

Appendix B: Stakeholder consultation comments table

2018 surveillance of [Older people: independence and mental wellbeing \(2015\)](#)

Consultation dates: 23 January to 5 February 2018

Do you agree with the proposal not to update the guideline?			
Stakeholder	Overall response	Comments	NICE response
Stellar Music	Yes	There is a lot of value in the current guideline	Thank you for your response.
Ideas for Ears	No	<p>Fundamental to all activities is communication and the sharing of conversation and information. The guidelines should therefore be updated to make specific reference to the communication issues that many older people experience.</p> <p>Within those most at risk of a decline in their independence and mental well-being are people with hearing loss. Consideration should be given to how easily people can hear and follow things in one-to-one situations and in</p>	<p>Thank you for your comments and for providing background information on the prevalence of hearing loss in older adults and the relationship with mental health.</p> <p>We recognise that hearing loss can have a major impact on the independence and mental wellbeing of older people and this has been reflected within NICE guideline NG32 – the first recommendation on principles of good practice highlights the need to ‘Ensure activities are inclusive and take account of a range of different needs (for example, think about the needs of older people with an age-related disability)’; and the glossary for the guideline</p>

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	<p>group situations, and what their level of comfort (and degree of difficult) is where there is e.g. background noise, poor acoustics, music playing at high volume.</p> <p>We would like to see the guidance updated to show due consideration of the high prevalence of hearing loss amongst the older people population and what this means for the design and delivery of interventions that are accessible and inclusive. Communication is at the heart of most of the interventions, which makes the need for a focus on hearing-related issues relevant and appropriate.</p> <p>The links between mental and cognitive health and hearing loss</p> <ol style="list-style-type: none"> 1. Hearing loss is the number one cause of Years Lost to Disability in those over 70 in Western Europe (Davis 2016) 2. Those with severe hearing loss are at five times more risk of developing dementia as those with normal hearing (Lin 2012) 3. In older age, people with hearing loss are at greater risk of social isolation and reduced mental well-being (Shield 2006) 4. Older people with hearing loss are two and a half times more likely to experience depression than those without hearing loss (Matthews 2013) and are also at increased risk of major depression (Davis 2011) 5. Hearing loss affects quality of life, including a person's perceptions of health, social interactions, physical function, and psychological function. (Dalton et al. 2003; Chia et al. 2007; Gopinath et al. 2012) 	<p>defines an age-related disability as 'any physical or mental impairment associated with ageing, such as a reduction in, or loss of vision, hearing, mobility or cognitive ability.' Recommendation 1.5 on identifying those most at risk of a decline in their independence and mental wellbeing recommends that 'staff in contact with older people can identify those most at risk of a decline in their independence and mental wellbeing (see implementation section). This includes being aware that certain life events or circumstances are more likely to increase the risk of decline. ... Others at risk includes those who ... have an age-related disability'.</p> <p>The implementation section of the guideline states within planning and partnership that local authorities and the NHS could 'Ensure their planning partnerships include older people and their representatives from ...community groups, for example, groups ... with a health condition or disability in common, such as a sensory impairment'. In relation to the design and delivery of interventions, Area 4: getting older people involved in activities highlights that when developing a plan to overcome barriers to getting involved, this could include 'providing help and advocacy for people with specific needs. For example: ... people who have difficulties seeing or hearing; and people who have problems with their flexibility, balance or mobility.' The training section states that training course content should be based on current knowledge of 'factors that threaten older people's independence and mental wellbeing', including 'how to identify older people most at risk of decline; and how to support and encourage older people to participate in community activities' all of which relates to hearing loss, as well as other sensory impairments, mental and physical health conditions. This guideline has been written to ensure that the needs of older</p>
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		<p>6. In older people there is strong correlations between hearing loss and cognitive decline (Lin 2013), mental illness and dementia (Lin 2011) and premature death (Friburg 2014, Contrera 2015)</p> <p>7. Hearing loss is associated with greater use of medical and social services (Genther et al. 2013)</p> <p>8. Hearing aid users exhibit less decline in the vitality domain than people who do not use hearing aids (Gopinath et al., 2012) and have a better average quality of life than non-hearing-aid-users (Hogan et al. 2009) - though they have a poorer average quality of life than the general population.</p>	<p>adults with varying conditions and as such, hearing loss is addressed and acknowledged in relation to age-related disability.</p> <p>With reference to your comment on the benefits of hearing aids to quality of life, this is beyond the remit of NICE guideline NG32, but there is a NICE guideline currently in development: Hearing loss in adults: assessment and management that offers advice on providing hearing aids and assistive listening devices, and giving information and support to people with hearing loss.</p> <p>In relation to incorporating the Accessible Information Standard into the guideline, from 31 July 2016 all organisations that provide NHS care or adult social care are legally required to follow the Accessible Information Standard. However, NICE is not a provider of care and its guideline recommendations are not subject to legal obligations, as stated in the NICE charter. It is outside the scope of the guideline to stipulate this legislation in its recommendations, but it is included in the list of standards users are expected to follow on the Making decisions using NICE guidelines page on the NICE website.</p> <p>NICE is committed to the provision of quality information to the public. In December 2009 NICE was certified as a quality provider of health and social care information by The Information Standard - a certification scheme for health and social care information aimed at the public.</p>
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Tees Esk and Wear Valleys NHS Foundation Trust	Yes	It would be helpful to add clarification regarding responsibility for providing interventions. i.e., whether this should be delivered by primary care or secondary care providers.	Thank you for your comment. We do not provide details within the recommendations on who should take action, but further details are available in the implementation section . The remit of the guideline is to say what works and we would only say who should deliver if there was evidence that this impacted on effectiveness.
Cambridge Institute of Public Health, University of Cambridge	No	No comments provided	Thank you for your response.
Action on Hearing Loss	No	<p>Action on Hearing Loss, formerly RNID, is the UK's largest charity working for people with deafness, hearing loss and tinnitus. Our vision is of a world where deafness, hearing loss and tinnitus do not limit or label people and where people value and look after their hearing. We help people confronting deafness, tinnitus and hearing loss to live the life they choose, enabling them to take control of their lives and removing the barriers in their way. We give people support and care; develop technology and treatments and campaign for equality.</p> <p>Throughout this response we use the terms 'people with hearing loss' to refer to people with all levels of hearing loss and 'people who are deaf' to refer to people who are profoundly deaf who use British Sign Language (BSL) as their first or preferred language.</p>	<p>Thank you for your comments.</p> <p>In relation to addressing 'deafness and hearing loss as important factors that if unaddressed or not properly managed, may lead to a decline in the mental wellbeing and independence of older people', the management of deafness and hearing loss is not the remit of NICE guideline NG32, but this is addressed in an in-development NICE guideline: Hearing loss in adults: assessment and management. However NICE guideline NG32 does recognise that hearing loss can have a major impact on the independence and mental wellbeing of older people through recommendations relating to age-related disability, which has been defined in the glossary as 'any physical or mental impairment associated with ageing, such as a reduction in, or loss of vision, hearing, mobility or cognitive ability': principles of good practice highlights the need to 'Ensure activities are inclusive and take account of a range of different needs (for example, think about the needs of older people with an age-related disability)' and Recommendation 1.5 recommends that 'staff in contact with older people can identify those most at risk of a decline in their</p>

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		<p>Action on Hearing Loss disagrees with NICE's decision not to update the Older people: independence and mental wellbeing guideline. At present, we believe this guideline does not take full account of the prevalence and impact of deafness and hearing loss. We call on NICE to update this guideline to specifically reference deafness and hearing loss as important factors that if unaddressed or not properly managed, may lead to a decline in the mental wellbeing and independence of older people. This guideline should also be updated to include references to legislation and national guidance which aims to improve the quality of care and the accessibility of services for people who are deaf or have hearing loss.</p> <p>Section one provides background information on the prevalence and impact of deafness and hearing loss. Section 2 provides an overview of the community services and activities that can help older people who are deaf or have hearing loss look after their health and remain independent for longer. Section 3 sets out our recommendations for updating this guideline.</p> <p>1. <u>Background</u></p> <p>1.1. <u>Prevalence and impact of hearing loss</u></p>	<p>independence and mental wellbeing (see implementation section). This includes being aware that certain life events or circumstances are more likely to increase the risk of decline. ... Others at risk includes those who ... have an age-related disability'.</p> <p>Thank you for the background information on the prevalence of hearing loss in older adults and the relationship with mental health, and the benefits of hearing aids, the latter will be addressed in the in-development NICE guideline: Hearing loss in adults: assessment and management.</p> <p>Comments and evidence on lip-reading classes were addressed in the consultation of the draft NICE guideline NG32. As noted in the response to consultation on the draft guideline, providing access to lip-reading classes could be offered when implementing recommendation 1.2 on Group-based activities. During the surveillance review no evidence was identified on lip-reading classes and their impact on mental wellbeing.</p> <p>Services provided by local authority sensory services are not within the scope of this guideline. Thank you for the information on voluntary services, this would be covered by the implementation section of the guideline. Please note that within this section there is a focus on addressing the needs of people with hearing loss: within planning and partnership it is stated that local authorities and the NHS could 'Ensure their planning partnerships include older people and their representatives from ...community groups, for example, groups ... with a health condition or disability in common, such as a sensory impairment'. In relation to the design and delivery of interventions, Area 4: getting older people involved in activities highlights that when developing a plan to overcome barriers to getting involved, this could include 'providing help and advocacy for</p>
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	<p>More than 11 million people have hearing loss across the UK, around one in six of the population.¹ Over 70% of people over 70 years old have hearing loss due to their age.² Due to the aging population, by 2035, estimates suggest that there will be approximately 15.6 million people with hearing loss.¹</p> <p>There are also over 900,000 people with severe or profound levels of hearing loss.¹ Some people with severe or profound levels of hearing loss may use British Sign Language (BSL) as the first or preferred language and may consider themselves part of the Deaf community, which has shared values, history and culture. Based on the 2011 census, estimates suggest that there are at least 24,000 people across the UK who use British Sign Language (BSL) as their first or preferred language.¹</p> <p>Evidence shows that hearing loss is a serious health condition that can have an adverse impact on a person's health and quality of life.³ The World Health Organisation (WHO) also notes that hearing loss is now the fourth</p>	<p>people with specific needs. For example: ... people who have difficulties seeing or hearing; and people who have problems with their flexibility, balance or mobility.' The training section states that training course content should be based on current knowledge of 'factors that threaten older people's independence and mental wellbeing', including 'how to identify older people most at risk of decline; and how to support and encourage older people to participate in community activities' all of which relates to hearing loss, as well as other sensory impairments, mental and physical health conditions.</p> <p>Hearing loss is specifically addressed and acknowledged in relation to age-related disability. However this guideline has been written to ensure that the needs of older adults with varying conditions are taken into account, detailed recommendations concerning the needs associated with a particular condition are not possible; as such publications specific to hearing loss will not be added to the guideline.</p> <p>In relation to your comment on NICE Quality Standards 50 Mental wellbeing of older people in care homes, older adults living in a care home or who attend one on a day-only basis were not included within the scope of NG32.</p>
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		<p>leading cause of years lived with disability, up from 11th in 2010.⁴ People with hearing loss are more likely to use health services and hearing loss has been associated with an increased burden of disease amongst adults and an increased risk of mortality.⁵</p> <p>The communication barriers caused by hearing loss may lead to people withdrawing from social situations and becoming isolated.⁶ For example, one study found that people with hearing loss are more likely to experience emotional distress and withdraw from social situations.⁷ Older people who are deaf living in care homes may be at risk of loneliness and loss of cultural identity if they are unable to communicate in a meaningful way with care staff or other people. Evidence suggests that poor communication or lack of awareness of Deaf culture can lead to ineffective care and deterioration in health and wellbeing.⁸</p>	<p>In relation to incorporating the Accessible Information Standard into the guideline, from 31 July 2016 all organisations that provide NHS care or adult social care are legally required to follow the Accessible Information Standard. However, NICE is not a provider of care and its guideline recommendations are not subject to legal obligations, as stated in the NICE charter. It is outside the scope of the guideline to stipulate this legislation in its recommendations, but it is included in the list of standards users are expected to follow on the Making decisions using NICE guidelines page on the NICE website.</p> <p>NICE is committed to the provision of quality information to the public. In December 2009 NICE was certified as a quality provider of health and social care information by The Information Standard - a certification scheme for health and social care information aimed at the public.</p> <p>Please note that during a surveillance review only new evidence published after the end date of the evidence searches that informed the original guidelines recommendations, or after the end of a previous surveillance review search will be assessed for their potential impact on recommendations. For surveillance of NG32 this is from 1st January 2014 (please see surveillance review</p>
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		<p>Unaddressed hearing loss has also been associated with depression, anxiety and other mental health problems.⁹ For example, one study showed that older people who did not use hearing aids were more likely to report sadness, depression, worry, anxiety and paranoia.¹⁰ Evidence suggests that hearing loss doubles the risk of depression.¹¹ People who are deaf may be reluctant to contact their GP due to communication barriers¹² and when they do, poor deaf awareness may lead to misdiagnosis or under-diagnosis of mental health problems.¹³</p> <p>There is also growing evidence of link between hearing loss and dementia.¹⁴ Research shows that mild hearing loss doubles the risk of developing dementia, with moderate hearing loss leading to three times the risk, and severe hearing loss five times the risk.¹⁵</p>	<p>consultation document). Please also note, decisions made on publications already highlighted as part of the stakeholder consultation on a draft guideline will not be re-considered as part of the surveillance process decision.</p>
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		<p>A recent study identified hearing loss as the largest modifiable risk factor for dementia.¹⁶ If removed, the study states that 9% of dementia cases could be prevented.¹⁶ Hearing loss can complicate the symptoms of dementia for example by making communication more difficult and in some cases hearing loss can even be misdiagnosed as dementia due to the appearance of similar symptoms.¹⁷ The NICE hearing loss draft guideline states that unaddressed hearing loss in people with dementia will “significantly affect understanding and will exacerbate underlying cognitive difficulties”.¹⁸ Estimates suggest that properly diagnosing and managing hearing loss in people with dementia could save the NHS £28 million per year by supporting older people to remain independent for longer.¹⁹</p> <p>1.2. <u>Benefits of hearing aids</u></p> <p>There is good evidence from systematic reviews²⁰ and randomised control trials²¹ showing that hearing aids</p>	
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	<p>improve quality of life and are a cost-effective form of treatment for people with hearing loss. For example, a recent Cochrane review found that hearing aids are effective at improving hearing related quality of life, health related quality of life and listening ability of adults with mild or moderate hearing loss.²² Research shows that hearing aids reduce the risk of loneliness and depression.²³ Some early research also suggests that they may also reduce the risk of dementia.²⁴ A comprehensive economic analysis carried out by NICE to support the development of the hearing loss guideline also confirms that hearing aids are a cost-effective form of treatment for people with hearing loss.¹⁸</p> <p>1.3. <u>Undiagnosed hearing loss</u></p> <p>Many more people could benefit from hearing aids than are currently doing so - less than two-thirds of people who could benefit from hearing aids currently have them.²⁵ Negative stereotypes about hearing loss and hearing aids as well as fear of stigma itself can be a significant barrier</p>	
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		<p>stopping people from seeking help.²⁶ Hearing aids are most effective when fitted early, but evidence suggests that people wait 10 years on average to seek help for their hearing loss and the average age of those referred for a hearing test is in the mid-70s.²⁷</p> <p>Older people may view hearing loss as an inevitable part of the ageing process²⁸ and hearing loss may be difficult to diagnose if people have communication and memory problems due to dementia or other long-term conditions.¹⁹ Many older people with hearing loss will also have other health problems such as frailty and physical impairments so they may need additional support to visit their audiologist. If they are unable to attend audiology appointments due to other long-term conditions, older people will need access to support in their own homes or in care homes.</p> <p>It has been estimated that over 80% of older people living in care homes have hearing loss to get hearing test and</p>	
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	<p>use their hearing aids.²⁹ Our <i>A World of Silence</i>²⁸ report shows that older people in residential care homes are less likely to want address their hearing loss without support – and that care staff found it difficult to encourage them to seek help. The report found that staff had a lack of training in this area and that hearing loss was often seen as less important compared to other issues such as sight loss, pain or safeguarding. Some care staff also lacked the know-how to carry out basic hearing aid maintenance.</p> <p>1.4. <u>Barriers to communication</u></p> <p>Older people who are deaf or have hearing loss may struggle to access health and social care services when they need to due to the lack of accessible alternatives to the telephone, poor deaf awareness or the lack of communication support.</p> <p>2. <u>Community services and activities for people who are deaf or have hearing loss</u></p> <p>2.1. <u>Lipreading classes</u></p> <p>Lipreading classes teach people with hearing loss to recognise lip shapes and patterns and how to use context and facial expressions to help them make sense of conversations. Lipreading classes also provide information</p>	
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	<p>and advice on assistive technology and other services that can help people with hearing loss. They also provide an opportunity for people with hearing loss to meet, support each other and share their experiences.</p> <p>Our <i>Not Just Lip Service</i>³⁰ report identified a range of benefits lipreading classes can bring for people with hearing loss, such as:</p> <ul style="list-style-type: none"> • Improvements in people's ability to recognise lip shapes and patterns and a better understanding of communication skills to help people understand speech. • Increased confidence and assertiveness in talking to others about their hearing loss and asking them to change their behaviour to facilitate good communication. • Feeling less negative about their hearing loss and being able to manage their hearing loss better in social situations and in the workplace. <p>Action on Hearing Loss was also funded by the Department of Business, Innovation and Skills (BIS) to test out innovative ways of delivering lip-reading classes for working age people with hearing loss. The project found that online resources can improve access to information on</p>	
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		<p>lipreading and face-to-face interactions through workshops, and have an important role to play in encouraging people to seek help for their hearing loss.³¹</p> <p>2.2. <u>Local authority services</u></p> <p>Depending on their level of need, older people who are deaf or have hearing loss may also benefit from other forms of support provided or funded by local authority sensory services. This could include:</p> <ul style="list-style-type: none"> • Equipment to help people live safely and independently in their own home such as amplified telephones, Textphones, personal listeners and smoke alarms with flashing lights. • Rehabilitation support to help people learn communication strategies and access other forms of support that can help them, such as benefits and Access to Work. • Communication support to help people who are deaf or have hearing loss access local services. For example, the provision of a qualified BSL interpreter. • Access to peer support groups such as hearing loss clubs or Deaf Clubs. • Drop-in advice sessions (with communication support) on benefits, bill payments or legal issues. 	
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		<p>2.3. <u>Voluntary services</u></p> <p>In some parts of the country charities, such as Action on Hearing Loss, provide support services for people who are deaf or have hearing loss. These include help with hearing aid cleaning and maintenance, Deaf clubs or hearing loss clubs, and information on other services and technology.</p> <p>3. <u>Recommendations</u></p> <p>The Department of Health and NHS England's <i>Action Plan on Hearing Loss</i>³² states that hearing loss is a major public health issue that has an “enormous personal, social and economic impact throughout life.” The Action Plan is clear that properly diagnosing and managing hearing loss is a “major factor in maintaining independence and achieving healthy ageing”. Tackling the growing prevalence and impact of deafness and hearing loss is now a national priority and we call on NICE to update this guideline to specifically reference deafness and hearing loss as key factors that local authorities and NHS services must consider when planning community activities for older people.</p>	
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		<p>Although the guideline does acknowledge the need for local authorities and NHS services to take account of “age-related disabilities” when planning community activities, we believe these references alone are insufficient. Given the scale of the public health challenge and the need for urgent action, we believe including specific references to deafness and hearing loss and relevant national guidance in the guideline provides clear direction for quality improvement. We call on NICE to update the following Recommendations and Implementation sections in the guideline:</p> <ul style="list-style-type: none"> • Recommendation 1.1.4 should be updated to include a reference to NHS England’s Accessible Information Standard.Error! Bookmark not defined. The Standard sets out a clear five step process to make sure people with disabilities and sensory loss get the support they need to communicate well and understand information when accessing health and social care. The Standard is mandatory for providers of NHS care and publicly funded adult social care. The Care and Support Statutory Guidance³³ also states that local authorities must take account of the Accessible Information Standard when providing information and advice. The Standard sets out a consistent approach for improving the accessibility of 	
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		<p>community services for people with disabilities and sensory loss and is therefore highly relevant for ensuring successful implementation of Recommendation 1.1.4</p> <ul style="list-style-type: none"> • We call on NICE to update Recommendation 1.5.3 to include specific references to deafness and hearing loss as key risk factors that staff in contact with older people need to be aware of. Research shows that unaddressed deafness and hearing loss can lead to feelings of loneliness and social isolation. People with hearing loss also have an increased risk of depression and dementia (see section 1.1). Ensuring deafness and hearing loss are properly diagnosed and managed is crucial for improving wellbeing and for helping older people stay independent for longer. Given that hearing loss often goes undiagnosed, targeted interventions to encourage older people to seek help for their hearing loss are especially important, to ensure they are able to access and benefit from hearing aids. Recommendation 1.5.3 should also include a reference to NHS England's <i>What Works: Hearing Loss and Healthy Ageing</i>³⁴ which provides information for Clinical Commissioning Groups (CCGs) on the prevalence and impact of deafness and hearing loss. The document also provides guidance for CCGs on how to commission high quality services for people who are deaf or have hearing loss. 	
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		<ul style="list-style-type: none"> • The “Planning and partnerships” section should be updated to include a reference to NHS England’s JSNA guide. This guide³⁵ has been co-produced by NHS England, the Local Government Association, the Association of Directors of Public Health and other stakeholders, and will be published later this year. The guide provides the data, evidence and insight to help local authorities and NHS commissioners develop robust hearing needs assessments to meet local needs. Tackling the growing challenge of deafness and hearing loss requires a co-ordinated response between health and social care services. It is therefore crucial that deafness and hearing loss are properly included in JSNAs. • The “local assets and needs assessment” section should be updated to include specific references to the impact of deafness and hearing loss on older people’s health and quality of life and the barriers to communication older people who are deaf or have hearing loss may face when participating in local activities. This section should also reference NHS England’s Accessible Information Standard Error! Bookmark not defined. as key source of guidance for addressing communication barriers. NHS England’s JSNA guide³⁵ should also be referenced a key source of data and evidence for local authorities 	
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		<p>and NHS commissioners when assessing local needs and planning services.</p> <ul style="list-style-type: none"> The “getting older people involved in activities” section should reference NHS England’s Accessible Information Standard Error! Bookmark not defined. and the <i>What Works: Hearing Loss and Healthy Ageing</i>³⁴ document as key sources of guidance to help local authorities and NHS services improve the accessibility of community activities for older people who are deaf or have hearing loss. <p>The “training” section should specifically reference deafness and hearing loss as key issues that need to be included in training courses for health and social care practitioners working with older people. Older people who are deaf may be at risk of a deterioration in health and wellbeing if they are unable to communicate in a meaningful way with other people. Research shows that hearing loss increases the risk of depression and dementia. There is good evidence that hearing aids can improve quality of reduce health risks, but many more people could benefit from hearing aids than are currently doing so (see section 1.1.). Health and social care practitioners have important role to play in encouraging older people to seek help for their hearing loss. The NICE</p>	
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		Mental wellbeing of older people in care homes guideline ³⁶ states that care staff should ensure older people and people with other conditions get regular hearing tests and are referred to their GP, to ensure early diagnosis and prompt access to treatment.	
Compassion in Dying	No	The current guidance would be greatly improved if specific information about planning ahead for end-of-life care and/or for a potential loss of capacity were included within the recommendation, particularly regarding information provision and staff training.	Thank you for your comment. NICE guideline NG32 covers interventions to maintain and improve the mental wellbeing and independence of people aged 65 or older and how to identify those most at risk of a decline; information about planning ahead for end-of-life care and/or for a potential loss of capacity is out of scope for this guideline. Please note that there are a number of NICE guidelines that focus on end of life care in different populations, for further information please see the End of life care webpage.
Beth Johnson Foundation	Yes	No comments provided	Thank you for your response.
British Society of Audiology Adult	No	Whilst it is noted that the context of this guideline recognises the prevalence of hearing difficulties in older people, we think there could be stronger reference to the	Thank you for your comments.

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<p>Rehabilitation Interest Group (ARIG)</p>		<p>importance of overcoming hearing and communication difficulties throughout the guideline and even as a separate recommendation.</p> <p>We think this is particularly important as many of the recommendations within the guideline, which aim to ensure independence and mental wellbeing, will rely on good communication abilities in order for them to be effective.</p> <p>Furthermore, an inability to hear and communicate results in poor social participation in everyday life that can lead to social isolation, loneliness and mental health problems. There is documented evidence that hearing loss is a risk factor in dementia (2-5x increase in risk ratio depending on level of hearing loss). The recent Lancet commissioned publication by Livingstone et al on Dementia has highlighted that hearing loss is the top modifiable risk factor for dementia.</p> <p>Specifically: 1.1 Principles of good practice</p> <p><i>1.1.4 Ensure activities are inclusive and take account of a range of different needs (for example, think about the needs of older people with an age-related disability).</i></p> <p>Specific reference to hearing and communication difficulties could be included here.</p> <p>The recommendations within 1.2 Group based activities; 1.3 One-to-one activities and 1.4 Volunteering will only be effective if any communication difficulties are first identified and managed as appropriate (e.g. hearing aids, remote microphones, effective communication strategies)</p>	<p>We recognise that hearing loss can have a major impact on the independence and mental wellbeing of older people and this has been reflected within NICE guideline NG32. This guideline has been written to ensure that the needs of older adults with varying conditions are taken into account, detailed recommendations concerning the needs associated with a particular condition are therefore not possible. And as such, it would not be possible to make reference to all relevant NICE guidelines, including Hearing loss in adults: assessment and management.</p> <p>Thank you for your suggestions to changes to the recommendations, however within the recommendations age-related disability does include hearing loss – the glossary specifically defines it as ‘any physical or mental impairment associated with ageing, such as a reduction in, or loss of vision, hearing, mobility or cognitive ability’; and the implementation section addresses issues you have raised concerning the delivery of the recommended interventions.</p>
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		<p>1.5 Identifying those most at risk of a decline in their independence and mental wellbeing</p> <p>As well as older people with hearing loss being at risk of decline in these areas they are at additional risk due to the challenges they face in engaging with the very activities that are being recommended.</p> <p>It's is noted that within the <i>Areas for Implementation: Area 4: getting older people involved in activities</i> Consider developing a plan to overcome the barriers to getting involved, people who have difficulties seeing and hearing are referenced.</p> <p>The guideline should reference the new NICE Hearing loss in adults guidance due for publication in May 2018</p>	
Esoteric Practitioners Association	No	<p>We do not agree with the proposal to not update the guidelines. It is inconceivable for the guideline not to be updated. This goes against the very essence of life, nature and cycles built on constant change and evolution. We evolve as a community and human beings, not by standing still but by deepening our understanding of why we're here and our relationship with self and each other.</p>	<p>Thank you for your comments. Decisions on whether a guideline should be updated are based on publish evidence that indicates a recommendation(s) is incorrect or that additional recommendations covered within the scope of the guideline could be made. No evidence was identified through this surveillance review to indicate any of the recommendations are out of date. For further details on how we assess whether an update is required please see Developing NICE guidelines: the manual.</p>
NADP (National Association of Deafened People)	No	<p>Recent research shows increasing evidence that untreated hearing loss and cognitive decline are linked.</p> <p>Dawes P, Emsley R, Cruickshanks KJ, Moore DR, Fortnum H, Edmondson-Jones M, et al. (2015) Hearing Loss and Cognition: The Role of Hearing Aids, Social</p>	<p>Thank you for your comments and for providing background information that untreated hearing loss and cognitive decline are linked.</p>

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		<p>Isolation and Depression. PLoS ONE 10(3): e0119616. https://doi.org/10.1371/journal.pone.0119616</p> <p>Hearing Loss and Cognitive Decline in Older Adults</p> <p>Frank R. Lin, MD, PhD; Kristine Yaffe, MD; Jin Xia, MS; et al</p> <p>Qian-Li Xue, PhD; Tamara B. Harris, MD, MS; Elizabeth Purchase-Helzner, PhD; Suzanne Satterfield, MD, DrPH; Hilsa N. Ayonayon, PhD; Luigi Ferrucci, MD, PhD; Eleanor M. Simonsick, PhD; for the Health ABC Study Group, Article Information, JAMA Intern Med. 2013;173(4):293-299. doi:10.1001/jamainternmed.2013.1868</p> <p>People with hearing loss need to retain their previous interests as much as possible. While groups for people with hearing loss provide peer support and often much needed information on how to live with hearing loss, many people who lose their hearing in later life lose contact with former friends, colleagues and interests because they can no longer communicate with people who have normal hearing.</p>	<p>We recognise that hearing loss can have a major impact on the independence and mental wellbeing of older people and this has been reflected within NICE guideline NG32.</p> <p>The guideline has recommendations relating to age-related disability, which has been defined in the glossary as ‘any physical or mental impairment associated with ageing, such as a reduction in, or loss of vision, hearing, mobility or cognitive ability’: principles of good practice highlights the need to ‘Ensure activities are inclusive and take account of a range of different needs (for example, think about the needs of older people with an age-related disability)’ and Recommendation 1.5 recommends that ‘staff in contact with older people can identify those most at risk of a decline in their independence and mental wellbeing (see implementation section). This includes being aware that certain life events or circumstances are more likely to increase the risk of decline. ... Others at risk includes those who ... have an age-related disability’.</p> <p>The implementation section of the guideline also has a focus on addressing the needs of people with hearing loss: within planning and partnership it is stated that local authorities and the NHS could ‘Ensure their planning partnerships include older people and their representatives from ...community groups, for example, groups ... with a health condition or disability in common, such as a sensory impairment’. In relation to the design and delivery of interventions, Area 4: getting older people involved in activities highlights that when developing a plan to overcome barriers to getting involved, this could include ‘providing help and advocacy for people with specific needs. For example: ... people who have difficulties seeing or hearing; and people who have problems with their flexibility, balance or mobility.’ The training section states that training course</p>
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			content should be based on current knowledge of 'factors that threaten older people's independence and mental wellbeing', including 'how to identify older people most at risk of decline; and how to support and encourage older people to participate in community activities' all of which relates to hearing loss, as well as other sensory impairments, mental and physical health conditions.
Do you have any comments on areas excluded from the scope of the guideline?			
Stakeholder	Overall response	Comments	NICE response
Stellar Music	Yes	I am engaged in Music at the Bedside for the elderly in the University Hospital of North Durham and I could find no reference to the well-researched benefits of music for a variety of conditions associated with ageing	Thank you for your comment. We have included published evidence of interventions which include music within the surveillance review (please see Appendix A). These have often looked at music and singing combined, as singing –based interventions and other creative activities are recommended within NG32, we felt that this covers other music-based activities. It is noted within the guideline that 'the committee agreed that the evidence (evidence statement 1.1.7) demonstrated clear support for a range of art- and music-based interventions'.
Ideas for Ears	Yes	Ref 1.1.1 – reference needs to be made to hearing conditions. More than 70% of people aged 70+ have some degree of hearing loss, making it a huge issue for older people. For a range of reasons, not least stigma, it is also something that people often avoid talking about even though it can have a serious impact on their comfort, enjoyment and participation.	Thank you for your comments. We can only address issues raised about areas excluded from the scope . Background information within the scope does not get amended. In relation to the detail you have provided, it is not possible to provide this level of detail within NG32 as the guideline addresses the needs of older adults with varying conditions, detailed

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		<p>The high prevalence of isolation, depression and dementia amongst this group is well-document. See a list of some of the research at foot of this document.</p> <p>Ref 1.1.3 – Rooms with poor acoustics are typically incredibly uncomfortable for hearing aid users and make hearing, listening and understanding conversation far more difficult than it need be. Noise is also very difficult, for hearing aid users and non-hearing aid users. Indeed, as we get older, it becomes harder for our brains to process speech in noise, most especially if that noise is lots of conversational chatter.</p> <p>It is important to ensure that the spaces/rooms selected for group activities have good acoustics and that noise is contained and managed. If community halls and other places, which are typically echo-y and have little noise absorption, then the venue may not be suitable (i.e. it may not be appropriately accessible to those with hearing loss or those with other conditions such as hyperacusis).</p> <p>Consideration should be given as to whether the venue should have noise/acoustic panels installed. If cost is an issue, even some portable noise absorbent panels placed together would help, as this would offer people a quieter spot to make social conversation easier.</p>	<p>recommendations concerning the needs associated with a particular condition are therefore not possible. Please see the response above to your comments for further details.</p>
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		<p>Ref. 1.1.2 - when discussing the design and delivery of activities with participants, the subject of hearing should ideally be included on the agenda. Awareness is required for how easily people hear in a range of scenarios e.g.</p> <ul style="list-style-type: none"> • One to one in a quiet location • One to one in an echo-y room • One to one in a noisy room • One to one in a noisy and echo-y room • When there is group discussion or lots of conversational background noise in each of the above scenarios • When they are listening to a presenter / announcement made to a group in a quiet/acoustically poor/noisy space • When a microphone is used or not used, and when a hearing loop or other assistive equipment is used (many people lack knowledge and awareness of devices and equipment that can help them hear in different situations/scenarios). <p>Ref. 1.1.4 – ability to hear, listen and follow things is absolutely fundamental to the delivery of good practice of all other activities. It is very common for people with hearing loss to not identify as ‘disabled’ by their hearing loss and to feel ‘not properly deaf’. Their difficulties in social situations can nonetheless be considerable (e.g. hearing instructions, chatting with others at their table in lunch clubs, hearing group announcements etc).</p>	
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		<p>Ref. 1.2.1 - Consideration should be given to volume levels and to whether by pushing up the volume you are introducing discomfort, especially for hearing aid users and those with sensitive hearing. More volume does not equate with greater speech intelligibility.</p> <p>Ref. 1.2.2 – Consider introducing practical sessions on ‘good hearing and listening’. As part of this, talk about hearing in a positive way (e.g. ‘hearing ability’ rather than ‘hearing loss’, ‘products to bring sound into your hearing threshold’ rather than ‘deaf equipment’).</p> <p>Consider introducing themes of good hearing and listening through other activities. E.g.</p> <ul style="list-style-type: none"> • Use of assistive technology e.g. learn to use tablets at the same time as having fun trying out speech-to-text apps that automatically display what someone is saying as they’re saying it, or setting up music systems so they play music that matches your specific hearing profile. • When running sessions on internet-enabled TVs, look also at ‘TV loops’ and other devices that aid hearing and ensure people know how to access subtitles. • Hold lipreading taster sessions and share information and examples of tones/words/sounds being misunderstood. • Dexterity activities and giving people the chance to try finger spelling. • Make hearing loops available and bring an audiologist along to a session to troubleshoot hearing aids that aren’t loop-enabled. 	
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		<ul style="list-style-type: none"> Help people learn how they can bring about change to the hearing/listening environments they encounter by providing feedback (or complaining) in appropriate and effective ways. <p>Ref. 1.5.3 – as hearing loss is a big indicator of risk of decline in independence and mental well-being then it should be included on this list.</p> <p>Use of hearing aids has been shown to reduce the risk of social isolation and cognitive decline but many people are not proficient hearing aid users and lack confidence and knowledge in how to get the most from them. They also often lack confidence and knowledge in use of wireless tech that can be used with and without hearing aids to enhance experiences.</p>	
Tees Esk and Wear Valleys NHS Foundation Trust	No	No comments provided	Thank you for your response.
Cambridge Institute of Public Health, University of Cambridge	No	No comments provided	Thank you for your response.

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Action on Hearing Loss	Yes	<p>We call on NICE to extend the scope of this guideline to include community activities that will help older people who are deaf or have hearing loss live safely and independently. The scope document states that interventions that cover “management of a chronic medical condition or disability” are not included in the scope of this guideline. We believe the guideline scope is too narrow and excludes some community activities that may benefit older people who are deaf or have hearing loss. As stated in comment 1, unaddressed deafness and hearing loss can lead to feelings of loneliness and social isolation. As well as hearing aids, research shows that lipreading classes can help people manage their hearing loss better. People who are deaf or have hearing loss may also benefit from other forms of support such as drop in sessions to help people look after their hearing aids, support groups and advocacy services (see Section 2 in comment 1).</p>	<p>Thank you for your comments. Extending the scope to include community activities that will help older people who are deaf or have hearing loss live safely and independently would be a major change to the scope which would represent a new guideline. There is however an in-development NICE guideline: Hearing loss in adults: assessment and management.</p> <p>The scope does not exclude activities that may benefit older people who are deaf or have hearing loss, but there is the exclusion of older adults who ‘have substantial health or social care needs, for example, due to dementia or another pre-existing cognitive impairment’. Please see the response to your comments on hearing aids and lip-reading classes in the relevant section above.</p>
Compassion in Dying	Yes	<p>Service user data collected from our free information line and via our community outreach projects highlight that planning ahead to ensure that their future treatment and care will align with their values and preferences provides a great sense of empowerment and relief for older people. *</p> <p>For example in 2016 and 2017, we supported over 8,500 people to plan ahead through our information services and of those who provided feedback 98% said they had felt great peace of mind as a result.</p>	<p>Thank you providing this information.</p> <p>NICE guideline NG32 covers interventions to maintain and improve the mental wellbeing and independence of people aged 65 or older and how to identify those most at risk of a decline; information about planning ahead for end-of-life care and/or for a potential loss of capacity is out of scope for this guideline.</p> <p>Please note that there are a number of NICE guidelines that focus on end of life care in different populations, for further information please see the End of life care webpage.</p>

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		<p>As such, we believe that supporting older people to plan ahead for their treatment and care at the end of life is an important mechanism for ensuring their independence and wellbeing and should therefore fall within the scope of the guideline with links to other related documentation on dementia and mental capacity for example.</p> <p>Moreover, in light of national policies on dementia and on end-of-life care, including early interventions such as support for planning ahead for treatment and care within this guidance would be particularly useful.</p> <p>* For more information, please see our summary reports of the My Life, My Decision project during which we reached over 7,000 older people with information and support on planning ahead for end-of-life care and/or for a potential loss of capacity. 83% of those who completed an advance care planning document as a result of this support said it had given them greater peace of mind and a sense of empowerment.</p> <p>https://compassionindying.org.uk/wp/wp-content/uploads/2017/03/CID_SUMMARY-REPORT_MLMD_WEB.pdf</p>	
Beth Johnson Foundation	No	No comments provided	Thank you for your response

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British Society of Audiology Adult Rehabilitation Interest Group (ARIG)	Yes	See previous comments provided in Q1	Thank you for your comment. Please see response above.
Esoteric Practitioners Association	Yes	<p>We offer the experience of hundreds of EPA members, clients, families and communities living extra-ordinary lives from child to elder. This evidence needs to be listened to captured, and shared with others. We do so here.</p> <p>We</p> <p>1 expose and challenge the absence of qualitative evidence in NICE guidance. We have our own evidence of how we feel in our bodies that no amount of quantitative research can prove. Doing case studies and qualitative research, evaluating the studies and data that has been provided, it is certain that qualitative studies record evidence of true changes.</p> <p>https://medicineandsergebenhayon.com/2018/01/13/improving-our-health-not-limiting-or-controlling-the-word-evidence/</p> <p>2 expose the omission of self care and well-being. It makes no sense in a system that cannot afford to hold people's hands, with dis-enabling medicine and social care approaches that shy away from the dirty word 'responsibility' (essentially because if you ask a client to take greater responsibility for their own health care then you better well be taking more responsibility yourself! Many health, social care and other professionals with a lived authority of self care and can vouch for its foundational and profound impact on their lives. One social care practitioner at the age of 60 took responsibility</p>	<p>Thank you for your comment. Please note that the evidence used to inform the recommendations within the guideline consist of both quantitative and qualitative research. Further information can be found in the evidence reviews that informed the guideline - please see the evidence page for the guideline.</p> <p>Recommendations concerning the mental health benefits of walking are provided in Mental wellbeing in over 65s: occupational therapy and physical activity interventions</p>

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	<p>for her own health and began a dedicated self care programme.</p> <p>Now aged 66, her sense of self worth is extra-ordinary, lives without any medication and works purposefully 24/7 as a carer. When on leave works in other sectors paid and unpaid, is a trustee of a small aged care charity, and participates in other other community activities. The quality of life lived is vital, vibrant, purposeful. This is just one example of many documented testimonies. It is well known that many people take better care of their homes and cars than they do of themselves. Acceptance of this consciousness must be exposed and questioned for the damage it causes the majority of people let alone the to society as a whole. Self care is a fundamental and loving relationship with self based often on practical self nurturing daily activities: eating food that heals not harms, sleeping when tired, participating in regular in gentle exercise, being tender with the body. Self care is integral to life, it is not an add on, or external intervention. It is part of the way we live.</p> <p>The role of everyone, especially medical health care professionals and carers is to look after themselves well before they look after others. It is impossible to properly look after others when we do not look after ourselves.</p> <p>An acceptance of qualitative evidence would give NICE access to a wealth of evidence and personal testimonies from people of all ages who have transformed their lives through self care. See unimedliving 'before and after' http://www.unimedliving.com/before-and-after/before-and-after-alcohol/alcohol-abuse-a-360-turnaround.html</p> <p>3 present simple example of effectivity of walking - Walking as nature intended needs to be re-claimed.</p>	
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		<p>Different walking models currently accepted and, promoted by the fitness and exercise industry, often linked to fitness, speed, distance, challenge and endurance. They measure quantity rather than quality, number of paces, miles, or speed achieved. We emphasise the benefit of walking without targets. Instead, we recommend the qualitative aspects of walking: moving with presence, connected to the body and breath or whole body walking. This is the how of walking, not what. Walking with quality and connected to the body takes us out of our heads enhances mental health and well-being. It is holding, cleansing and therapeutic. This is whole body walking, walking from the whole body with the whole body in connection to the flow of the movement.</p>	
NADP (National Association of Deafened People)	Yes	<p>The guideline needs to be updated to advise that all Activities held indoors should as much as possible be held in premises with full disabled access meeting the current building standard including a hearing loop making them accessible to people with hearing aids. If requested speech to text support should also be available.</p> <p>Activity organisers should be alert to the fact that unwillingness or refusal to take part in an activity may be due to loss of confidence or fear of not being able to communicate.</p>	<p>Thank you for your comments on the guideline.</p> <p>If services are provided by an NHS or social care provider then they are legally required to follow the Accessible Information Standard. For all providers, the implementation section of the guideline, Area 4: getting older people involved in activities highlights that when developing a plan to overcome barriers to getting involved, this could include 'providing help and advocacy for people with specific needs. For example: ... people who have difficulties seeing or hearing; and people who have problems with their flexibility, balance or mobility.' The training section states that training course content should be based on current knowledge of 'factors that threaten older people's independence and mental wellbeing', including 'how to identify older people most at risk of decline; and how to support and encourage older people to participate in community activities' all of which relates to hearing loss, as well as</p>

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			other sensory impairments, mental and physical health conditions. This guideline has been written to ensure that the needs of older adults with varying conditions and as such, hearing loss is addressed and acknowledged in relation to age-related disability.
Do you have any comments on equalities issues?			
Stakeholder	Overall response	Comments	NICE response
Stellar Music	No	No it is very well considered.	Thank you for your response.
Ideas for Ears	Yes	<p>Ideas for Ears would argue that equality, diversity and inclusion cannot be achieved without better consideration of hearing-related issues.</p> <p>Access and inclusion is impacted because people with hearing loss withdraw because situations become overly difficult for them, or are the sound/noise is uncomfortable. Simple things can have a big impact e.g.:</p> <ul style="list-style-type: none"> • Clear speaking and so face can be seen • Writing down words that can be easy to mishear (e.g. names and numbers) • Appropriate use of microphones • Appropriate use of hearing loops • Venues that are comfortable (acoustics and noise levels are well-managed) • Venues with appropriate lighting (to aid lipreading) <p>Provision of BSL interpreters, where requested, is also important but this is not a solution for the vast majority, as</p>	Thank you for your comment. Hearing-related issues are addressed within the guideline in reference to 'age-related disabilities', there is also specific mention of sensory impairments (please see responses above to your previous comments).

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		BSL users represent fewer than 1% of those with hearing loss.	
Tees Esk and Wear Valleys NHS Foundation Trust	No	No comments provided	Thank you for your response.
Cambridge Institute of Public Health, University of Cambridge	Yes	There are major gaps in research about non-individually based interventions (ie whole context and environment) which benefit all, given knowledge about limited reach and enhanced inequality that arises from individually based approaches.	Thank you for your comment. The scope of the guideline includes community level interventions, but did exclude 'planning for the built environment to meet older people's needs including 'age-friendly city' initiatives' as this is an area covered within the in-development NICE guideline Physical activity and the environment (update)
Action on Hearing Loss	Yes	As stated in comment 1, we believe the current guideline does not take full account of the communication barriers older people who are deaf or have hearing loss may face when participating in community activities. We call on NICE to update the guideline to include specific references to NHS England's Accessible Information Standard in the Recommendations and the Implementation sections of the guideline (see Section 3 in comment 1).	Thank you for your comment on referencing NHS England's Accessible Information Standard. The standard covers organisations that provide NHS care and/or publicly-funded adult social care, while the services and interventions recommended within NG32 may be provided by these organisations, many will be delivered by local providers such as charities and faith organisations. While all organisations that provide NHS care or adult social care are legally required to follow the Accessible Information Standard since July 2016, NICE is not a provider of care and its guideline recommendations are not subject to legal obligations, as stated in the NICE charter. It is outside the scope of the guideline to stipulate this legislation in its recommendations, but it is included in the list of standards users are expected to follow on the Making decisions using NICE guidelines page on the NICE website.

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Compassion in Dying	Yes	<p>Our community outreach activities have highlighted that culturally appropriate, person-centred support for planning ahead is severely lacking for older LGBT and BAME communities.</p> <p>For example, the South Asian and Somali Communities we worked with had concerns about religious beliefs being ignored while older LGBT people worried that their partners would not be allowed to participate in their care.</p> <p>The tailored information we provided about Lasting Powers of Attorney, Advance Decisions to Refuse Treatment and Advance Statements helped them document their preferences, gave them peace of mind and allowed them to live well now.</p> <p>Such efforts need to be rolled out and scaled up if older people are to be meaningfully supported to lead independent and healthy lives.</p> <p>Please see the following documents for further information:</p> <ol style="list-style-type: none"> 1. LGBT- https://compassionindying.org.uk/library/planning-ahead-lgbt-community/ 2. South Asian Community - https://compassionindying.org.uk/library/tea-talk-samosas/ 	<p>Thank you for your comments. The needs of older LGBT adults and BAMER groups has been taken into account during development of the guideline, further details can be found in the equality impact assessment. Information about Lasting Powers of Attorney, Advance Decisions to Refuse Treatment and Advance Statements is out of scope for this guideline.</p>
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Appendix B: stakeholder consultation comments table for 2018 surveillance of Older people: independence and mental wellbeing (2015)

		Somali Community - https://compassionindying.org.uk/library/tie-camel-first/	
Beth Johnson Foundation	No	No comments provided	Thank you for your response.
British Society of Audiology Adult Rehabilitation Interest Group (ARIG)	No	No comments provided	Thank you for your response.
Esoteric Practitioners Association	Yes	We say self care and responsibility applies equally to social care, health and medical professionals as it does to patients. After all are we not all patients? We have evidence to prove that social care, health and medical professionals, who practice self care, offer exceptional quality of care for patients and clients. In other words, there are positive benefits of being treated by people who consciously and consistently take care of themselves. Self care is not just for self, but for humanity as a whole, with ripple effects felt not just by clients, but families and communities. We say, heal the world by first healing yourself.	Thank you for your comment.
Royal College of Nursing		This is to inform you that the Royal College of Nursing have no comments to submit to inform on the above surveillance review at this time	Thank you for letting us know that you have no comments at this time.

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