23/11/2015 to 21/12/2015

Organisation name	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Action on Hearing Loss	General	General	<p>Action on Hearing Loss is the charity formerly known as RNID. Our vision is of a world where deafness, hearing loss and tinnitus do not limit or label people and where people value and look after their hearing. We help people confronting deafness, tinnitus and hearing loss to live the life they choose. We enable them to take control of their lives and remove the barriers in their way. We give people support and care; develop technology and treatments and campaign for equality.</p> <p>Our response will focus on key issues that relate to people with hearing loss and people who are d/Deaf (specifically those who have additional complex needs). We are happy for the details of this response to be made public.</p> <p>General comments</p> <p>Action on Hearing Loss welcomes the NICE guideline on people's experience in adult social care services: improving the experience of care for people using adult social care services. We support the broad aims of the guideline to improve aspects of social care services for people who use them. People who are d/Deaf or have hearing loss often struggle to access social care services due to unsuitable contact methods, correspondence and information, and the lack of communication support, such as a working hearing loop or a qualified British Sign Language (BSL) interpreter, during social care assessments. There is also evidence to suggest that large numbers of older people who live in care homes have undiagnosed hearing loss and are at risk of deteriorating health</p>	<p>Thank you for your response.</p> <p>The guideline aims to cover all users of adult social care services, and this broad population will include people with a range of needs, capabilities, and conditions. It is not possible to provide detail on all of these within the scope, but please be assured that people with hearing loss and those who are deaf who use adult social care services are included in the scope and guideline. Where we identify appropriate evidence of relevance to the scope questions on the issues you raise, it will be considered by the guideline committee (GC) during development.</p>

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			<p>and wellbeing.</p> <p>People who are Deaf and have additional needs such as mental health problems, learning or physical disabilities may require specialist care and support that respects the culture and values of the Deaf community– including the provision of communication support, such as a qualified BSL interpreter or relay interpreter – but this is not always provided. The commissioning of care and support does not always take account of the communication needs of people who are d/Deaf, in addition to other complex needs related to physical impairments. Adult social care services must use specialist service planning tools to make sure people who are d/Deaf have choice and control over how their care is provided.</p>	
Action on Hearing Loss	General	General	<p>Hearing loss is a long term condition which affects more than eleven million people in the UK, about 1 in 6 of the population. The prevalence of hearing loss increases with age. Over 71.1% over 70 year olds have some form of hearing loss. With the ageing population, the number of people with hearing loss is set to grow in the years to come. By 2035, there will be approximately 15.6 million people with hearing loss in UK - that's a fifth of the population. Based on 2011 census, we estimate that there are at least 24,000 across the UK who use sign language as their main language – although this is likely to be an underestimate.¹</p> <p>People with hearing loss may find it difficult to communicate with family and friends, which can lead to emotional distress, reduced social activity and feelings of loneliness². People with</p>	Thank you for this information. The experiences of people with hearing loss who use or have used social care services are in scope for this guideline.

¹ Action on Hearing Loss (2015) Hearing Matters, available at: www.actiononhearingloss.org.uk/hearingmatters

² Gopinath et al (2012) 'Hearing-impaired adults are at increased risk of experiencing emotional distress and social engagement restrictions five years later'. Age and Ageing, 41 (5), 618–623; Monzani et al (2008) 'Psychological profile and social behaviour of working adults with mild or moderate hearing loss'. Acta Otorhinolaryngologica Italica, 28 (2), 61-6; Arlinger (2003) 'Negative consequences of uncorrected hearing loss – a review'. International Journal of Audiology, 42 (2), 17-20; Héту et al (1993) The impact of acquired hearing loss on intimate

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			<p>hearing loss are more likely to develop paranoia, anxiety and other mental health issues – for example evidence shows that hearing loss doubles the risk of developing depression³.</p> <p>Hearing loss has also been associated with more frequent falls⁴, diabetes⁵, stroke⁶ and sight loss⁷. Evidence suggests that up to 40% of those with a learning disability have some level of hearing loss, and that this often goes undiagnosed or is misdiagnosed⁸. There is also evidence of link between hearing loss and cardiovascular disease⁹.</p> <p>There is strong evidence of link between hearing loss and dementia. Research shows that people with mild hearing loss are almost twice as likely to develop dementia compared to people with normal hearing. The risk increases threefold for</p>	

relationships: implications for rehabilitation. *Audiology*, 32 (3), 363-81, Pronk et al (2011) Prospective effects of hearing status on loneliness and depression in older persons: identification of subgroups. *International Journal of Audiology*, 50 (12), 887-96.

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

⁴ Lin and Ferrucci (2012) Hearing loss and falls among older adults in the United States. *Archives of internal medicine*, 172 4, 369-371.

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

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

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

⁸ Kiani R and Miller H (2010) Sensory impairment and intellectual disability *Advances in psychiatric treatment*. 16, 228–235; Foundation for people with learning disabilities, 2015. *Hearing Loss*. [Online]. Available from: <http://www.learningdisabilities.org.uk/help-information/learning-disability-a-z/h/hearing-loss/> [Accessed 18th November 2015].

⁹ Rosenhall and Sundh (2006) Age related hearing loss and blood pressure. *Noise health*, 8(31), 88-94

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			<p>people with moderate hearing loss and fivefold for people with severe hearing loss¹⁰. Hearing aids help people with hearing loss stay socially active, reduce the risk of loneliness, depression and mental health issues¹¹, and new evidence suggests they may reduce the risk of dementia¹². However, evidence suggests that many people are waiting too long to get their hearing tested. Research shows that people wait on average ten years before seeking help for their hearing loss. When people eventually do seek help, GPs fail to refer 45% people with hearing loss for a hearing assessment. Hearing aids are most effective when fitted early¹³, there is very good evidence from randomised control trials¹⁴ and systematic reviews¹⁵ that hearing aids improve quality of life.</p>	

¹⁰ Lin FR et al. (2011) 'Hearing loss and incident dementia'. Archives of Neurology, 68 (2), 214-220; Gurgel et al (2014) Relationship of Hearing Loss and Dementia: A Prospective, Population-Based Study. Otology & Neurotology. 35 (5), 775-781; Albers et al (2015) At the interface of sensory and motor dysfunctions and Alzheimer's disease. Alzheimers and Dementia Journal, 11 (1), 70-98.

¹¹ Gopinath et al (2012) Hearing-impaired adults are at increased risk of experiencing emotional distress and social engagement restrictions five years later. Age and Ageing, 41 (5), 618-62; Pronk et al (2011) Prospective effects of hearing status on loneliness and depression in older persons: identification of subgroups. International Journal of Audiology, 50 (12), 887-96; National Council on the Aging (2000) The consequences of untreated hearing loss in older persons. Head and Neck Nursing, 18 (1), 12-16; Acar et al (2011) Effects of hearing aids on cognitive functions and depressive signs in elderly people. Archives of Gerontology and Geriatrics, 52 (3): 250-2; Mulrow et al (1992) Sustained benefits of hearing aids. Journal of Speech and Hearing Research, 35 (6), 1402-5.

¹² Deal et al (2015) Hearing impairment and cognitive decline: A pilot study conducted within the atherosclerosis risk in communities neurocognitive study. American Journal of Epidemiology, 181(9), 680-90; Dawes et al (2015) Hearing Loss and Cognition: The Role of Hearing Aids, Social Isolation and Depression. PLoS ONE 10(3): e0119616; Gurgel et al (2014) Relationship of hearing loss and dementia: A prospective, population-based study. Otology and Neurotology, 35 (5), 775-81; Lin et al (2011) Hearing loss and incident dementia. Archives of Neurology, 68 (2), 214-220; Lin et al (2013) Hearing loss and cognitive decline in older adults. Internal Medicine, 173(4), 293-299; Uhlmann et al (1989) Relationship of hearing impairment to dementia and cognitive dysfunction in older adults. Journal of the American Medical Association, 261, 1916-1919; Pronk et al (2011) 'Prospective effects of hearing status on loneliness and depression in older persons: identification of subgroups'. International Journal of Audiology, 50 (12), 887-96; Amieva et al (2015) Self-Reported Hearing Loss, Hearing Aids, and Cognitive Decline in Elderly Adults: A 25-Year Study. Journal of the American Geriatrics Society, 63 (10), 2099-2104.

¹³ Davis et al (2007) Acceptability, benefit and costs of early screening for hearing disability: A study of potential screening tests and models. Health Technology Assessment, 11, 1-294

¹⁴ Mulrow et al (1990) Quality-of-life changes and hearing impairment, a randomized trial. Annals of Internal Medicine, 113 (3), 188-194; Mulrow et al (1992) Sustained benefits of hearing aids. Journal of Speech & Hearing Research, 35 (6), 1402-5; Yueh et al (2001) Randomized trial of amplification strategies. Archives of Otolaryngology -- Head & Neck Surgery, 127 (10), 1197-204; Jerger et al (1996) Comparison of conventional amplification and an assistive listening device in elderly persons. Ear & Hearing, 17 (6), 490-504.

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Action on Hearing Loss	General	General	<p>Most hearing loss is age related, and many people with hearing loss are likely to have other health conditions such as physical impairments, sight loss, dementia or cancer. This can cause complications - for example hearing loss can be misdiagnosed as dementia or make symptoms of dementia appear worse¹⁶. People who are Deaf who use BSL are at greater risk of poor health. For example, research shows BSL use may have worse outcomes for cardiovascular disease due to the lack of health information in accessible formats, communication challenges, financial constraints and stress¹⁷. Diagnosing and managing deafness and hearing loss, and taking a person's deafness and hearing loss into account when diagnosing and managing other conditions is vital for good communication and care.</p> <p>In general, the guideline must make reference to:</p> <ul style="list-style-type: none"> - The accessibility of services. In line with the Care Act 2014, information and advice relating to care and support for adults and support for carers produced by local authorities must show due regard to the needs of people who use services and must be readily available in formats they can receive and understand. To make sure people who use services can participate fully in the assessment process, communication support such as (working) hearing loop or qualified BSL/ Deafblind manual interpreter must 	<p>Thank you for this information.</p> <p>The purpose of the scope is to set out the areas and questions that the guideline will seek to address. It does not include conclusions about the evidence that may pre-empt the process of evidence review and discussion by committee. If we identify appropriate evidence on this issue in relation to the experience of users of adult social care and the scope questions, it will be considered by the Guideline Committee (GC) during development.</p>

¹⁵ Chisholm et al (2007) A systematic review of health-related quality of life and hearing aids: Final report of the American Academy of Audiology task force on the health-related quality of life benefits of amplification in adults. *Journal of American Academy of Audiology*, 18, 151-183; Bess (2000) The Role of Generic Health-Related Quality of Life Measures in Establishing Audiological Rehabilitation Outcomes. *Ear and Hearing*, 21 (4),74S-79S; Sprinzi & Riechelmann (2010) Current trends in treating hearing loss in elderly people: a review of the technology and treatment options – a mini-review. *Gerontology*, 56 (3), 351-8.

¹⁶ Action on Hearing Loss (2013) *Joining up*, available at: www.actiononhearingloss.org.uk/joiningup; Burkhalter CL et al (2009) Examining the effectiveness of traditional audiological assessments for nursing home residents with dementia-related behaviours. *Journal of the American Academy of Audiology* 20 (9): 529-38; Boxtel van MPJ et al (2000) 'Mild hearing impairment can reduce verbal memory performance in a healthy adult population'. *Journal of Clinical and Experimental Neuropsychology*, 22 (1), 147-154.

¹⁷ McKee et al (2011) Perceptions of cardiovascular health in an underserved community of deaf adults using American Sign Language. *Disability and Health*, 4 (3), 192-197.

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			<p>be provided for all those who need it. Providers of adult social care must also meet the requirements of NHS England's Accessible Information Standard¹⁸, which provides clear guidance for identifying, recording and meeting the communication and information needs for people with sensory loss and learning disabilities – including people who are d/Deaf or have hearing loss.</p> <ul style="list-style-type: none"> - The communication and care needs of people who are d/Deaf or have hearing loss. Age related hearing loss is one of the most common long term conditions affecting older people with care and support needs. In line NICE's quality standard for the mental wellbeing of older people in care homes¹⁹, providers of adult social care must be alert to the early signs of hearing loss, test for hearing loss, record instances of hearing loss and also be aware of the GP referral pathway for assessment and treatment. People who are Deaf who use BSL and identify themselves as part of the Deaf community must have their identity and culture valued and respected. BSL is formally recognised as a language in its own right and adult social care services must meet their legal requirements under the Equality Act 2010 not to discriminate against people with protected characteristics. When planning and arranging services, adult social services must consider the appropriateness of care and support services for people from different communities, cultures and beliefs. 	
Action on Hearing Loss	3	57	We welcome the inclusion of "Access to services (including information, advice and support)" as a key aspect of service user experience. People who are d/Deaf or have hearing loss may require additional support to make sure they can communicate effectively and understand the information they	Thank you for your response. This guideline will cover the experience of all users of adult social care services. This is a large and diverse group of people some of whom, we agree, are likely to be using

¹⁸ <https://www.england.nhs.uk/ourwork/patients/accessibleinfo-2/>

¹⁹ NICE (2013) Mental wellbeing of older people in care homes. QS50

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			<p>are given.</p> <p>When contacting adult social care services people who are d/Deaf or have hearing loss may require:</p> <ul style="list-style-type: none"> - Textphones – devices where a person can type what they want to say rather than speaking through a mouthpiece - Next Generation Text (NGT) - a service which allows people with hearing loss to contact someone using a telephone using a textphone or the NGT app on a smartphone, tablet or PC. NGT service connects the person to relay assistant who reads their written messages aloud and types the reply - Email - SMS text - Instant messaging - BSL video relay – this is where a BSL interpreter translates what is being said to a BSL user during a video call <p>People who are d/Deaf or have hearing loss may also need communication support for face-to-face contact such as:</p> <ul style="list-style-type: none"> - Hearing loops – which transmit sound through magnetic field to a hearing aid to improve speech clarity and understanding. These need to be maintained and switched on. - Speech-to-text reporters – who type verbatim (word for word) accounts of what is being said and the information appears on screen in real-time for users to read. - Notetakers – who produce a set of notes for people who can't take their own because they are lipreading or watching a BSL interpreter. An electronic notetaker takes notes using a laptop whereas a manual notetaker takes handwritten notes. - BSL interpretation through a qualified communication professional 	<p>technologies to support engagement in their care.</p> <p>The contribution that these technologies make to users' experiences of services will be in scope for this guideline. The effectiveness of specific technology would not be covered by the scope of this guideline'.</p>

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			<p>For many Deaf people who use BSL, English may be their second language; therefore it is important that all information is written in plain English and easy to understand. Where there is complex text, BSL translation of information may be required either through a qualified BSL interpreter or BSL video translation (where a BSL translation of written or typed information is recorded on video).</p>	
Action on Hearing Loss	3	58-62	<p>We welcome the inclusion of “assessment (including financial assessment) and care planning”, “managing care”, “delivering and coordinating care and support, including transition between services” and “monitoring, reviewing and evaluating care” as key aspects of the person’s experience. The guideline must consider the importance of good communication when carrying out assessments, planning care and support and in the on-going management and review of care</p> <p>Support services which could benefit people who have been recently diagnosed with hearing loss could include:</p> <ul style="list-style-type: none"> - Peer support groups - Hearing therapy and specialist counselling services – which can help people with hearing loss come to in terms with their hearing loss, manage their hearing loss better and signpost to other services, such as a local authority sensory service teams - Lipreading classes – which help people recognise lip shapes and patterns, and how to use context and facial expressions to help make sense of conversations. <p>People who are d/Deaf or have hearing loss could also benefit from aids and adaptations including:</p> <ul style="list-style-type: none"> - Amplified telephones which amplify voice and have an amplified ringtone. Some may have a built in light that flashes when the phone is ringing. - Hearing aid compatible telephones – telephones with hearing loop settings. 	<p>Thank you for raising these important points. Effective communication does fall within the remit of the scope. The ability of the Guideline Committee (GC) to make recommendations that relate to these issues will depend upon the availability of appropriate evidence in each area.</p>

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			<ul style="list-style-type: none"> - Conversors – portable listening devices which enhance directional sound. - Vibrating pads that respond to ringing smoke alarms/doorbells/telephones <p>Most hearing loss is age related, and many older people with hearing loss will also have other health conditions such as physical impairments, sight loss, dementia or cancer (please see comment 1 for references). To ensure good communication and care, care managers and care staff:</p> <ul style="list-style-type: none"> - Must be alert to the early signs of hearing loss, record instances of hearing loss and also be aware of the GP referral pathway for assessment and treatment. The guideline must reference NICE's quality standard for the mental wellbeing of older people in care homes which states that providers of adult social care must be alert to the early signs of hearing loss, test for hearing loss, record instances of hearing loss and also be aware of the GP referral pathway for assessment and treatment²⁰. - Ensure that hearing aids are working and are with the service user when they move from one care setting to another, and that there are clear processes for storing hearing aids and ensuring they are used. - Must display good deaf awareness (for example speaking slowly and clearly and facing the person whilst speaking) and are able to carry out basic hearing aid maintenance such replacing batteries, ear mould cleaning and retubing. Care staff should also be familiar with assistive equipment which may benefit people with hearing loss such as hearing loops, amplified telephones and TV listeners. - Must have robust processes in place for identifying, recording and meeting the communication needs of people 	

²⁰ NICE (2013) Mental wellbeing of older people in care homes. QS50

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			<p>with hearing loss, in line with NHS England's Accessible Information Standard, which becomes mandatory for all health and social care providers from 31st July 2016. The standard ensures people with hearing loss understand the information they are given and are able to participate fully in decisions about their care²¹.</p> <ul style="list-style-type: none"> - Ensure the care environment is suitable for people with hearing loss, for example ensuring care homes have low levels of background noise. Poor acoustics in rooms such as echoes from hard surfaces can cause high levels of background noise. Soft furnishings can help minimise this problem. To enable people with hearing loss who lip read to understand what is being said, rooms should be well lit and free of shadows or glare²². - As a general principle, people should be actively involved and engaged in discussions about their care, not only through provision of communication support and written information in accessible formats, but also by making sure the planning and delivery of adult social care focuses on the needs of the individual. In particular, people who are Deaf with additional needs may require specialist support that respects the culture and values of the Deaf community. People who are Deaf may use BSL as their first or preferred language, so care and support must include the provision of communication support such as BSL interpreters. We have produced guidance on person centred care and care planning for people who are Deaf and use BSL, for more information please see our Person Centred Practices webpage http://www.actiononhearingloss.org.uk/supporting- 	

²¹ <https://www.england.nhs.uk/ourwork/patients/accessibleinfo-2/>

²² Echaliier, M (2012). A World of Silence. Available at: www.actiononhearingloss.org.uk/aworldofsilence

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Action on Hearing Loss	3	63	We welcome the inclusion of "Involving people using services in policy and strategies for local services improvement" as a key aspect of experience valued by people using services. To make sure the design and delivery of services meets the needs of people who d/Deaf or have hearing loss, the guideline must consider the availability of communication support and written information in accessible formats. Under the Equality Act 2010, adult social care services are required to make reasonable adjustments for people with physical or mental impairments who have substantial difficulties when accessing services. For more information on reasonable adjustments for people who are d/Deaf or have hearing loss, please see comment 2.	Thank you for raising this important issue. Where appropriate evidence is identified on the issue accessible information, it will be considered by the Guideline Committee (GC) during guideline development. The final guideline and recommendations will depend upon the available evidence, and GC discussion and consensus.
Action on Hearing Loss	3	67-68	An important aspect of how well services support people to be actively involved in the planning and delivery of their care is the provision of communication support and written information in accessible formats. Our Life Support ²³ research shows that more than a quarter (26%) of local authorities in England who responded to our survey did not offer a textphone number or special telephone service for people who are d/Deaf or have hearing loss. Most also failed to provide a suitably qualified BSL interpreter when a person needed information or an assessment and more than a quarter (29%) did not offer advocacy support for people who are d/Deaf or have hearing loss.	Thank you for your comment. A call for evidence in relation to the scope questions will be published alongside the final scope for this guideline, and you may wish to consider submitting this research as part of your response.
Action on Hearing Loss	3	69-73	We welcome the inclusion of the views of people on how well services "support them to participate in family, social and community life (including employment)", "work with people who use them to ensure the right care is delivered at the right time" "meet their social and emotional needs". We recommend redrafting the fourth point under section 2 to include communication needs, for example "meet their social,	Thank you for your comment. We recognise that communication – and support for communication – is a key issue for many users of adult social care services, including those with hearing loss, people who are visually impaired, people with dementia, and a range of other conditions. We feel that communication is a means of support and is therefore represented / included in the scope as written.

²³ Calton (2012) Life Support: The provision of social care for people with hearing loss, available at: www.actiononhearingloss.org.uk/lifesupport

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			<p>emotional and communication needs”.</p> <p>Under the Care Act 2014, adult social care services must provide a full range of care and support services that improve the health and wellbeing of people using services. Our Life Support research shows that many people who are d/Deaf or have hearing loss are not getting the help they need. In England, fewer than half of respondents (46%) said they take into account communication needs when allocating personal budgets. All respondents provided equipment for the home, and a high proportion offered advice, support occupational therapy, but more than 10% did not offer crucial interpretive support²⁴.</p> <p>The prevalence of hearing loss increases with age and many older are at risk of social isolation and other health problems such as depression and dementia. There is good evidence that timely access to hearing aids can improve quality of life, help people stay socially active and reduce health risks including the risk of depression and dementia (see comment 1 for full references). The diagnosis and management of hearing loss and taking hearing loss into account when diagnosing and managing other conditions are crucial for good communication and care. However, our A World of Silence²⁵ research suggests that many older people in care homes have undiagnosed hearing loss and are at risk of poor quality care. Many people we talked to in care homes didn't want to address their hearing loss – and care home staff found it difficult to encourage them to seek help. Care staff admitted that hearing loss was sometimes seen as less important than other issues such as sight loss, pain and safeguarding and some care staff</p>	

²⁴ Calton (2012) Life Support: The provision of social care for people with hearing loss, available at: www.actiononhearingloss.org.uk/lifesupport

²⁵ Echaliier, M (2012). A World of Silence. Available at: www.actiononhearingloss.org.uk/aworldofsilence

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			didn't know how to use hearing loops and TV listeners and others lacked the know-how to carry out basic hearing aid maintenance.	
Action on Hearing Loss	4	90	"2.1 What methods and approaches are used to monitor and evaluate the experiences of people who use services?" We welcome the inclusion of this question, and feel that the guidance needs to include how views of people with more complex needs, and limited communication, will be monitored and evaluated.	Thank you for your comment. Where evidence on the issue that you raise is identified in relation to the scope questions, it will be considered by the GC during guideline development.
Alzheimer's Society	General	General	<p>Alzheimer's Society welcomes the development of guidelines on improving people's experiences of adult social care services. An Alzheimer's Society survey of people with dementia in 2015 found that 26% of respondents were not involved in decisions about their care and support. In addition, over half of respondents (53%) to the same survey reported feeling anxious or depressed recently. This could be as a result of a number of reasons, but it does highlight that people with dementia may not have a positive experience of care and support which subsequently has an impact on quality of life.</p> <p>We also hope that the final quality standards resulting from this work will help to drive up standards in quality of care. If this is the case, it could prevent the need for more costly interventions such as emergency hospital admissions or having to go into a care home.</p> <p>Therefore, we support the development of guidelines which can improve the experiences of adults using social care services.</p>	<p>Thank you for your comment.</p> <p>A call for evidence has been published alongside the final scope, and we encourage you to submit evidence that is relevant to the scope questions in response.</p>
Alzheimer's Society	1	17-21	Alzheimer's Society recommends that people receiving NHS continuing healthcare are included in the list. NHS continuing healthcare, although funded by the clinical commissioning group is a package of care and support. Our anecdotal evidence tells us that people with dementia and their carers find the assessment process of NHS continuing healthcare	Thank you for raising this issue, which we agree is important. The guideline will apply to all social care services, including those commissioned through Clinical Care Groups. If appropriate evidence is identified on the assessment or appeals process which applies to these services, it will be considered by the Guideline Committee (GC) as they develop

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Organisation name	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			complex and the appeals process is particularly stressful. Therefore, this particular package of care must not be ignored in the final guidelines.	the guideline. A call for evidence will be published alongside publication of the final scope for this guideline, and we would encourage you to submit any relevant publications as part of this.
Alzheimer's Society	1	23	Alzheimer's Society welcomes the list of audiences for the guidelines, which covers many people and bodies. However, we have concerns that people who purchase their own care are included in the same category as commissioners. From the description it is also not clear whether this is referring to people who have personal budgets, or people who are funding their own care. Alzheimer's Society recommends that there are separate bullet points for commissioners, people who receive personal budgets and self-funders	Thank you for your comment. We have clarified the final scope to ensure that individuals purchasing their own care (either with their own funds, or with a personal budget) have equivalent status to other commissioners.
Alzheimer's Society	2	28	Alzheimer's Society is pleased to see that the guidelines will also be relevant to providers and commissioners of health services which interface with adult social care services. Alzheimer's Society recommends that NHS continuing healthcare is given a specific mention in this point in recognition of this complex package of care which crosses between health and social care.	Thank you for your comment. We recognise that different commissioning arrangements and appeals processes present different challenges for service users. Where appropriate evidence is identified on the issue of complex packages of care it will be considered by the Guideline Committee (GC) as they develop the recommendations.
Alzheimer's Society	3	53-64	<p>The purpose of the guideline is not clear in this section. We believe that the views of people using social care services are key to improving their experiences, as much as ensuring people have choice and control in decisions about their care. However, this is confused in the draft scope. Commissioners and care providers may wish to gain an understanding of people's experiences of access to services, assessment, managing care, and delivering and coordinated care and support, whereas monitoring and reviewing care, and involving people in local policy and strategy development are mechanisms for gaining an insight into people's experiences. Alzheimer's Society recommends that this section is divided in the final guidelines :</p> <ul style="list-style-type: none"> • Key aspects of experience that are valued by service users; 	<p>Thank you for your response. Lines 53 – 64 in the draft scope are part of section 1.3, which sets out the proposed areas that the guideline aims to cover. This will determine where we look for evidence, and here the scope states that we will look for evidence on services users' experience of these activities in adult social care, and the extent to which these activities are valued by them.</p> <p>The issues and questions set out in 1.5 provide more detail on how we anticipate key areas may be addressed during development – questions 1 and 2 focus on service user experience, and question 3 will require the GC to consider evidence on the effectiveness of different approaches to service user engagement. However, until the relevant evidence has been identified and appraised by the NICE Collaborating</p>

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			<ul style="list-style-type: none"> Key mechanisms for gathering people's experiences of care. 	Centre for Social Care (NCCSC) and considered by the GC, it is not possible to anticipate the structure of any final recommendations.
Alzheimer's Society	3	53-73	Alzheimer's Society has concerns that the scope has not made reference to different communication methods which may need to be used in order to gather the experiences of people with dementia who use adult social care services. Alzheimer's Society is currently undertaking a project into the communication methods to use in order to involve people with more advanced dementia in service development. The outcomes of this study will be useful to feed into the final quality standards. We recommend that the final quality standards should, at least, signpost to sources of information on how to engage people with cognitive impairments in service improvement processes. These links should be included in the new section on 'key mechanisms for gathering people's experiences of care' (as recommended above).	<p>Thank you for your comment, which raises an important point. We recognise that many users of adult social care services will make use of support, advocacy and / or technology to help them engage with their care.</p> <p>This draft scope relates to a NICE social care guideline, which will then be used to develop a quality standard on this topic – however, NICE quality standards have their own development and consultation processes, which you can find here.</p> <p>The scope includes all users of adult social care services, including dementia – this is a very broad range of service users, many of whom may require support or advocacy to engage with their care. Section 1.3 of the scope sets out general key areas, which are then developed into a more detailed set of questions in section 1.5. Support and technology used by those with dementia to engage with social care services would be included within questions 2 and 3 in this section – space does not permit us to specify the range of potential support or technologies for all relevant groups and conditions here.</p> <p>A call for evidence in relation to the scope questions will be published alongside the final scope for this guideline, and we would encourage you to submit any available evidence on the study you mention in response to this call.</p>
Alzheimer's Society	4	85-105	Alzheimer's Society has concerns that there is no mention in the draft scope of engaging with people with people with a cognitive impairment, especially people in the later stages of dementia, who would be excluded from sharing their experiences of social care services as this could be seen as too challenging. It is important to remember that, as dementia	<p>Thank you for your comment.</p> <p>This scope covers all users of adult social care services and is thus very broad, covering people with a range of needs and capabilities. This includes people with dementia, as well as people with a range of other physical or mental health issues that make use of adult social care services. Many of these will</p>

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			progresses and a person's needs increase so will their dependence on care and support. Therefore, it is of utmost importance that people with in all stages of dementia are engaged in activities to share their experiences of social care. Alzheimer's Society recommends including, in the more detailed review questions once developed, questions around the methods and approaches to be used to engage with people with dementia, especially people who may not be able to communicate verbally.	use (or require) support in order to engage with their care, and this is stated as a key area in section 1.3. It is not possible for us to specify every group of service users in the scope, and it may be that the effectiveness and cost effectiveness of many condition-specific services or interventions may be covered by a topic-specific guideline. You may also be interested in the forthcoming NICE guideline on supporting decision making for people who lack mental capacity , and published guidelines on older people with social care needs and multiple long term conditions , and supporting people with dementia and their carers in health and social care .
Alzheimer's Society	9	214-230	In this section, there should also be recognition that the Care Act recommends local authorities engage service users in market shaping and service development, as stated in the guidance on market shaping. Alzheimer's Society recommends that this is included in the guidelines.	Thank you for your comment. The NCCSC also undertakes implementation work, to support dissemination and adoption of guideline recommendations which could include, if identified as a priority by the GC, service user engagement in service development.
Carers UK	General	General	Whilst we recognise that the services and support specifically for carers will be addressed in a separate NICE guideline, the services and support received by the person the carer looks after will still have an impact on the carer. Therefore it is not only the views of carers on how the services affect the person they care for, but how those services impact on them as carers that should be included in the scope of the guideline	Thank you for your comment. We recognise the importance of carer outcomes and of impact on carers of support services, the scope for this guideline is already considerable and we would not be able to look at the additional evidence you suggest with an appropriate level of care and attention. Support for carers is included in NICE's planned library of social care quality standards.
Carers UK	4-5	110-124	The outcomes for carers are inextricably linked to the kind of care available and provided to those they care for. It is imperative that outcomes for carers are considered in this guidance as well as guidance looking at carers' services and support.	Thank you for your comment. We recognise the importance of carer outcomes and of impact on carers of support services. As this is an area of significant research in its own right, the needs of carers is the focus of a separate guideline topic. Support for carers is included in NICE's planned library of social care quality standards.
Carers UK	3	67-68	This should include how and when the services support them 'and their carer' to be actively involved in their care planning and delivery	Thank you for your comment. We feel that the following text within section 1.3 addresses the issue of how and when services support people and their carers sufficiently well: 2 The views of people who use services, including

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				<p>carers' or family members' perceptions, of how well services:</p> <ul style="list-style-type: none"> - support them to be actively involved in their care planning and delivery - support them to participate in family, social and community life (including training, further education and paid and unpaid employment) - work with the people who use them to ensure the right care is delivered at the right time - meet their social and emotional needs and support their wellbeing.
College of Occupational Therapists	4	<p>110, 1.6 Main outcomes</p> <p>113 115</p>	<p>Within the list of outcomes there is no mention of <i>productivity</i> or <i>home</i>.</p> <p>121 Consider including work and changing to: <i>Participation in work, social and community activities</i>.</p> <p>The home maybe included within the other outcomes such as;</p> <ol style="list-style-type: none"> 1. Wellbeing and quality of life (related to health and social wellbeing). 3. Choice and control. <p>For many older people, for example, remaining in their choice of home is their primary focus and outcomes related to aids, adaptations, care and support packages sit within this overarching goal.</p>	<p>Thank you for your comment. We have added 'including training and education, paid and unpaid employment' in response to a number of stakeholder comments.</p> <p>Where we identify evidence on the impact of whether or not someone is able to remain at home, in relation to their experience of adult social care services, it will be considered by the guideline committee (GC) as they develop the recommendations.</p> <p>This initial list of outcomes is not intended to be exhaustive. Where we identify evidence of other relevant outcomes about service user experience of adult social care or the aspects of services that are valued by users not listed here, including the issues you raise, it will be considered by the Guideline Committee (GC).</p>
Department of Health	General	General	<p>The draft refers to consulting with carers, which we assume means family members, rather than professional care staff, but not with family members who aren't necessarily carers directly (if you are in a care home, for example, your family will provide little if any actual care, but will often have regular close contact with you and be able to speak for you). We suggest it would be good for NICE to include family who may not actually provide care in the people they consult. This may be especially helpful in cases where peoples' capacity to respond may be limited.</p>	<p>Thank you for your comment. Carers, family members and advocates are referred to in the introduction to the scope, and we have now included family members' and advocates' views in section 1.6.</p>

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Department of Health	General	General	We assume that they will cover people across the full range of care settings – residential care, domiciliary care, adult placements, etc. It doesn't actually spell that out in the draft as far as we can see. Is our assumption correct?	The scope states that the guideline covers all adult social care services, delivered in all settings. This includes all of the settings you mention. We have added 'provided in any setting' to section 1.2 so that it is very clear.
Disability Rights UK	General	General	<p>Whilst we think all the areas in the scope proposal should be included it feels very established service orientated and not really in keeping with the personalisation approach of the Care Act. We suggest including the following: -</p> <ul style="list-style-type: none"> • Support for care and support planning • Support with managing a personal budget and/or direct payment • Support with implementing and commissioning own care including the employment of personal assistants 	<p>Thank you for your comment. These issues are all intended to be included within the current scope, however we have amended the wording in the final scope in the introductory section to make clear that the guideline is relevant for 'people who purchase their own care'.</p> <p>We have also updated section 1.3 to make reference to the following activities as being within scope:</p> <ul style="list-style-type: none"> - Access to services (including information, advice and support). - Assessment (including financial assessment) and care planning. - Choosing and managing care. - The views of people who use services, including carers' or family members' perceptions, of how well services support them to be actively involved in their care planning and delivery.
Down's Syndrome Association	1	17	<p>The guidelines are also relevant to social workers involved in the development and review of adult care plans (under the Care Act) including those working in transition. A good assessment of care and support needs which is regularly reviewed is the basis of ensuring:</p> <ul style="list-style-type: none"> • people have a good experience of adult social care services and • Service providers are clear about their obligations in providing that care 	<p>Thank you – we recognise that social workers involved in the development and review of adult care plans will be a key audience for this guideline, which is aimed at a range of providers, practitioners and commissioners including 'practitioners working in adult social care services in all settings'.</p> <p>Thank you for highlighting the importance of transition, this has been raised by several stakeholders and will be an important consideration for the Guideline Committee (GC). We have also cross referred to the NICE guideline on transition from child to adult services.</p>
Down's Syndrome Association	1	22	The guidelines are also relevant to advocates. There are many people with a learning disability who depend upon the support of well-informed advocates. The guidelines could offer	Thank you for this helpful comment – we have amended the scope to include advocates in the introductory section.

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			Please insert each new comment in a new row	Please respond to each comment
Down's Syndrome Association	2	38	<p>advocates the expertise to do this effectively by providing a benchmark.</p> <p>In relation to the issue of accessing the experiences of hard to reach vulnerable groups –</p> <ul style="list-style-type: none"> • The DSA helpline provides evidence of service users experience of social care • The DSA Having a Voice Focus Groups (membership - adults with Down's syndrome) can contribute their experiences and expectations of adult care services to the developers. 	<p>Thank you for this information. A call for evidence will be published alongside publication of the final scope for this guideline, and we would encourage you to submit any publications – such as evaluations, audits or qualitative research – that have been produced from the work of the DSA helpline in response to this call.</p>
Down's Syndrome Association	3	69	<p>The scope should include – <i>support them to participate in family, social and community life (including education, training and employment)</i>. It is vital for the well-being of adults with Down's syndrome and others with a learning disability that they continue to have opportunities to learn and develop in adulthood; too often their abilities are underestimated by those who provide care for them.</p>	<p>Thank you for your comment. We have amended the scope to include further education, training, paid and unpaid employment.</p>
Down's Syndrome Association	3	71	<p>Continuity of care is a key issue for people's experience of social care services. The impact of constantly changing members of an individual's care team is a frequent complaint to our helpline. This inconsistency is of particular concern for someone with cognitive impairment as routine and stability are vital components of their care.</p> <p>Therefore this scope statement should be more explicit and read– <i>work with the people who use them to ensure the right care is delivered at the right time by the right people.</i></p>	<p>Thank you for your comment. We recognise the importance of this issue to stakeholders, as a number have raised it in their consultation response. We have tried in the scope to distinguish between the types of activities that services may use to improve service user experience and engagement (these are detailed in section 1.3); the 'experiences' or outcomes that may result from these activities, and how important they are to service users (examples of which – including continuity of care - are given in 1.6), The scope has been written in this way with the aim of placing service user experience at the heart of the guideline, including using the available evidence to understand what is important to them. This means that, where we identify appropriate evidence about the importance of continuity of care to service users, it will be considered by the Guideline Committee (GC) during development. The content of the recommendations and final guideline will be determined by the available evidence and the consensus of the GC.</p>

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				A call for evidence will be published alongside publication of the final scope for this guideline, and we would encourage you to submit any relevant publications on continuity of care as part of this.
Down's Syndrome Association	3	73	The guideline scope should also make specific reference to maintaining good health at this point. Many people in receipt of care are dependent upon care providers being alert to possible health complications. People with Down's syndrome are predisposed to certain medical conditions, including cardiac disease, thyroid disorders, hearing impairment, visual problems, coeliac disease and Alzheimer's disease, most of which are treatable. If left untreated, these conditions can cause secondary complications and seriously affect the overall well-being of the individual, as well as resulting in unnecessary costs, which may be avoided. The DSA (like other similar organisations) provides free information, advice, training and access to our medical advisory service to support care providers in their role.	Thank you for your comment. Where we identify relevant evidence about the experience of users of adult social care services in relation to their physical health (for example, in accessing relevant health services) that relates to the scope questions it will be considered by the GC during development.
Down's Syndrome Association	3	77	The DSA agrees that health services are not part of the remit of this guideline scope. However supporting adults to maintain good health and to access health services is the responsibility of the carer (in agreement with the user) as this relates to the well-being principle (Care Act 2014).	Thank you for your comment. Where we identify relevant evidence about the experience of users of adult social care services in relation to their physical health (for example, in accessing relevant health services) that relates to the scope questions it will be considered by the GC during development.
Down's Syndrome Association	3	78	Whilst accepting the necessity of cost-effectiveness it is important to note that this is an area of confusion often caused by misinformation from statutory services. Adults with Down's syndrome and their family carers require clarity regarding their entitlement to services following an assessment of eligible needs and the range of options available to them. Many do not have access to information advice and support from an independent body.	Thank you for your comment. NICE social care guidelines seek to assess both the effectiveness and the cost effectiveness of interventions and approaches, where possible. We recognise that the issues you raise are important to many service users, and where we identify relevant evidence on access to services, including information and support, complaints procedures, and choosing and managing care, it will be considered by the guideline committee (GC) as they develop the recommendations.
Down's Syndrome	4	110-124	Many service users still feel they are the subject of care rather than active participants within it, they feel they have no choice	Thank you for your comment. We have amended the final scope to include a reference to care management. This can be

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Association			and control and accept information related to cost e.g. blanket policies, without question. The DSA would like to see either as part of 115 – 3 or as an additional outcome: <i>Understanding of the process of their care and the options available to them.</i>	found under 'Areas that will be covered' in section 1.3
Down's Syndrome Association	4	85 - 109	The DSA would like to see reference made in this section to the link between user experience and the outcomes identified in an individual's care plan under the Care Act. Outcomes are central in assessing user experience if the care plan has been properly informed.	Thank you for your comment. People's experience of assessment, care planning and delivery of care plans under the Care Act is in scope for this guideline. This would include their experience of identifying, and reviewing progress against the achievement of relevant outcomes.
Down's Syndrome Association	5	127	The NICE guidance <i>Transition from children's to adult's services</i> should be referenced here. The experience of adults receiving care can only be improved when a planned transition occurs where services work together and the eligible health and social care needs of the individual are identified in their care plan along with how those needs will be met.	Thank you for your comment. We have added a reference and link to this guideline.
Families Together	5	120	Continuity of Care – This is highly dependent upon the quality of information that is provided. For example, if someone has had a brief hospital admission, or even just a visit to A&E following a crisis, and requires support upon discharge there should be a thorough assessment of need and any risk factors involved before the case is handed over for community support. This is particularly important for new cases where people have not previously been known to services. Our experience is that, as patient numbers increase and there is more pressure upon the system, the correct information to support safe discharge is less available.	Thank you for your comment. If we identify appropriate evidence on this issue in relation to the experience of users of adult social care and the scope questions, it will be considered by the Guideline Committee (GC) during development. A call for evidence will be published alongside publication of the final scope for this guideline, and we would encourage you to submit any relevant publications on continuity of care as part of this.
Families Together	8	202	Increasing people's control and choice over the services they use – this is an important principle but there is concern that as social care services are increasingly transferred under the umbrella of the health service there will be less variety of provision available to meet individualised needs. At the same time, as funding to the third sector becomes harder to obtain and the time scales for secure funding become shorter, it is more difficult to plan and resource alternative options for	Thank you for your comment. If we identify appropriate evidence on this issue in relation to the experience of users of adult social care and the scope questions, it will be considered by the Guideline Committee (GC) during development.

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			delivering care and support. Therefore, people's options may be reduced. It is important that integrated services maintain what is currently good practice in adult social care and that the medical model is not the only way in which services are delivered.	
Families Together	9	219	Physical and mental health – when a local authority is assessing a person's needs there should be greater flexibility given in their eligibility criteria when mental health is being assessed as this is frequently something that can fluctuate. For example, self care may become difficult for someone at times not for physical reasons but because their motivation has declined because of adverse mental health.	Thank you for your comment. If we identify appropriate evidence on this issue in relation to the experience of users of adult social care and the scope questions, it will be considered by the Guideline Committee (GC) during development.
Independent Age	2	51	We note that residential care is not specifically mentioned anywhere in the draft scope. We see this as a key area of social care where understanding and improving people's experience is crucial. As care homes and nursing homes are not just places of care, but also places where people live, their day-to-day experience of the residential care 'service' will have a direct and disproportionate influence on their overall quality of life. Compared to other forms of social care, it is also more difficult for people to change to a different provider if they are dissatisfied – particularly if they are very elderly or frail – so it is even more important to get the experience right first time.	Thank you for your comment. We recognise that residential care is an important setting for this guideline to consider, and we have amended the scope so that inclusion of residential settings is clear.
Independent Age	3	57	We strongly agree that the information, advice and support provided to people to help them choose a care service for themselves or a loved one is an essential aspect of quality of experience to get right. Not only is it critical in determining the level of choice and control that people have over the care they receive, but it can often be the first impression that people have of the care system, and can colour their overall impressions and experiences (i.e. whether a service feels closed and uninviting as opposed to welcoming and supportive). Again, we feel that this is an area where residential care in particular is currently lagging behind the rest of the social care sector. We would welcome best practice	Thank you for your comment. We have amended section 1.3 of the scope to ensure that it is clear that choosing and managing care are included.

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Organisation name	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			guidance from NICE on this.	
Independent Age	4	110	We note that the list of main outcomes includes both subjective (or perceived) and objective outcomes, as well as some that are both subjective and objective, such as independence, and security and personal safety. We are keen to see subjective outcomes given precedence, as these will be the ones that are most closely linked to service user experience. We would question whether resource use and cost-effectiveness, though important to consider, are relevant outcomes here.	Thank you for your comment. The list in section 1.6 is not ordered in terms of importance. The content of the final guideline and recommendations will be determined by the evidence that we are able to identify in relation to the questions set out in the scope, and on the views and consensus of the Guideline Committee (GC).
Independent Age	7	160	We would suggest including another stage in the pathway, in between assessment and care planning and management of care, covering 'choosing care', given the emphasis on choice and control in the Care Act 2014 and elsewhere, as noted in the context section of the document.	Thank you for your comment. The pathway is a draft, and will be developed and adapted as the guideline develops.
Lancashire Care NHS Foundation Trust	4	104	What are the barriers and facilitators related to improving the experience of adults using social care services? Mental Capacity is not mentioned in this scope but enabling capacity and involvement in decision making by service users and their family and friends is key information to help us to improve services.	Thank you for your comment. Mental capacity is not excluded as an issue from the scope, and the views of carers on the experience of those they care for of adult social care services are listed within the key areas. If we identify appropriate evidence on this issue in relation to the experience of users of adult social care and the scope questions, it will be considered by the Guideline Committee (GC) during development. You may also be interested in the forthcoming NICE guideline on supporting decision making for people who lack mental capacity
Local Government Ombudsman	General	General	<p>The draft scope makes no reference to complaint-handling being included within the focus of the guideline.</p> <p>It could be argued that this is implicit in parts of the draft document (e.g. page 3, line 62; page 4, lines 90-100; page 5, lines 116-117). We feel that complaint-handling should be explicitly considered whilst developing the guideline for the following reasons.</p> <p>Firstly, it is vital that people are empowered to speak up and that their concerns are appropriately addressed to ensure that</p>	Thank you for your Comment. Where we are able to identify appropriate evidence on complaints and appeals, as they relate to people's experience of adult social care services, it will be considered by the Guideline Committee (GC) as they develop the recommendations.

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			<p>they receive good-quality personal care. At the individual level, this supports the achievement of several main outcomes that have already been identified (e.g. page 5, lines 1, 3, 11).</p> <p>Secondly, a robust complaint-handling procedure is itself a mechanism to drive service improvement. At the service level, this supports the achievement of several other main outcomes that have already been identified (e.g. page 5, lines 4-6).</p> <p>In these ways, the number and nature of complaints received about adult social care services provide an important measure of the experience of the people who use those services. To this end, in partnership with Parliamentary and Health Services Ombudsman and HealthWatch, we published a report that sets out a user-led framework for complaint-handling in health and social care which may be useful in developing the scope and content of the guideline.</p>	
London Fire and Emergency Planning Authority	General	General	<p>LFB welcome the opportunity to comment on the draft scope guideline People's experience in adult social care services: improving the experience of care for people using adult social care services which defines what the guideline will (and will not) cover. We note that the guideline will provide recommendations on the aspects of social care services that are important to the people who use them and how to improve adults' experiences of social care services, and that it will be used to develop the quality standard for this topic.</p> <p>This is of interest to LFB due to the prevalence of people receiving personal care and practical support in the occurrence of fatal fires and those where injuries were serious enough to require lengthy hospitalisation.</p>	<p>Thank you for your comment.</p> <p>The guideline will focus on the experience of adults using social care services, including the aspects of services they most value – and how to improve service user experience. Unfortunately, whilst we recognise the importance of the issue you raise here, detailing the specific components of assessment are not in scope for this particular guideline.</p>

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			<p>Our published evidence²⁶ shows that people with social care and support needs arising from physical, mental and cognitive health issues are significantly at risk from fire. As such, we have worked with Skills for Care, the UK Home Care Association (UKHCA), the Care Quality Commission and the Prime Minister's Dementia Challenge Group to raise awareness of these fire risk factors and the means to reduce them.</p> <p>Our work with Skills For Care lead to knowing how to identify and reduce fire risk for people receiving personal care and practical support being a requirement of the Care Certificate for care staff. However, our evidence²⁷ shows that opportunities to identify and reduce the risk of fire are sometimes still missed.</p> <p>We would therefore ask that the guideline, and subsequent quality standard for this topic, includes a requirement for an assessment of fire risk to be carried out as part of the care planning process and contains a prompt to contact the local fire and rescue service for advice on reducing fire risk tailored to the person's individual need and circumstances.</p>	
MIND	General	General	We welcome the development of this guideline, its comprehensive approach to settings and populations served, and the emphasis on involvement.	Thank you for your comment and support for this guideline.

²⁶ Fire Safety of People in receipt of Domiciliary Care – FEP 1952
<http://moderngov.london-fire.gov.uk/mgconvert2pdf.aspx?id=920>

²⁷ Review Of Accidental Dwelling Fires and Fatalities – FEP 2484
<http://moderngov.london-fire.gov.uk/mgconvert2pdf.aspx?id=4384>

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MIND	3	57-58	We welcome the inclusion of access and assessment. A major concern which is likely to become more acute during the development of the guideline, given budget constraints, is establishing eligibility for support. One aspect of this is the setting of high thresholds of eligibility. It will be important for the guideline to acknowledge the current environment without compromising the quality that it is there to promote.	Thank you for your comment. We recognise that social care services operate within resource and financial pressures. Where evidence is identified on aspects of eligibility and support relevant to the experience of users of adult social care services and the scope questions, it will be considered by the Guideline Committee (GC) as guideline is developed. However, the setting of eligibility thresholds themselves are beyond the remit of NICE social care guidelines.
MIND	3	57-58	Another aspect of establishing eligibility is the difficulty for people with some conditions in having their care and support needs recognised, especially if these needs fluctuate or the required support is preventive. This is a concern for people with mental health problems. This should be addressed in the guideline and may be appropriate for inclusion in the equality impact assessment.	Thank you for your comment. We have clarified the Equality Impact Assessment to ensure that people with mental health problems are clearly identified as a key group. The review work will include looking for any evidence on the experiences of particular groups and highlighting any equalities issues.
MIND	3	57-58	Access and assessment should address ending of care and support provision as well as the beginning of the process.	Thank you for your comment. We have amended the scope to include leaving care in this section.
MIND	4	104	We agree with this question and would like to be assured that it will be interpreted in an inclusive way – i.e. to include barriers and facilitators connected with delivering aspects of care valued by service users, not only specific quality improvement tools and approaches.	Thank you for your comment. Barriers and facilitators are used in a broad sense here, to imply any service-related, social, cultural or other factor that may impact on service user experience. The content of the final guideline and recommendations, however, will depend upon the evidence that we are able to identify in relation to the questions set out in the scope, and on the views and consensus of the Guideline Committee (GC).
MIND	5	113	We agree with this on the understanding that 'health' means physical and mental health equally.	Thank you for your comment. Mental and physical health are a part of 'health and wellbeing' listed here. We have added 'mental health' to this line to clarify this.
MIND	5	115	Choice and control – as stated in the equality impact assessment, consideration will need to be given to people who may lack capacity. This should include 1) ensuring people are still enabled to make the decisions for which they do have capacity (e.g. a person may not have capacity to decide on their package of care, but be able to make other decisions, e.g. about who they see or what they eat or wear) and 2) even	Thank you for your comment. If we identify appropriate evidence on this issue in relation to the experience of users of adult social care and the scope questions, it will be considered by the Guideline Committee (GC) during development.

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			where people do lack capacity to make a decision they should still be supported to be involved in it, and to participate as much as possible	
NHS England	General	General	How will this stimulate the capturing and addressing of experiences of young adults i.e. those up to 25 to ensure that services are meeting their specific needs e.g. peer support/integration with other young adults?	Thank you for your comment. As you know, the content of NICE recommendations and final guidelines is determined by the available evidence, and by the views and consensus of the guideline committee (GC). Primary research will not be conducted during guideline development, but where we are able to identify appropriate evidence on this issue in relation to the experience of users of adult social care and the scope questions, it will be considered by the Guideline Committee (GC) during development.
NHS England	2	51	Would be useful to be explicit whether this is in the home setting and care home settings	Thank you – the scope is intended to cover both settings. This is covered by section 1.2 of the scope which states it covers: 'All settings where adult social care is provided. This includes services funded by local authorities and by people themselves, provided in any setting.'
NHS England	3	59	Suggest an addition of choosing care provision	Thank you for your comment. We have amended point 1 of section 1.3 to include 'Choosing and managing care'
NHS England	3	66	Include also how well they are supported to choose the right support	Thank you for your comment. We have included 'choosing and managing care' in the final scope.
NHS England	5	120	Also include co-ordination of care between health and social care providers	Thank you for your comment. We anticipate that we will identify other relevant outcomes during development, and if we identify appropriate evidence on the issue of coordination of care between health and social care providers, it will be considered by the Guideline Committee (GC).
Parkinson's UK	General	General	We strongly support the amended guideline title, following the scoping workshop where a number of organisations made similar points. Parkinson's UK believes that a more specific focus on 'improving experience' of adult social care users is a useful addition to the document and will mean that the final guideline is of more direct relevance for people using social care services.	Thank you for your comment and support for the guideline.

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			We also welcome the inclusion of research questions relating to improving experience for people using adult social care services.	
Parkinson's UK	3	65	<p>Parkinson's UK welcomes the recognition of the importance of carers' perspectives on adults' experiences of social care. However, we feel that the wording on line 65 is ambiguous.</p> <p>It is not clear whether subsection two simply seeks carers' views of how well services support the person they care for, or whether it aims to understand how carers themselves are impacted by the social care services put in place to support the adults they care for (in terms of enabling them to take breaks from caring and arrange respite care).</p> <p>Although we recognise that carers are exempt from the scope of the consultation, the experiences of people with care needs and carers are closely interrelated and therefore cannot be separated easily.</p> <p>We therefore feel the experience of carers and the extent to which they feel supported to continue their vital role, as a result of the provision of social care support for the person they care for, is of real relevance to any discussion of 'adult social care experience' and should be explicitly examined in the guideline.</p>	Thank you for your comment. Section 1.3 has been edited to make clear that the guideline will 'include how carers' perceive the care provided to the people they care for so that it is clear that it relates to carers' views of the experiences of the service user that they care for. Support for carers is included in NICE's planned library of social care quality standards.
Picker Institute Europe	General	General	We welcome plans to develop a guideline on the experiences of people who use adult social care services. This will help to raise the profile of user experience as an issue in measuring, understanding, and improving the quality of care in adult social care settings. We are broadly supportive of the draft scope and would like to offer some comments and suggestions that we hope will prove useful.	Thank you for your comment.
Picker Institute Europe	General	General	We welcome the draft scope because evidence on experiences of adult social care is relatively limited compared to health care experiences. However, measuring user experiences in adult social care raises different challenges to	Thank you for your comment. We agree – that is why we have structured the key questions for the scope as they are set out, so that we begin work for the guideline by reviewing the available evidence on service user experience. This will allow

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			<p>health care, particularly because many providers treat smaller numbers of users; traditional quantitative methods like surveys can be a poor fit. The development of the guidance should therefore consider a range of methods for gathering feedback and recognise that different methods may be required for different settings. This is especially important for some key areas covered by the guidance, such as Monitoring and Evaluation of Care. To that purpose, observational methods may be particularly useful in care home settings, like SOFI 2 (Short Observational Framework for Inspections). SOFI 2 is a tool developed by the CQC and the University of Bradford's School of Dementia Studies to capture the experiences of people who use services and have difficulties communicating their experience of care. The observations produced are useful to raise questions about care practice that is then followed up by checking other sources of evidence. There are relatively few observational tools available at present, but they provide a useful way of gathering feedback from people who may otherwise be unable to report their own experiences.</p>	<p>the Guideline Committee (GC) to gain an overview of the issues and aspects of services most important to adult users of social care, rather than trying to fit social care experience into any pre-existing framework.</p> <p>NICE guidelines are developed using a process of rapid systematic review, committee deliberation and stakeholder consultation – the content of the final guideline and recommendations will depend upon the available evidence and committee consensus. Whilst we recognise that there may be gaps in the available primary evidence, developing new primary evidence is beyond the scope of NICE guidelines.</p>
Picker Institute Europe	General	General	<p>We would like to stress that treating people's experiences of adult social care as self-contained would make the scope of this guideline too narrow. Most users of adult social care at least occasionally have contact with health care providers and the health care of adult social care users can be a weak point in overall care. Guidelines on people's experiences of adult social care need to consider how users interact with other services and how they receive health care in adult social care settings. Research on care homes quality may take as a reference the approach used for investigating quality of care of older people, people with frailty and long-term conditions, as well as people approaching to the end of life. To this purpose, research linked to the findings of the relevant national surveys, as well as informed by the narrative for coordinated support for older people by National Voices, may be informative.</p> <p>An example of such a research may be provided by the CQC</p>	<p>Thank you for your comment. We recognise that users of adult social care services will also be users of health (and other) services too. At present, patient experience in adult NHS services and user experience in adult mental health services are covered by pre-existing NICE guidelines – this guideline will provide additional recommendations for adult social care.</p> <p>People's experiences of transitions between services are included in the scope of this guideline. Where appropriate evidence is identified that relates to the issues you raise it will be considered by the Guideline Committee (GC) during development</p>

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			<p>review of the provision of health care to those in care homes released in March 2012, which included substantial focus on people's experiences of health care. The aim of the review was to look at how well the health care needs of people living in care homes were met, based on commissioning and provider behaviours. The scope for the review set out to consider practice not just in individual care homes, but to focus attention on the rights of people in care homes to access NHS services that met their needs. This included GP services and pathways for continence care, NHS support for care homes to ensure quality of health care through direct provision of district nursing services, and training for care home staff. In order to carry out this research, CQC inspectors visited 81 care homes from within nine primary care trust areas and spoke to managers, residents and staff as well as observing care and checking case files.</p>	
Picker Institute Europe	General	General	<p>Above, we have highlighted that different approaches may be required for monitoring and evaluating people's experience of adult social care compared to in health care settings. Large-scale survey methods are widely used in health care to measure experiences, and are presented in social care via the national Adult Social Care Survey and Adult Social Care Carers Survey. These are useful and important collections but there are limitations to the potential to use survey methods in some social care services.</p> <p>These limitations are discussed more broadly in The Adult Social Care Survey Feasibility Study (2013), which was a joint undertaking by the Picker Institute Europe and the King's Fund to examine the feasibility of developing and implementing a new survey of adult social care for the Care Quality Commission (CQC). The study acknowledged the complexity of the social care landscape, previous surveys on adult social care, and the challenges involved in designing a feasible and affordable study to measure user experiences at specific sites</p>	<p>Thank you for this information, which is very relevant to the guideline.</p> <p>A call for evidence has been published alongside the final scope, and we would strongly encourage you to submit any relevant evidence in response to this call.</p>

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			<p>Please insert each new comment in a new row</p> <p>and providers. In this study, we recommended a twofold strategy:</p> <ul style="list-style-type: none"> - Firstly, to develop a postal survey of domiciliary care users that could be implemented with larger home care providers. Secondary recommendations included enhancing the coverage and sharing of information from other surveys, for example the Ipsos MORI 'Your Care Rating' survey, and providing social care service providers with a recommended methodology to help ensure good standards in survey design and implementation. - The second part of the strategy would see the CQC using the Health and Social Care Information Centre Adult Social Care Survey – as modified to align with CQC's requirements - to systematically capture the experiences of adults who use social care services. <p>The findings of this work may prove relevant to the guideline development, particularly in terms of the way monitoring and evaluation methods can be applied, and we would recommend this document is retrieved and reviewed.</p> <p>Further references:</p> <ul style="list-style-type: none"> - CQC (2012), <i>Meeting the health care needs of people in care homes</i>. Available at: http://www.cqc.org.uk/content/meeting-health-care-needs-people-care-homes. - Picker Institute Europe & The King's Fund (April 2013). <i>Adult Social Care Survey Feasibility Study</i>. Available at: http://www.cqc.org.uk/sites/default/files/documents/adult_social_care_survey_feasibility_study_final_report.pdf. 	<p>Please respond to each comment</p>
Picker Institute Europe	General	General	As NICE has commendably informed the guidance with the Picker principles of patient-centred care, it would be useful	Thank you for your comment.

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			<p>considering dignity and respect of people during the different stages of care transition. Therefore, other key areas that need more clarification regard Assessment and Care Planning and Involvement. In here, we think that specific research would be required to assess quality of care at home (after people leave specialized care centres), people engagement and ability to maintain social interaction at community level, people involvement in decisions about their own care, and communication with health professionals and/or carers.</p> <p>On a final note, we would encourage NICE to consider, even at this early stage in the guideline development, how the impact of the work could be maximised. We would highlight that users and their carers and families will be an important audience for the guidelines, and appropriately accessible reports should be produced and published at the close of the project to highlight what users should expect from adult social care, in order to make the public aware of what the guideline establishes for them and make more visible the guideline itself.</p>	<p>The scope aims to place service user experience at the heart of the guideline, using the available evidence to understand what is important to them and how to improve experience across all adult social care services. This means that, where we identify appropriate evidence on the issues you raise here, it will be considered by the Guideline Committee (GC) during development.</p> <p>The content of the recommendations and final guideline will be determined by the available evidence and the consensus of the GC.</p> <p>Primary research is outside of the process and methods for the development of NICE guidelines, which employ a process of rapid systematic review, committee deliberation and consultation to develop and finalise recommendations – you can read more about NICEs methods and processes here.</p> <p>NICE guidelines are accompanied by complementary Information for the Public documents to help raise awareness. The NCCSC also has a remit to support dissemination and adoption of guideline recommendations which could include developing tools for key stakeholders, where they have been identified as a priority.</p>
RNIB	2	51 and 52	<p>It would be helpful to clarify early on in the document, that social care provision provided by local authorities also includes preventative services, and not just long term care support. It is not clear in the topic guide, whether preventative services are included.</p> <p>Under the Care Act local authorities have a statutory duty to prevent, reduce and delay a person's future care needs.</p> <p>For people with a visual impairment, local authorities provide rehabilitation support to help people adapt to their sight loss by providing support and training in skills for independent living and mobility. These services are delivered by staff that have</p>	<p>Thank you for your response. We have amended the final scope to make clear that experience of relevant preventive and rehabilitation services is included.</p> <p>You may also be interested in the in-development NICE social care guideline on intermediate care, including reablement, which is due to be published in July 2017.</p>

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			<p>the skills, knowledge, and experience to understand the unique challenges faced by people with a visual impairment including qualified rehabilitation officers.</p> <p>Rehabilitation services for blind and partially sighted people must be commissioned in line with the Care Act 2014.</p> <p>The services must be fit for purpose and meet the assessed needs of an individual.</p> <p>Rehabilitation support can include:</p> <ul style="list-style-type: none"> • Teaching mobility and confidence skills to negotiate the outside safely, and to get to key identified destinations. This can include how to use a white cane safely and correctly. • Teaching indoor mobility skills, for example how to get upstairs, and minimise the risk of falling or tripping. • Identifying and providing the right walking aids and equipment to support with mobility and daily living. • Teaching skills and helping to build confidence to complete tasks at home safely. For example, safe kitchen skills, and how to clean and maintain the home. • Identifying and providing appropriate aids and minor adaptations to help achieve assessed outcomes. • Identifying appropriate emotional support needs. <p>The appropriate intervention should ensure blind and partially sighted people have choice, control, enjoyment and independence in daily living and to make the most of their sight.</p> <p>Rehabilitation support may also be provided as part of a wider social care package. For example, local authorities are able to 'pause' a care assessment whilst a person receives</p>	

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			<p>preventative support, or the two may run in parallel together.</p> <p>For many people with a visual impairment rehabilitation support may be the only service they receive. It is therefore important that the NICE scope covers the whole spectrum of social care experiences.</p>	
RNIB	3	53	Preventative service should also be referenced here, please see above comments.	<p>Thank you for your response. Social care services that aim to manage or reduce future care needs are included in this guideline, which applies to all social care services for adults.</p> <p>You may also be interested in the in-development NICE social care guideline on intermediate care, including reablement, which is due to be published in July 2017.</p>
RNIB	3	57	Advocacy is missing from list.	Thank you for your comment. The term 'support' is intended to cover a range of activities, including advocacy – we have also now included advocates in the introductory section.
RNIB	3	73	We welcome the inclusion of emotional support. However, it may be appropriate to also reference wellbeing at this stage, given that this underpins the Care Act Wellbeing, and is referenced later on in the document	Thank you for your comment. We have included reference to wellbeing within the outcomes section.
RNIB	4	110	<p>The list of main outcomes is a good starting point, and we welcome that more outcomes will be included in the final scoping document. This is important, as the initial outcomes do not fully unpick some of the experiences of social care that blind and partially sighted people have had.</p> <p>There are a number of reoccurring issues which blind and partially sighted people often raise about their experiences of social care.</p> <ul style="list-style-type: none"> • That you only know what you know at time of accessing services. We have often heard from people that they are asked what support they would like to receive. We have been told, that this is not helpful, as their response is often 'I don't know, because I don't know what support is out there.' People may be happy 	Thank you for your comment. The list in section 1.6 is not exhaustive, and not ordered in terms of importance. We may identify other relevant outcomes during development: We have tried in the scope to distinguish between the types of activities that services may use to improve service user experience and engagement (these are detailed in section 1.3); the 'experiences' or outcomes that may result from these activities, and how important they are to service users (examples of which – including continuity of care - are given in 1.6), The scope has been written in this way with the aim of placing service user experience at the heart of the guideline, including using the available evidence to understand what is important to them. This means that, where we identify appropriate evidence with outcomes of importance to service users not listed here, it will be considered by the Guideline Committee (GC) during

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			<p>Please insert each new comment in a new row</p> <p>with the quality of support they have received, but when they are often frustrated to discover that is more that a local authority could have offered. RNIB currently have a survey live, which is collecting peoples experiences of social care. Early findings indicate that a high percentage of people, who haven't received rehabilitation, would have said they would have benefited from some sort of preventative support. Initial findings of our survey can be made available on request.</p> <ul style="list-style-type: none"> • Related to this is the quality of assessments that people receive, including how they are conducted and what involvement the person has had in the process. Assessments start the moment the individual has contact with the local authority, and therefore not everyone may be aware that they are being assessed. We are also aware that there has been a drop in some local authorities of the number of people being referred to rehabilitation support. RNIB is concerned that people may not be receiving an assessment that specifically recognised the specific needs of people with a visual impairment. • Another area which can impact upon a person's experience of social care is how long they have had to wait for an assessment and then to receive a service. RNIB's recent research 'My Voice' shows that nine per cent had to wait more than six months and seven per cent waited more than a year for a visit from social services. One in five people reported that they had never received a visit. A number of participants in the My Voice survey commented that the issue was not the support they received, but the time they had to wait to receive it. They were happy with the support they received eventually, but often had to wait a long time, in some cases years, to get that support. 	<p>Please respond to each comment</p> <p>development The content of the recommendations and final guideline will be determined by the available evidence and the consensus of the GC.</p> <p>A call for evidence will be published alongside publication of the final scope for this guideline, and we would encourage you to submit any relevant publications as part of this.</p>

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			Please insert each new comment in a new row http://www.nrib.org.uk/knowledge-and-research-hub-research-reports-general-research/my-voice	Please respond to each comment
RNIB	6	119	We welcome the inclusion of the outcome 'Ability to carry out activities of daily living with or without support.' We recommend that the role of aids and adaptations is also considered. Many people with a visual impairment rely on aids and adaptations. Local authorities have a statutory obligation to assess and provide aids and adaptations which help to prevent, reduce or delay future care needs. Initial findings from our survey show that there is a very large proportion of blind and partially sighted people have never been asked what aids and adaptations have supported them. Further information on the findings of the survey can be made available on request.	Thank you for your comment. If we identify appropriate evidence on this issue in relation to the experience of users of adult social care and the scope questions, it will be considered by the Guideline Committee (GC) during development. A call for evidence will be published alongside the scope, and we encourage you to submit any relevant evidence in response to this call.
RNIB	7	165	Sensory impairment should be listed as separate from physical disabilities, so that it is explicit that this group of people are included.	Thank you for your comment. We have included sensory impairment here to address the point that you raise.
Royal College of General Practitioners	General	General	A sensible and open ended approach which examines key areas in the range, quality, delivery and satisfaction with services. It would be helpful to consider the size and shape of the problem and how it has changed with demographic and societal norms and in a changing culture. Then to predict the future requirements over the next 5-10 years so that some estimate of the resources required can be made. There needs to be attention to emergency social care particularly around section orders under the Mental Health Act. It would be helpful to consult the front line staff-social workers, care attendants, home helps etc. about their ideas and problems around care and delivery. [PS]	Thank you for your comment. The guideline will make recommendations about improving the overall experience of users of adult social care services, which will be of interest to practitioners and service providers, as well as to service users themselves. The guideline committee – comprised of a range of practitioner, professional, research and community experts and service users, recruited through a competitive process – will each bring their own expertise to bear on consideration of the evidence. The content of the final guideline and recommendations will be determined by the available evidence, and GC consensus. Links to other pathways and other considerations will also depend on this. Organisations that represent front line carers are included in the list of stakeholders here and have been consulted during this exercise.
Royal College of General	3	53	1.3 - Social care can only be delivered if there are adequate resources supporting a local service which is responsive in a	Thank you for your response. We recognise that adult social care services, like health services, face both time and financial

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Practitioners			timely manner. At present in England there appears to be severe cuts in resources for social services with consequently minimal provision causing delays particularly in preventing hospital admissions and hospital discharges. There appears to be no publically available measures of services with response times. [MH]	pressures. A number of other social care guidelines address transitions and therefore this will not be covered here. Please see in particular: - Transitions between inpatient hospital settings and community or care settings for adults with social care needs - Transitions between children's and adults' services
Royal College of General Practitioners	3	75	Whilst there will be separate NICE guidelines for services and support for carers, there should be a key area under 1.3 to involve carers in care planning and care delivery using a triangulation of care model as developed in Somerset Mental health teams. This means that there is communication between the social care, the person using adult social care services and the family carers. Both health and social care notes should be structured to accept direct input from carers which reflect the carers perspective. [MH]	Thank you for your comment. In the scope, we have tried to distinguish between: the types of activities that may be used to improve service user experience and engagement (these are detailed in section 1.3); the 'experiences' or outcomes that may result from these activities, and how important they are to service users (examples of which – including continuity of care - are given in 1.6), The scope has been written in this way with the aim of placing service user experience at the heart of the guideline, including using the available evidence to understand what is important to them. This means that, where we identify appropriate evidence about the importance of – for example – involving carers in care planning, it will be considered by the Guideline Committee (GC) during development. The content of the recommendations and final guideline will be determined by the available evidence and the consensus of the GC. A call for evidence will be published alongside the final scope for this guideline and we would encourage you (or your colleagues) to submit any evidence you have on the approach you describe in response.
Royal College of Nursing	General	General	The Royal College of Nursing welcomes proposals to develop this social care guideline for improving adults' experience of social care services.	Thank you for your comment and support for the guideline.
Royal College of Nursing	General	General	Nurses are very much involved in this pathway of care. We strongly suggest that steps should be taken to include nurses as members of the guideline development committee. This	Thank you for your comment. We recognise the importance of including health professionals in the guideline committee. We will look to recruit a range of professionals to the Guideline

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			was not apparent in the scoping document.	Committee (GC). We would be grateful if you would encourage suitable members to apply.
Skills For Care	1	31	It is also relevant to learning providers in adult social care	Thank you for your comment. We agree that this guideline may be of relevance to learning providers in adult social care. The guideline may refer to education and training for those delivering social care where the evidence suggests this is appropriate, however training and education fall within the remit of other organisations to NICE and we would expect that the final guideline will be of use to them when planning and implementing training and development.
Skills For Care	2	52	Some social care services may be funded / commissioned by NHS	Thank you for your response. We recognise that some social care services may be funded or commissioned by the NHS through, for example, Clinical Commissioning Groups – this guideline will apply to all social care services, regardless of how they are commissioned.
Skills For Care	3	57	Usual term (in line with Care Act) is Information, Advice and Guidance	Thank you for your comment – as the guideline will provide guidance, we feel that the current wording is clearer for stakeholders.
Skills For Care	3	64	Add in: 'Choice and Control',	Thank you for your comment. We have included 'Choosing and managing care' in the final scope – however, please note that we have tried in the scope to distinguish between the types of activities that services may use to improve service user experience and engagement (these are detailed in section 1.3); the 'experiences' or outcomes that may result from these activities, and how important they are to service users (examples of which are given in 1.6), Feelings about (and / or objectively measured) changes in, for example, choice and control may be outcomes that result when services take steps to engage users in any of the areas set out in 1.3. The scope has been written with the aim of placing service user experience at the heart of the guideline, including using the available evidence to understand what is important to them.
Skills For Care	3	64	Important to reference 'dignity and respect' as underpinning all of these areas.	Thank you for your comment. The extent to which services are able to ensure or improve levels of dignity and respect that their users experience, and how important they are to service

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				users is in scope for this guideline.
Skills For Care	3	70	Add learning and education	Thank you - We have amended the scope to include further education, training, paid and unpaid employment.
Skills For Care	3	73	'health and wellbeing' important.	Thank you for raising this important point – Where we identify relevant evidence about the experience of users of adult social care services in relation to their physical health (for example, in accessing relevant health services) that relates to the scope questions it will be considered by the GC during development.
Skills For Care	3	73	Add in: 'accessing their health needs'. Often social care services support people to do this as it is absolutely vital for health and wellbeing, especially for those with long term conditions. This is not the same as including health services in your review which you clearly state you are not doing in line 77. We agree with this approach.	Thank you for raising this important point – Where we identify relevant evidence about the experience of users of adult social care services in relation to their physical health (for example, in accessing relevant health services) that relates to the scope questions it will be considered by the GC during development. .
Skills For Care	3	73	Should give consideration to capacity issues and use of advocates	Thank you for your comment. Advocacy and related support are within the scope of this guideline, and we have included advocates in the introductory section so that it is clear they are included in the scope. Where relevant evidence is identified that addresses capacity in relation to adults experience of social care services it will be considered by the guideline committee during the development of the guideline. You may also be interested in the forthcoming NICE guideline on supporting decision making for people who lack mental capacity .
Skills For Care	4	105	Key questions seem good. More detailed questions should reflect key areas outlined.	Thank you for your comment. Draft protocols for evidence reviews, including more detailed questions, will be agreed with the Guideline Committee (GC) once development begins.
Skills For Care	5	113	Wellbeing and quality of life depends on people being supported to access health and social care services as well as employment, social and educational needs.	Thank you for your comment. Where we identify relevant evidence about the experience of users of adult social care services in relation to their physical health (for example, in accessing relevant health services) that relates to the scope questions it will be considered by the GC during development.
Stroke	2	41	The Stroke Association welcomes the guideline looking at a	Thank you for this response: We agree that equity is a key

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Association			range of potential inequalities, particularly race, which is a key risk factor of stroke. If you are South Asian, black African or black Caribbean, you are at a higher risk of stroke than other people in the UK. Black people are twice as likely to have a stroke compared to white people and black and South Asian people tend to have strokes at a younger age compared to white people. ²⁸ While it is not fully understood why this is the case, it is probably connected to the fact people in these groups are more likely to have conditions such as high blood pressure or diabetes. ²⁹ As stroke is the biggest cause of complex disability in the UK, many individuals are – and will continue to be - reliant on social care to some degree.	issue for this guideline, and there are a number of factors which may influence individuals' experience of adult social care services. Where evidence is available, the Guideline Committee (GC) will consider all of the issues set out in the final scope in relation to the experience of adult social care services.
Stroke Association	2	42	We would like to see socio-economic inequality being included in the range of inequalities that the guideline will look at. People from the most economically deprived areas of the UK are around twice as likely to have a stroke than those from the least deprived areas, meaning more people are likely to be reliant on social care services. People from the most economically deprived areas are also three times more likely to die from a stroke than those from the least deprived areas and this is therefore a key inequality which needs to be addressed. ³⁰	Thank you for your comment. We recognise that income, and socio-economic group, will be important factors that influence adults' experience of social care – partly because the need for social care is correlated with lower income, and partly because lower income may influence the type of care that people get, for example by impacting on individuals ability to purchase care and support services privately. We have amended the scope so that it is clear that, where evidence is available, socio-economic differences in the experience of adult social care services will be considered by the GC.
Stroke Association	3	54	In this section, we would like to see a particular focus on people's ability to recover from illness and access to immediate rehabilitation and longer term support, which is a major issue for stroke survivors and their families. While there have been significant improvements in acute stroke care, there remain serious gaps and variation in the provision of post-acute care, meaning many stroke survivors are not receiving the rehabilitation they so desperately need to make as full a	Thank you for your comment. The guideline will cover people's experience of rehabilitation and reablement services, where they are provided by adult social care services. The effectiveness and cost effectiveness of these services will be covered by the in-development NICE social care guideline on intermediate care, including reablement , which is due to be published in July 2017.

²⁸ https://www.stroke.org.uk/sites/default/files/stroke_statistics_2015.pdf

²⁹ <https://www.stroke.org.uk/what-stroke/are-you-risk-stroke/what-makes-you-more-risk-stroke>

³⁰ https://www.stroke.org.uk/sites/default/files/stroke_statistics_2015.pdf

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			recovery as possible. The Stroke Association found that 43% of stroke survivors wanted more therapy support once discharged from hospital. ³¹ There should also be a focus here on helping people back to work after illness and vocational rehabilitation. A third of all stroke occur in working age people but nearly 70% of stroke survivors between the ages of 25 and 59 were unable to return to work after stroke. This could be related to the patchy nature of vocational rehabilitation commissioning. ³²	
Stroke Association	3	60	We support NICE looking at the co-ordination of care and support, including the transition between services. The Stroke Association found that nearly half (48%) of stroke survivors and their carers had problems caused by either poor or non-existent co-working between health and social care providers. ³³ This will become an even more pressing issue given the ongoing and deep cuts to local authority budgets, as well as the proposed devolution of health and social care services to some local authority areas.	Thank you for your response. We agree this is likely to be an important issue for service users.
Stroke Association	3	75	We support and welcome NICE's intention to produce separate guidance on services and support for carers but we would like to see this work done as soon as possible. Carers of stroke survivors face real struggles dealing with the link between health and social care services, as well as their relationships with the stroke survivors themselves, and they need support. A survey conducted by the Stroke Association in 2013 discovered two thirds of carers experienced difficulties in their relationship with the stroke survivor and of these, 1 in 10 had broken up with their partner, or considered doing so. It also	Thank you for your comment. We recognise the importance of carer health, support and outcomes. NICE will consider your comment as part of their ongoing work to schedule guideline development.

³¹ https://www.stroke.org.uk/sites/default/files/stroke_statistics_2015.pdf

³² https://www.stroke.org.uk/sites/default/files/stroke_statistics_2015.pdf

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			found that 72% of carers felt ill-prepared to take on their role as a carer, with 79% experiencing anxiety. ³⁴	
Stroke Association	3	77	We strongly encourage NICE to include in its 'areas that may be covered' some focus on the mental health services available to adults in the social care system. Psychological rehabilitation is crucial to stroke recovery yet it remains the area of stroke rehabilitation with the longest delays. The latest Sentinel Stroke National Audit Programme (SSNAP) data highlights problems in the availability of rehabilitation. For example, there is a median waiting time of over 10 weeks for psychological support following stroke, with a quarter of patients waiting 5 months or more. ³⁵ This is despite a maximum recommended waiting time of 14 days for psychological therapy. Stroke survivors commonly experience depression and/or anxiety which can hamper their recovery. A third reported to the Stroke Association that they experienced post-stroke depression and 20% experienced emotionalism in the first 6 months after stroke. ³⁶	Thank you for your comment. We recognise that a range of health and mental health services are important to (and used by) users of adult social care services. It is worth noting that adult mental health is already covered by NICE clinical guidelines on patient experience and on service user experience in adult mental health .
Stroke Association	5	113	We would like there to be an emphasis not just on the maintenance of wellbeing and quality of life but improvement in wellbeing and quality of life. With the appropriate support and rehabilitation, stroke survivors' wellbeing and quality of life can improve significantly in the months and years following their stroke so access to support is extremely important. Despite this, we know that around 11% of stroke survivors are discharged directly in to residential care homes. ³⁷ Few clinical commissioning groups commission rehabilitation services for those in care homes and it is essential that this situation	Thank you for your comment. This guideline will focus on the experience of users of adult social care services, what service users value, and how to improve those experiences. Wellbeing is included as an outcome within section 1.6 of the guideline. . You may be interested in the in-development NICE social care guideline on intermediate care, including reablement , which is due to be published in July 2017.

³⁴ https://www.stroke.org.uk/sites/default/files/feeling_overwhelmed_final_web_0.pdf

³⁵ <https://www.rcplondon.ac.uk/projects/outputs/sentinel-stroke-national-audit-programme-ssnap>

³⁶ https://www.stroke.org.uk/sites/default/files/stroke_statistics_2015.pdf

³⁷ www.strokeaudit.org/Documents/Results/National/JulSep2014/JulSep2014-PublicReport.aspx

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			improves to ensure no-one is written off and that all stroke survivors are given every opportunity to make the best possible recovery..	
The British Association of Social Workers	General	General	My view is that you are asking the right questions. However the detail of how questions could be asked has not been scoped. Many service users would struggle to complete satisfaction and other questionnaires, so included in the scoping should be a commitment to use methods and formats to capture the experience of people using adult social care services that go beyond the standard methodologies. Thought needs to be given to using visual and other easy read methods and particular thought needs to be given to reaching those who may be hard to reach, including languages other than English. To help with getting a picture of what can be complex situations in terms with satisfaction there needs to be the perspective of service users, (carers – which is covered elsewhere) and staff who work with service users.	Thank you for your comment. Section 1.5 lists key questions for the guideline, and the issue you raise will be covered in part by Q2.
The Patients Association	1	13	The Patients Association welcomes the guidelines on improving adult's experience of social care.	Thank you for your response.
The Patients Association	1	17	The Patients Association is pleased that the guidelines provide a comprehensive range of stakeholders placing an importance on both users, families and carers and people who purchase their own care, who are an expanding user group for social care.	Thank you for your comment.
The Patients Association	1	18	Guidelines for practitioners working in adult social care are paramount and it's important that practitioners should be engaged with and empowered by these guidelines. Guidelines are only effective when this happens.	Thank you for your comment. We agree that practitioners will be a key audience for this guideline, and they are specifically mentioned on p1 of the final scope.
The Patients Association	3	54	There also needs to be consideration as to whether users are aware of a named social care professional they can use as a contact point and whether they are able to contact them in case of a need for clarification or if they are expressing a concern.	Thank you for your comment. If we identify appropriate evidence on this issue in relation to the experience of users of adult social care, it will be considered by the Guideline Committee (GC) during development.
The Patients Association	3	57	Access to services. Consideration should be given to users concerns around knowing how to access social care, what is	Thank you for your comment. We agree this is an important issue, and evidence will be sought on all relevant aspects of

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			available to them and their rights.	access to services as part of the guideline development. Final recommendations and considerations will be determined by the Guideline Committee (GC), and based on the available evidence.
The Patients Association	3	62	While service users want to be included in decisions about their care it should be noted that users are often anxious about raising concerns or making a complaint about their social care experience because they fear recriminations. This needs to be considered in the evaluation of social care.	Thank you for your comment. Where appropriate evidence is identified on people raising concerns or complaints, this will be considered by the Guideline Committee (GC) during guideline development. The final guideline and recommendations will depend upon the available evidence, and GC discussion and consensus.
The Patients Association	3	63	The Patients Association supports users active involved in their care planning and delivery. Users should be able to discuss how they feel about the information that they have been given and if this information empowers them to better understand their situation.	Thank you for raising this point – information and support is within the scope of this guideline, as well as other aspects of engagement. Where appropriate evidence is identified on these issues, it will be considered by the Guideline Committee (GC) during guideline development. The final guideline and recommendations will depend upon the available evidence, and GC discussion and consensus.
The Patients Association	3	69	Along with employment there should also be consideration of non-paid work.	Thank you for your comment. We have amended the scope to include further education, training, paid and unpaid employment.
The Patients Association	3	73	There should also be a consideration of user's health and wellbeing as 'Wellbeing and quality of life (related to health and social wellbeing).' Line 113 Page 5 is a consideration in main outcomes.	Thank you for your comment. We have included wellbeing in this section.
The Patients Association	4	103	As well as looking at the effectiveness of tools and approaches such as digital technologies or advocacy services there should be understanding of what types of users access these tools, how available they are to all users and consider limitation on this access through user group.	Thank you for your comment. If we identify appropriate evidence on this issue in relation to the experience of users of adult social care and to the scope questions, it will be considered by the Guideline Committee (GC) during development.
The Patients Association	4	98	There should be consideration as to how users who have helped services or an organisation are fed back to in the interests of transparency.	Thank you for your comment. If we identify appropriate evidence on this issue in relation to the experience of users of adult social care and the scope questions, it will be considered by the Guideline Committee (GC) during development.
The Patients Association	6	157	The Patients Association welcomes this pathway and the need to work in an integrated way and across organisational	Thank you for your comment and support for the pathway.

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			boundaries so user needs can be met in a holistic manner.	
The Patients Association	8	192	The Patients Association believes that 32% of people reporting they had as much control as they wanted over their daily life is much too low and requires urgent improvement.	Thank you for your comment. A call for evidence will be published alongside publication of the final scope for this guideline, and we would encourage you to submit any relevant publications on control of daily life as part of this.
The Patients Association	9	211	The Patients Association agrees that a personalised approach to user's health and social needs must occur in tandem with information and advice provided to users to allow them to make informed decisions about their care.	Thank you for your comment.
The Patients Association	9	221	Participation in non- paid work should also be seen as a measure of wellbeing.	Thank you for your comment. Non-paid work is now referenced explicitly in the scope.
The Patients Association	9	227	The Patients Association agrees that people's views and experiences provide vital information about how well the services they use are meeting their needs and The Patients Association is also pleased that their experiences will be used as evidence for change.	Thank you for your comment and support for the guideline.
Young Epilepsy	General	General	The draft scope should reflect the integrated nature of service provision by including health services and access to additional support such as benefits. This will help future-proof the guidelines for the full integration of health and social care by 2020. At present, there are weaknesses in the way particular services link with each other. For example, people with learning disabilities experience more barriers to accessing mental health provision than physical health provision.	Thank you for your comment. At this point in time, patient experience of health services and service user experience in adult mental health services are covered by separate guidelines.
Young Epilepsy	General	General	The draft scope should be more explicit in how it measures the experience of adults who lack mental capacity and how these individuals should be supported to defend their rights.	Thank you for your comment. This guideline will cover all adults using social care services, and those who lack mental capacity are included in its remit. More detailed protocols for each review question will be developed with the Guideline Committee (GC) following publication of the final scope. If we identify appropriate evidence on this issue in relation to the experience of users of adult social care and the scope questions, it will be considered by the GC during development.
Young	2	51	NICE should ensure that third sector and private organisations	Thank you for your comment. A wide range of organisations

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Epilepsy			are effectively involved in the development and delivery of the guidelines.	<p>are encouraged to register as stakeholders including voluntary, community and private sector bodies. Stakeholders can contribute to guideline development by providing feedback initially on the draft scope, and subsequently on the draft guideline.</p> <p>In addition, the Guideline Committee (GC) comprises a range of 12-14 stakeholders. These people will be from different types of organisations, bringing a wide range of experience, and will include people who use services and their carers. They will be recruited through a formal application process.</p>
Young Epilepsy	3	55	Transition from child to adult services should be included as a key aspect of experience. This links to the proposed outcome on continuity of care. There should be clarity around the funding arrangements for young people's social care.	Thank you for your response. We recognise that transition from child to adult services is a key issue for young people, and where we are able to identify appropriate evidence on this in relation to the scope questions it will be considered by the Guideline Committee (GC) during development. Please see also the NICE guideline on Transitions between children's and adults' services
Young Epilepsy	3	57	The guidelines should set out how care is managed across different areas, for example where the local authority and health authority boundaries are not coterminous.	Thank you for your comment. The guideline will aim to provide recommendations on improving the experience of the users of adult social care services. The NCCSC also undertakes implementation work, to support dissemination and adoption of guideline recommendations. This work seeks to address barriers that hinder effective management of care.
Young Epilepsy	3	63	The involvement of people in local service improvement should include how Healthwatch has supported individuals to contribute to this work.	<p>Thank you for your comment. Where appropriate evidence is identified on the issue on involving people in improvement activities, it will be considered by the Guideline Committee (GC) during guideline development. The final guideline and recommendations will depend upon the available evidence, and GC discussion and consensus.</p> <p>A call for evidence will be published alongside publication of the final scope for this guideline, and we would encourage you to submit any relevant publications as part of this.</p>

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Young Epilepsy	3	65	A key area should be how well services support individuals to defend their rights, e.g. by providing information on rights under law and how service users and carers can navigate the legal system.	Thank you for your comment. The issue of information provision is in scope for this guideline. The final guideline and recommendations will depend upon the available evidence, and GC discussion and consensus.
Young Epilepsy	3	67	The guidelines must ensure that measurements of individuals' involvement in their care planning and delivery is not tokenistic.	Thank you for your comment. Where appropriate evidence is identified on measurement of individuals' involvement in care planning and delivery, it will be considered by the Guideline Committee (GC) during guideline development. The final guideline and recommendations will depend upon the available evidence, and GC discussion and consensus.
Young Epilepsy	3	75	The draft scope currently excludes short breaks, designating these as a support service for carers. Short breaks should be included as a setting as this is clearly a provision of care as well.	Thank you for your comment. The experience of adults on short breaks as part of adult social care services is included in the scope of this guideline – we have not listed every type of intervention or service here in the scope, but where we identify appropriate evidence on this issue in relation to the experience of users of adult social care, it will be considered by the Guideline Committee (GC) during development.
Young Epilepsy	3	79	The guideline will need to take into account the wider context of cuts to funding, without compromising the rights of service users.	We recognise that adult social care services operate in an environment in which there is pressure on available resources, and that individual areas and services must make decisions that impact on service provision with service user needs and their rights in mind. This guideline will make recommendations about the aspects of services that are important to service users, and effective ways of improving service user experience.
Young Epilepsy	4	90	The systems in place should ensure the meaningful involvement of service users and carers. This should include consideration of how the views of adults who lack mental capacity can be sought.	Thank you for your comment. The scope sets out the areas in which evidence will be sought, and does not attempt to draw conclusions about the approaches, interventions or systems that need to be included in the final guideline. The content of the recommendations and final guideline will be determined by the available evidence and by the views and consensus of the guideline committee. Adults who lack mental capacity, their experience of adult social care services and their engagement in their care are included in the scope under 'all people aged 18 or over who use adult social care services'

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				You may also be interested in the forthcoming NICE guideline on supporting decision making for people who lack mental capacity
Young Epilepsy	5	115	Assessments of choice and control should include the scope of choice available to those with personalised budgets.	Thank you for your comment. If we identify appropriate evidence on this issue in relation to the experience of users of adult social care and the scope questions, it will be considered by the Guideline Committee (GC) during development.
Young Epilepsy	5	116	The guideline should ensure that the satisfaction of adults who lack mental capacity is measured effectively. This group are at particular risk of having their rights ignored.	Thank you for your comment. If we identify appropriate evidence on this issue in relation to the experience of users of adult social care and the scope questions, it will be considered by the Guideline Committee (GC) during development – this group are included in the current scope as ‘people over the age of 18 who use adult social care services’. You may also be interested in the forthcoming NICE guideline on supporting decision making for people who lack mental capacity .

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