

**National Institute for Health and Care Excellence
Mental wellbeing of older people in care homes
Quality Standard Consultation Comments Table
5th July – 2nd August 2013**

ID	Comment ID	Stakeholder	Statement No	Comments Please insert each new comment in a new row.	Response Please respond to each comment
001	1	Amore Care – Part of the Priory Group	Introduction	It is a very welcome explanation which focuses on the 'whole person'. For people with dementia, this is particularly positive due to the social and emotional needs for this group. Current thinking is that for people with dementia, the emotional person comes to the fore. I am so pleased that this draft has been developed for consultation	Thank you for your comment.
016	2	Social Care Institute for Excellence	Introduction	The draft QS reflects SCIE's analysis of the available knowledge to support improvement in this area of practice. SCIE's Dignity in Care and Personalisation Guides are referenced. Additionally, SCIE's forthcoming Guide on access to health services for older people in care homes (pub Autumn 2013) may be relevant to the development of this QS. I have referenced the draft Guide against the quality statements below	Thank you for your comment. The SCIE guide on access to health services for older people in care homes has been added as source guidance for the quality standard.
017	3	St Christopher's Hospice	Introduction	Please ADD: Already 19% of the population die in care homes. This will increase as the UK population continues to age and increase in number. Mental wellbeing MUST take account of end of life care.	Additional text has been added to the equality and diversity considerations section for each statement regarding end of life care. The text highlights the importance of the needs and preferences of people who are approaching the end of their life. The End of life care quality standard is comprehensive, cross cutting and applicable across all settings. This quality standard has been added to the <i>Related Quality Standards</i> section.
012	4	British Association of Behavioural and Cognitive Psychotherapies	Questions for consultation Q1	Three important specific areas appear to be omitted: a) a specific section on identifying and responding to dementia (rather than it being lost within 'common mental health conditions'. This could specify the range of interventions, including using holistic assessment and psychosocial approaches as the first line approach to behaviour that is seen as challenging. b) a specific section on pro-active involvement of families. Evidence suggests that quality of life is greater for people with dementia when family members continue to stay involved. The	a) The Mental wellbeing of older people in care homes quality standard addresses a wider population than people who have dementia. The quality statements therefore need to be applicable to all older people in care homes rather than groups of older people with specific conditions. NICE has produced two quality standards specifically addressing the topic of dementia. These are: Dementia (quality standard 1); and Supporting people to live well with dementia (quality standard 30).

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				<p>Please insert each new comment in a new row.</p> <p>relationship between family and the care home is a clear quality marker. For people with dementia, maintaining relationships with family members after admission to a care home is challenging, and family members may find it difficult to visit or know how best to be involved. (See, for example, Gaugler, J.E., Anderson, K., Zarit, S.H. and Pearlin, L.I. (2004), "Family involvement in nursing homes: effects on stress and well-being", Aging & Mental Health, Vol. 8, pp. 65-75.) The care home needs to proactively welcome and engage family members and offer support to them so that they can engage in the ways that are most helpful to themselves and their relative with dementia. They have a key role in supporting personal identity, and in helping identify needs related to mental health, physical health and sensory impairment.</p> <p>c) a specific section on the social environment of the care home. Living communally is what marks out the care home from other means of providing for an individual's care needs, and it is a strange situation for many older people, who may not have lived communally for many years. Well-being may be strongly influenced by the social mix, the behaviour and attitudes of others, use of shared and communal space and so on. Some consideration as to how this is handled in a positive way to enhance well-being would be welcome. Physical and social environment and staff attitudes and the culture of the home will all be relevant here. The quality standard here might be around interactions in communal areas of the home – and observational measures such as Dementia Care Mapping or the SOFI tool developed for inspectors might be appropriate measures.</p>	<p>Please respond to each comment</p> <p>b) The quality standard has been amended to give a greater emphasis on the role of families, friends and carers and the importance of relationships. The QSAC felt that it was more appropriate to emphasise the involvement of families throughout the quality standard rather than adding a specific section.</p> <p>c) The quality statement about personal identity has been amended to place greater focus on social inclusion, human interactions and access to social networks. The statement has also been updated to stress the importance of maintaining and developing personal identity during and after the transition to the care home. The QSAC felt that it was more appropriate to amend this statement rather than adding a specific section on the social environment of the care home. A link to the Dementia Care Mapping tool has been added to the quality standard.</p>
016	5	Social Care Institute for Excellence	Questions for consultation Q1	Does this draft qs accurately reflect the key areas for quality improvement	Thank you for your comment.
022	6	Durham County Council	Questions for consultation Q1	The Service feel the draft quality standards reflect the key areas for quality improvement, particularly quality standard 1 in relation to 'meaningful activity'.	Thank you for your comment.
024	7	The Older People's Commissioner for Wales	Questions for	The draft quality standard appears to be quite comprehensive with a rationale rooted in NICE's broad definition of "wellbeing;"	Thank you for your feedback.

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			consultation Q1	<p>a definition consistent with my own thinking. My Framework for Action (2013-2017) outlines my priorities and the changes I expect to see for older people, as well as the role I will play in delivering these changes. These include embedding wellbeing at the heart of public services, driving up the quality of health and social care, protecting and improving community services, standing up for older people at risk of harm and tackling prejudice, inequality and discrimination. In keeping with elements of the NICE proposal, my Framework for Action calls for a greater focus on quality of life; this is fundamental to the success of delivering public services that meet the needs of older people.</p> <p>I have developed a “Quality of Life” model- which is synonymous with the concept of wellbeing referred to in the NICE guidelines-based on my conversations with over 5,000 older people. Older people, who have told me that their lives have value, meaning and purpose when they:</p> <ul style="list-style-type: none"> • Feel safe and are listened to, valued and respected; • Are able to get the help they need, when they need it, in the way they want it; • Live in a place which suits them and their lives; • Are able to do the things that matter to them. <p>In order to do this, it is vital that we recognise the multiple and diverse identities that are embodied by older people. Not only for Public Services to respond to their particular needs but in order that we recognise their contribution and individuality and are able to truly develop the principles of relationship-centred care across all care settings. To this end, it is very reassuring to see that the NICE proposal recognises that older people in care homes have individual needs that vary in complexity and, as such, must be treated as individuals. This is a key point and I would recommend that it be further promoted to ensure that service providers adopt practices that respond to those individual needs. It is therefore encouraging that the quality</p>	<p>As part of the development of quality standards areas are prioritised for development into statements following a stakeholder engagement exercise and discussion at the first meeting of the QSAC. The QSAC acknowledged that a number of the quality statements describe care that should be expected as a minimum. However, they agreed that in practice this type of care is not currently being delivered and we are aware of a large amount of current practice evidence that supports this. The QSAC strongly agreed that the quality standard does not simply promote a move towards a minimum standard but emphasises the importance of person-centred care and the needs and preferences of older people in care homes which are essential elements required for a change in culture. We hope this is evident and clear throughout.</p> <p>While it is not within the remit of quality standards to comment on specific integrated care models, the NICE Support for Commissioning document that will be published alongside the quality standard may make suggestions about how commissioners may want to work with other organisations. In addition, the quality standard sets out the expectation that services should be commissioned from and coordinated across all relevant agencies encompassing all of the person’s needs and their whole care pathway. We agreed that a person-centred, integrated approach to providing services is fundamental to delivering high-quality care to older people in care homes and this is set out in the introduction.</p> <p>It is not within the remit of NICE or quality standards to enforce regulatory requirements of local authorities, commissioners or providers but we do expect the quality standard to contribute to improvements in the care home sector.</p>

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				<p>Please insert each new comment in a new row.</p> <p>standard also includes consideration of equality and diversity and recognises the potential for the culturally nuanced composition of a care home. I also agree that enabling older people in care homes to be involved in all decisions about their care is fundamental to their mental wellbeing.</p> <p>I would urge however, that the NICE quality standards aim to drive the highest standards in the quality of life and care of older people and not simply move towards the stated minimum standard. In this way, the implementation of the standard is empowered to drives forward a cultural shift and ongoing improvement, above and beyond that which is simply deemed as adequate.</p> <p>I would also suggest that there be provision made in the quality standard to promote greater inter-agency/organisational working in which a culture of openness and transparency is cultivated and encouraged so that organisations and bodies such as (local authorities, health boards and trusts, CSSIW and CCW, for example in Wales) can and will share best and poor practice and other forms of information that will endorse, encourage and advance improvement across the care home sector. With this in mind, the NICE proposal that local authorities and commissioning services work with providers is useful; however, I would urge that consideration be given to the implementation of some form of regulatory requirement in order to make the measure enforceable.</p>	<p>Please respond to each comment</p>
001	8	Amore Care – Part of the Priory Group	Questions for consultation Q2	Time will always be a determinant issue in achieving the quality standards. A cultural shift is required toward individuality and away from task centeredness and institutionalisation.	Thank you for your comment.
012	9	British Association of Behavioural and Cognitive Psychotherapies	Questions for consultation Q2	Given the provisos re systems and structures, some of the measures proposed do appear practicable, although the risk highlighted above of homes meeting the standard but missing the point remains. The quality measures proposed for structure and process in relation to 'Personal Identity' appear least likely to be helpful. In general, across the quality statement measures, who is responsible for 'local arrangements' – again there is a	<p>The NICE Support for Commissioning document that is published alongside the quality standard provides more information about how the quality statements and measures may be implemented.</p> <p>The Adult Social Care Outcomes Toolkit, which is listed as a data source, contains a self-completion questionnaire</p>

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				Please insert each new comment in a new row. lack of identifying exactly who is responsible for what. Is it local authorities and other commissioning services? If so, could this be made explicit? Why not use a simple well-being tool with those residents who are able to complete it?	Please respond to each comment which asks questions relevant to the quality statements. This can be adapted locally for residents to complete.
016	10	Social Care Institute for Excellence	Questions for consultation Q2	The quality measures are clear and collectable. They consider local arrangements for integrated care as well as specific workforce skills. HQIP, with SCIE, has been commissioned by DH to develop a dementia quality audit tool for care homes. NICE quality measures will be of relevance to this work	Thank you for your comment.
019	11	Research into Practice for Adults	Questions for consultation Q2	The data proposed can be collected. However, it is unclear if it is measuring what's required. The measures indicated are an additional dataset to current arrangements, therefore greater clarity for providers is required as to the purpose of the dataset and what it is intended to demonstrate. Potentially local arrangements could be linked to CQUINS to incentivise providers in terms of data collection. The data collection lacks an overall measure of well-being to ascertain if the implementation of the quality standards has a positive impact on the mental wellbeing of older people in care homes. The focus of the measures is on the measurement of individual activities such as assessments rather than the broader outcome on wellbeing as 'life satisfaction' and 'happiness'. As Allen states "Emotional wellbeing is broader than just the presence (or absence) of common mental health problems and so we also include life satisfaction and levels of happiness" (Allen 2008: 13). REFERENCE: Allen, J (2008) "Older People and Wellbeing" IPPR (available at http://www.ippr.org/images/media/files/publication/2011/05/older_people_and_wellbeing_1651.pdf)	The data sources provided offer examples of existing national data collection which may be relevant and could be adapted locally. The data sources provide examples of ways of measuring and evidencing achievement against the quality statements contained in the quality standard. The NICE Support for Commissioning document that is published alongside the quality standard provides more information about how the quality statements and measures may be implemented. The QSAC felt that the measures identified are appropriate for the quality statements that have been developed. The statements on meaningful activity and personal identity include measures relating to how older people feel.
022	12	Durham County Council	Questions	The Service already have systems in place, through the Quality	The proposed sets of quality measures may be used as a

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			for consultation Q2	<p>Band Assessment Toolkit for contracted services, to collect data which links to the proposed quality measures. However, the Service would question the need of having to report the data through to another source (if this is the intention) as this would be an additional burden for no purpose.</p> <p>The Service also wish to express concerns around the wording / suitability of inclusion of this question in the consultation. Is it not a forgone conclusion that if the systems and structures are in place you would be able to collect the data and therefore answer yes, however, if the systems and structures were not available you wouldn't be able to collect the data and therefore this would lead to a response of no?</p>	<p>Please insert each new comment in a new row.</p> <p>Please respond to each comment</p> <p>starting point for quality assessment at a local level and it is expected that organisations will decide locally how data linked to the quality measures is collected and reported. The question which asks 'If the systems and structures were available, do you think it would be possible to collect the data for the proposed quality measures?' is included to ensure NICE is aware of any barriers that may make it difficult or impossible to the collect the specific data required for the quality measures. For example, systems may be in place for data to be collected but the people providing the service may not have the necessary skills to collect it.</p>
031	13	Parkinson's UK and Lewy Body Society	Questions for consultation Q2	Dementia care mapping can be effective means of assessing the quality of care in an environment. Tools, such as the short observational framework for inspection (SOFI), can be used to capture the experiences of service users who are unable or struggle to express themselves. ¹	Text has been added to the Equality and diversity considerations sections of the statements about meaningful activity and personal identity suggesting that tools such as Dementia Care Mapping should be used to capture the experiences of people who find it difficult to provide feedback.
001	14	Amore Care – Part of the Priory Group	General	It would be helpful to have clarification about where we are with integrated teams. There are some areas of the country that are dismantling integrated team. The Multi-disciplinary or integrated services are vital for people with dementia where they work well.	Whilst the importance of co-ordinated services and integrated working is acknowledged in the quality standard NICE is unable to comment on the configuration of specific services. The NICE support for commissioners of dementia care very clearly recommends integrated services for people with dementia and NICE has signed up to Integrated care: our shared commitment and is supporting the Department of Health work on integration pioneers.
001	15	Amore Care – Part of the Priory Group	General	Excellent list which if endorsed will be of great benefit to people with dementia. I would add that people with dementia are entitled to training and development that has a principle of reflection and we cease to tar all people with dementia as having the potential to present with challenging behaviour. Training should encompass the significance of reality and	Thank you for your comment. It is not within the remit of this quality standard to comment on specific types of training. The Dementia quality standard includes a statement on appropriately trained staff.

¹ Alzheimer's Society (2013) Low expectations: attitudes on choice, care and community for people with dementia in care homes

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				Please insert each new comment in a new row. knowing the person before the dementia. Trying to bring people out of their reality can be futile and escalate a given situation where the individual become labelled as 'aggressive' or challenging. Training must firstly indicate that we must look to ourselves and understand how our approach and communication can be triggering a 'distress response.	Please respond to each comment
007	16	Life Story Network CiC	General	To ensure that all of these quality measures are both embedded and evidenced, it is vital that these are set within the culture of effective and transformational leadership within the home. Transformational leadership needs to be both articulated and measured as part of the whole process and an integral aspect of this is how staff within the care home are respected and valued.	Thank you for your comment.
007	17	Life Story Network CiC	General	Reference should be made to the key articles in the Human Rights Act (HRA), which underpin these quality statements. The HRA provides a legal framework and duty for care homes to work within.	NICE quality standards do not aim to include exhaustive lists of national acts or legal frameworks. The QSAC agreed that the most appropriate acts have been referenced for this quality standard.
007	18	Life Story Network CiC	General	The Department of Health (DH) funded Let's Respect for Care Homes needs to be referenced as a source of support and evidence underpinning these standards. Life Story Network www.lifestorynetwork.org.uk will be supporting the dissemination of this material with training on behalf of the DH.	NICE quality standards do not aim to include exhaustive lists of relevant sources and evidence. The QSAC agreed that the most appropriate sources have been referenced for this quality standard.
008	19	English Community Care Association	General	The English Community Care Association (ECCA) is the leading representative body for community care in England. Our members provide a wide range of services for adults with care and support needs including residential and nursing settings, homecare, housing and community-based support. Our members also deliver specialist care home services such as rehabilitation, respite, palliative care and mental health services. ECCA welcomes the draft mental wellbeing of older people in care homes quality standard and in particular the intention that, "services should be commissioned from and coordinated across all relevant agencies encompassing the whole pathway." The statements however lack clarity in terms of impact and outcome for residents. Without measuring impact and intervention this standard records information which of itself is limited and does nothing to evidence improvement of wellbeing for residents.	The QSAC felt that the quality statements that have been developed go much further than simply recording information. The proposed measures are assured for face validity and provide an important starting point for local quality assessment and adaption and are capable of evidencing improvements in wellbeing for people in care homes.
009	20	College of Occupational Therapists	General	We suggest clarifying the definition of wellbeing to reflect the importance of maintaining people at their optimum level of	The definition has been updated to reflect this suggestion.

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				<p>functioning - a key policy driver of health and social care as referred to in the Living Well with Dementia- a national dementia strategy (2009), the Care Bill (2013-2014) and a key principle of reablement, and avoiding unplanned hospital admissions.</p> <p>Proposed rewording: This quality standard covers the mental wellbeing of older people (65 years and over) receiving care in all care home settings, including residential and nursing accommodation, day care and respite care. This quality standard uses a broad definition of mental wellbeing, and includes key elements to support optimum functioning and independence such as life satisfaction, optimism, self-esteem, feeling in control, having a purpose in life, and a sense of belonging and support.</p>	
009	21	College of Occupational Therapists	General	<p>The existing quality statements do not reflect the importance of social interaction/ inclusion/ maintenance and development of relationships both within and outside the care home setting. This is recognised within the Care Homes for Older People National Minimum standards and the Care Homes Regulations 2001. (DH, 2003) in particular within Standard 13.</p> <p>This could be achieved by an additional Quality Statement for example: Older people in care homes are supported to engage with the community within and outside of the care home setting.</p> <p>Alternatively, this element could be incorporated with Quality Statement 1. For example: Older people in care homes have opportunities and support during their day to participate in meaningful activities that promote health and mental wellbeing and to engage with their community within and outside of the care home setting.</p>	The QSAC agreed that a separate statement on social interaction and relationships is not required. However, it was agreed that the quality standard required a stronger focus on these issues throughout the document. Text has been added to the quality standard to ensure that social inclusion and relationships have been adequately addressed.
009	22	College of Occupational Therapists	General	<p>Other tools freely available and applicable UK wide include Make Every Moment Count and the Managing Falls and Fractures from the Scottish Care Inspectorate. www.scswis.com/index.php?opti..._download&gid=963&Itemid=378</p>	Thank you for your comment. The quality standard does not aim to provide an exhaustive list of relevant available tools and it is felt that the most relevant policy and toolkits have been included in the quality standard.

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012	23	British Association of Behavioural and Cognitive Psychotherapies	General	<p>This list of five quality statements offers assessment in three domains (mental health; sensory impairment; and physical problems), the opportunity to participate in meaningful activities and enabling of personal identity.</p> <p>These are important domains in care homes, and each could undoubtedly contribute to greater mental well-being as defined in the document. However, they do not directly address the psychological and cognitive processes and evaluative judgements that contribute to life satisfaction, self esteem, having a purpose in life and so on. There is, for example, no mention of support for processes of adjustment and adaptation to living in a care home environment. There is a clear risk that care homes could, on paper, achieve these quality standards without fully embracing a person-centred approach (as envisaged on page 6). In the dementia care field, person-centred care involves much more than simply offering an individualised approach, it also encompasses valuing the person and those who provide care, seeing the world from the perspective of the person and offering a positive social environment . The ‘personal identity’ statement comes closest to this approach, but would benefit from further reinforcement of what this might involve. A life history sheet in the care home notes, never seen by care staff, is insufficient to achieve personal identity. ‘Meaningful activities’ are similarly prone to being offered in a way that does not entirely fit with person-centred care. Our suggestion is that following the section ‘Coordinated services’, there should be inserted a much stronger and clearer statement regarding person-centred care – this was the approach adopted by the NICE-SCIE dementia guideline (2006).</p>	The quality standard has been updated to include a greater emphasis on relationships, social inclusion and the transition into the care home. The definitions sections for the statements on meaningful activity and personal identity have been expanded to give more examples of what might be involved in offering opportunities for meaningful activity and enabling older people to maintain and develop their personal identity. It was felt that it was more appropriate to emphasise these aspects throughout the quality standard rather than including an additional section.
012	24	British Association of Behavioural and Cognitive Psychotherapies	General	Dementia appears to be the ‘elephant in the room’ in this document. The latest figures (Matthews et al, July 2013, The Lancet) show that 70% of care home residents in England have a dementia. Yes, we already have good NICE-SCIE guidelines and standards on dementia, but here the opportunity is to specifically address the issues relating to people with dementia	The existing NICE guidance and quality standards on dementia are applicable to all settings including care homes. As part of the development of quality standards areas are prioritised for development into statements following a stakeholder engagement exercise and discussion at the first meeting of the QSAC. The QSAC

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012	25	British Association of Behavioural and Cognitive Psychotherapies	General	The statement 'All health and social care practitioners.....in the quality standard' is such a catch-all to be virtually meaningless. There is a need to be much clearer about which practitioners are responsible for which actions and interventions, and for a clearer statement (perhaps in relation to each of the five quality statements) about the training and supervision that might be needed in each case.	Whilst it is not within the remit of the quality standard to specify who is responsible for particular actions and interventions, the NICE Support for Commissioning document offers more specific advice and information about how the quality standard may be implemented including what training might be required.
017	26	St Christopher's Hospice	General	Outcome measure instead of people manage their own support as much as they wish it should perhaps say 'Where able' first. This is particularly important for care homes with nursing where	Thank you for your comment. The Adult Social Care Outcomes Framework is a national publication developed by the Department of Health. It is not within the remit of

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				the majority of residents die within the first year following admission.	NICE to make any amendments to this framework.
017	27	St Christopher's Hospice	General	<ul style="list-style-type: none"> • There is little in the document about accounting for lack of capacity • No mention of end of life care despite a fifth of the UK population choosing to die in a care home • Very little on the importance of psychiatry input • The importance of assessing and managing symptoms • The importance of external teams – such as GPs – and their responsibility in the care of frail older people 	<p>The quality standard has been updated to make reference to the Mental Capacity Act and also to state that older people in care homes should have access to an advocate if needed.</p> <p>Additional text has been added to the equality and diversity considerations section for each statement regarding end of life care. The text highlights the importance of the needs and preferences of people who are approaching the end of their life. The End of life care quality standard is comprehensive, cross cutting and applicable across all settings. This quality standard has been added to the <i>Related Quality Standards</i> section.</p> <p>As part of the development of quality standards areas are prioritised for development into statements following a stakeholder engagement exercise and discussion at the first meeting of the QSAC. The QSAC prioritised the areas of care they felt were most important for older people in care homes, based on the development sources listed. Areas of care were prioritised where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. An additional statement on access to the full range of healthcare services has been added to the quality standard.</p>
018	28	Faculty of Public Health	General	The focus on holistic wellbeing, autonomy and sense of purpose is excellent. We are also pleased to see equality issues woven through the standard, although this aspect would need to be strengthened if it is to have any real impact.	The equality and diversity issues sections of the quality standard have been updated to place greater emphasis on these issues.
018	29	Faculty of Public Health	General	Ethnicity and sexual orientation are the big issues which are often overlooked and not sensitively or appropriately addressed.	The QSAC felt that the equality and diversity sections of the quality standard adequately address these issues.
018	30	Faculty of Public Health	General	The focus of the standards also seem to be quite medically focused, with identifying disease and mental health problems being high on the list. The guidelines would benefit from reflection on the quality of life gains from diagnosis of common	As part of the development of quality standards areas are prioritised for development into statements following a stakeholder engagement exercise and discussion at the first meeting of the QSAC. The QSAC prioritised the areas

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				conditions affecting elderly people, and how these compare with quality of life gains from health promoting activities.	of care they felt were most important for older people in care homes, based on the development sources listed. Areas of care were prioritised where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. It is not within the remit of the quality standard to make specific statements on or comparisons of quality of life gains. The areas within the quality standard you highlight reflect the need to ensure appropriate access to healthcare which has been consistently highlighted by the social care sector as an area for improvement for care homes which the quality standard could make an important comment on.
018	31	Faculty of Public Health	General	When people of any age are asked about wellbeing, relationships come very high up the agenda. Neither the briefing statement nor the quality standard seem to specifically address the social dimension. The document could benefit from the inclusion of the mantra "No decision about me, without me (or my family)".	The QSAC agreed that the quality standard required a stronger focus on relationships throughout the document. The quality standard has been amended to ensure that social inclusion and relationships have been adequately addressed.
018	32	Faculty of Public Health	General	The tone of the document is rather individualistic: we would like to see a recognition of the wider support and social systems such as friends, families and carers. Such networks can be vital at this stage of life and should be seen as essential assets to be supported, nurtured and developed.	The QSAC agreed that the quality standard required a stronger focus on relationships throughout the document. The quality standard has been amended to ensure that social inclusion, links with the community and relationships have been adequately addressed.
018	33	Faculty of Public Health	General	Many older people can give help, support and pleasure to others and this makes a difference to their own wellbeing. There is nothing about engagement with the wider community, which a care home is part of, or social activities such as singing or music. Anecdotally many care homes do this because it brings enjoyment. Many older people can make music for others to share.	The QSAC agreed that the quality standard required a stronger focus on relationships throughout the document. The quality standard has been amended to ensure that social inclusion, links with the community and relationships have been adequately addressed. The quality standard has been updated to include examples of social activities.
018	34	Faculty of Public Health	General	There is very little on nutrition and there is room to review the recent literature on the effect of, for example, sugar, fruit and vegetables and essential fatty acids on quality of life in older people.	As part of the development of quality standards areas are prioritised for development into statements following a stakeholder engagement exercise and discussion at the first meeting of the QSAC. The QSAC prioritised the areas of care they felt were most important for older people in care homes, based on the development sources listed. Areas of care were prioritised where practice is variable, or

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					where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. Nutrition was not prioritised as an area for quality improvement.
018	35	Faculty of Public Health	General	The term mental health disorders should be avoided: mental disorders is the term FPH uses.	The quality statement refers to mental health conditions. The inclusion of 'health' is in line NICE guidance and Department of Health policy documents.
018	36	Faculty of Public Health	General	The standard does not mention an important related issue: the use of only low doses of psychotropics, if needed at all (which sometimes may be the case for significant psychological distress). Doses should take into account often a low body weight and co-morbidities.	As part of the development of quality standards areas are prioritised for development into statements following a stakeholder engagement exercise and discussion at the first meeting of the QSAC. The QSAC prioritised the areas of care they felt were most important for older people in care homes, based on the development sources listed. Areas of care were prioritised where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators.
018	37	Faculty of Public Health	General	The document could include consideration of any steps that could be taken to reduce medication errors in general, which can affect quality of life, if not life itself.	Managing medicines in care homes is in the core library of quality standards planned for development. Therefore, it was not appropriate to develop a statement in this area as it will be addressed by the quality standard on this topic.
018	38	Faculty of Public Health	General	FPH would welcome a quality standard on mental wellbeing of older people in care homes: such a focus on older people living in their own homes is likely to have positive outcomes.	Thank you for your comment.
018	39	Faculty of Public Health	General	Finally – and often overlooked – are the needs of staff themselves, who are often low paid, young people. How are their emotional, physical and spiritual needs being met? Do they feel valued and are they being supported in their aspirations and dreams (meaning and purpose)? The Francis Report indicates that staff who are uncared for will be unable to carry out a care-giving role.	Addressing the needs of care home staff is outside of the scope of this quality standard.
019	40	Research into Practice for Adults	General	H: Organisational Factors The relevance of organisational factors is implicit throughout the Standards but no clear organisational requirements are specified. Discussion under each Standard could be more explicit about the importance of effective staff training and supervision. While there is limited empirical evidence relating	While it is not within the remit of quality standards to state the specific organisational requirements, the NICE Support for Commissioning document that will be published alongside the quality standard offers more specific advice and information about how the quality standard may be implemented including what training might be required.

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				<p>training and supervision to improved outcomes (Tsui 2005; Carpenter et al. 2012), Harkness and Hensley (1991) emphasise the positive effect of outcomes focused supervision and Schön (1983) links reflective practice to improved patient outcomes. In addition, Moriarty et al. (2010) emphasise the link between training on effective communication and improved social interaction, leading to improved mental wellbeing. It is therefore recommended that specific requirements on on-going training and supervision be incorporated in to each standard.</p> <p>REFERENCES:</p> <p>Allen, J (2008) "Older People and Wellbeing" IPPR (available at http://www.ippr.org/images/media/files/publication/2011/05/older_people_and_wellbeing_1651.pdf)</p> <p>BARNES, S. (2002) The design of caring environments and the quality of life of older people Ageing and Society, Volume 22, Issue 06, November 2002, pp 775-789</p> <p>Bradford Dementia Group. 2007. "Involving Families in Care Homes: A Relationship-Centred Approach to Dementia Care" Good Practice Guides</p> <p>Carpenter, J. et al. (2012) "Effective Supervision in Social Work and Social Care" SCIE Research Briefing available at http://www.scie.org.uk/publications/briefings/files/briefing43.pdf</p> <p>Curtis, S. (2010) "Space, place and mental health" Farnham: Ashgate.</p> <p>Day, P. (1985) "An interview: Constructing reality" British Journal of Social Work, Vol. 15, pp 487-499</p> <p>Department of Health (2010) "Dignity in Care Homes: Caring for People Affected by Dementia: A report on events held for care</p>	

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				<p>home staff to support national dignity action day in the south east" Social care and local partnerships programme</p> <p>Harkness D & Hensley H (1991) "Changing the focus of social work supervision: effects on client satisfaction and generalized contentment" Social Work 36 (6) pp.506-512</p> <p>Hitlin, S. "Values as the core of personal identity: Drawing links between two theories of self" Social Psychology Quarterly 2003 Vol. 66, Issue 2, pp 118-137</p> <p>Moriarty, J. et al. (2010) "Communication training for care home workers: outcomes for older people, staff, family and friends" SCIE Research Briefing available at: http://www.scie.org.uk/publications/briefings/files/briefing34.pdf</p> <p>PARKER, C. (2004) "Quality of life and building design in residential and nursing homes for older people" Ageing and Society, Volume 24, Issue 06, November 2004, pp 941-962</p> <p>Schön, D A (1983) "The Reflective Practitioner: how professionals think in action" London: Temple Smith</p> <p>Surr, C., Boyle, G., Brooker, D., Godfrey, M., and Townsend, J. (2005) "Prevention and Service Provision: Mental Health Problems in Later Life" Leeds: Centre for Health and Social Care, University of Leeds/ Bradford: Division of Dementia Studies, University of Bradford.</p> <p>Tsui, M. (2005) "Social Work Supervision, Contexts and Concepts". Sage, London.</p> <p>Westius et al. (2010) "Views of life and sense of identity in people with Alzheimer's disease" Ageing and Society Vol. 30,</p>	

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				Issue 07, October 2007 pp1257-1278.	
020	41	Royal College of Psychiatrists	General	These standards are all fairly basic levels of care that are already available and generally practiced in care homes. They are all important for optimising mental and physical wellbeing and functioning but they are not specifically about mental wellness.	As part of the development of quality standards areas are prioritised for development into statements following a stakeholder engagement exercise and discussion at the first meeting of the QSAC. The QSAC acknowledged that a number of the quality statements describe care that should be expected as a minimum. However, they agreed that in practice this type of care is not currently being delivered and we are aware of a large amount of current practice evidence that supports this.
020	42	Royal College of Psychiatrists	General	Gold standards for audits and monitoring are always useful and these ones are clear and commendable but these do not focus on mental wellbeing.	The QSAC agreed that the quality statements and measures focus on mental wellbeing. The proposed measures are assured for face validity and provide an important starting point for local quality assessment and adaption and are capable of evidencing improvements in wellbeing for people in care homes.
020	43	Royal College of Psychiatrists	General	A key factor in mental wellbeing for people who lack mental capacity is their immediate environment and the impact of staff morale. Levels of staff morale and psychological literacy could be considered, as well as audits of staffing levels and qualifications for their roles.	While it is outside of the scope of this quality standard to comment specifically on staff morale and levels of staffing, the NICE Support for Commissioning document offers more specific advice and information about how the quality standard may be implemented including what training might be required for staff.
020	44	Royal College of Psychiatrists	General	There is inadequate clinical contribution to the Advisory committee; no psychiatry or psychology input, and no clinicians specialising in working with older people. As a result this draft lacks some awareness of the care home setting and/or the complexities of the residents.	Standing membership of Quality Standards Advisory Committee (QSAC) that considered this topic does include a senior mental health nurse practitioner and a clinical psychologist. One of the specialist committee members also has specific expertise in the area of older people and residential care. When the specialist committee membership was discussed at the first meeting, the committee felt that the make-up was appropriate.
022	45	Durham County Council	General	No reference has been made to Care Quality Commission and how, or if, the quality standards fit with their own standards.	NICE quality standards are distinct products separate from essential standards and describe care that is above and beyond the CQC essential standards. Quality standards describe what high quality care should look like. The statements and measures in a NICE quality standard together indicate a high quality clinical service. The

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					<p>delivery of high quality care is signalled by good performance across the breadth of all statements and measures. If an organisation is performing poorly on many or all measures, it may mean that an organisation is at risk of not meeting CQC Essential Standards of Quality and Safety and of not complying with regulatory requirements. The Care Quality Commission may use data from quality standard measures in its risk estimations. It may also align any special reviews and studies it undertakes with the relevant quality standards.</p>
023	46	Optical Confederation	General	<p>The Optical Confederation represents the 12,000 optometrists, the 6,000 dispensing opticians and 7,000 optical businesses in the UK who provide high quality and accessible eye care services to the whole population. The Confederation is a coalition of the five optical representative bodies: the Association of British Dispensing Opticians (ABDO); the Association of Contact Lens Manufacturers (ACLM); the Association of Optometrists (AOP); the Federation of Manufacturing Opticians (FMO) and the Federation of Opticians (FODO). As a Confederation, we work with others to improve eye health for the public good.</p> <p>The Optical Confederation's Domiciliary Eyecare Committee (DEC) is committed to promoting the highest standards of patient care for those unable to attend a high street practice. It believes that high quality eye care should be available to all patients, regardless of whether the service is delivered in the patient's home or in the high street. Many care home residents will fall into this patient group.</p> <p>We very much welcome the inclusion of eye health and sensory impairment in the NICE standards for well-being under Quality Statement 3 and hope that future commissioning will increasingly focus on interventions that tackle preventable conditions and disease that have catastrophic impacts on the quality of life and impact adversely on outcomes across all Domains. Sight loss for example, has major adverse impacts on</p>	<p>Thank you for the information you have provided and for the offer of working with NICE. You have been added to our list of stakeholders for the Clinical Commissioning Group Outcomes Indicator Set (CCG OIS) programme. For more information on the programme please see the CCG OIS section of the NICE website. Please note that you will receive information about all topics that are in the process of having indicators developed.</p> <p>Please also note the forward planner for NICE quality standards that is available to view on the NICE website. This document provides information on topics planned for development as quality standards including the date of engagement and consultation exercises which enable you to provide comments on individual topics.</p>

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				<p>quality of life, mental health and wellbeing with over one-third of older people with sight loss suffering from depression ², and has been demonstrated to significantly increase the risk of falls and hip fractures.</p> <p>Sight loss, defined as partial sight or blindness in the better-seeing eye, affects people of all ages, but especially older people: 1 in 5 people aged 75 and 1 in 2 aged 90 and over are living with sight loss³. Good vision can have a great impact on an individual's independence, self esteem and general well-being enabling them to perform daily tasks and participate in recreational activities.</p> <p>A sight test conducted in a care home or a person's home may also detect changes in the eye due to cataract, macular degeneration, glaucoma or diabetic retinopathy, as well as other health problems such as raised blood pressure. Early detection of such conditions can often prevent serious sight loss.</p> <p>Care home staff, health visitors, families and home care services can play an important role in helping to ensure that eyecare is not neglected in this vulnerable group of people by arranging a home visit, or, for those who are more able, by arranging transport to take them to a local practice.</p> <p>The Optical Confederation would very much welcome the opportunity to work with NICE and NHS England to develop further indicators of sight loss and sensory impairment, which focus on prevention and amelioration to improve the outcomes across all Domains.</p>	
024	47	The Older People's Commissioner for Wales	General	I welcome the NICE proposals for a quality standard that aims to ensure the mental wellbeing of older people in all care home settings. Any measures that drive up the quality of life, and care, of older people must be actively encouraged and endorsed.	Thank you for the information you have provided and for the offer of sharing your review with NICE. Whilst we appreciate this offer we must follow a structured process and timeline when developing quality standards and

² Hodge, Barr and Knox (2010) Evaluation of emotional support; 5: Douglas et al (2006) Network 1000

³ Access Economics (2009) Future Sight Loss (1): The economic impact of partial sight and blindness in the UK adult population, 1.1 Definitions of Partial Sight and Blindness, p.3.

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				<p>I am frequently contacted by older people and their families about issues relating to poor quality of life and care in residential care settings in Wales and what I hear is of great concern to me. Time and again, I am told of incidents and occasions where residents have, at best, been treated with scant regard for their individual needs and wishes and, at worst, with a level of care that can best be described as neglectful and even abusive.</p> <p>The need for improvement is pressing, especially given the numbers involved. Older people (over the age of 65) represent 18% of Wales' total population. Of a total population of 563,000 older people living in Wales, nearly 5% reside in some form of permanent residential care. Of all older adult care homes across Wales, there are a total of 704 residential care settings, with 23,322 places.</p> <p>There are of course many examples of excellent quality of life and care; however, inconsistency and variance is an issue. In short, the provision of excellent quality of care in all care home settings is essential and anything less than this is unacceptable.</p> <p>I recently announced my review into the quality of life and care of older people in care home settings, a key priority of which will be to drive up the quality of lives of older people living in residential care homes in Wales. My review will showcase the voices, thinking and reflections of older people, their families and those who care for and support them, to find out whether older people living in care homes in Wales have a good quality of life. The NICE proposals reflect, to a large degree, the aims of my review in that it seeks to enhance the quality of life for older people with care and support needs. I would welcome the opportunity to discuss my review with NICE representatives and perhaps arrange on-going discussions and dialogue in order that we might share ideas and discuss the topic in greater detail. I look forward to hearing your thoughts on this.</p>	<p>therefore are unable to have discussions about your review at this stage in the process.</p> <p>Please note the forward planner for NICE quality standards that is available to view on the NICE website. This document provides information on topics planned for development as quality standards including the date of engagement and consultation exercises which enable you to provide comments on individual topics. Please also see the NICE website for more detail about how you can get involved.</p>

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024	48	The Older People's Commissioner for Wales	General	<p>In principle, and in short, my answer would be yes. However, before providing a response to this question, if you'll permit me, I would like to seek clarification in terms of what NICE proposes for implementation of the standard in Wales- given the devolved status of Wales' regulatory bodies? As you are aware, the regulatory structure in Wales, with regard to the care sector, is organised differently to that of England and is made up of the Care and Social Services Inspectorate Wales (CSSIW) and the Care Council of Wales (CCW).</p> <p>CSSIW inspect and regulate all care home settings in Wales. Its regulation includes the registration of service providers; the inspection services; responding to complaints and concerns about regulated services; and enforcement in cases where services do not comply with the law. CCW, on the other hand, regulates the social care profession in Wales; in particular, it aims to ensure that the social care workforce in Wales is safe to practice. CCW has a duty to investigate complaints of alleged misconduct made against registered social workers, social work degree students, social care workers and managers in Wales who allegedly do not meet the standards set out in the Code of Practice for Social Care Workers. CCW can take action when it receives this information and there is a process for investigating information and imposing sanctions on those whose suitability to remain on the Register and work in the social care sector in Wales is brought into question, including suspending and removing registrants from the Register.</p> <p>Given the differences in regulatory structure, I'd therefore be very interested in finding out how the quality standard would be implemented and overseen in Wales? I would also like to find out how NICE will ensure a uniform, consistent and enforceable approach to regulation in Wales?</p>	Thank you for your comment. NICE and the Welsh Assembly have an agreement in place that permits the use of NICE guidelines and quality standards within Wales. The application of these within Wales and its care structures is a matter for the devolved administration.
025	49	NHS England	General	NHS England has no substantive comments to make regarding this consultation	Thank you for your response.
026	50	Royal College of Nursing	General	The draft quality standard is clear and achievable. What does seem to be lacking is the evidence that these measures are not already in place. We are aware that these standards are already	As part of the development of quality standards areas are prioritised for development into statements following a stakeholder engagement exercise and discussion at the

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				being aspired to.	first meeting of the QSAC. The QSAC acknowledged that a number of the quality statements describe care that should be expected as a minimum. However, they agreed that in practice this type of care is not currently being delivered and we are aware of a large amount of current practice evidence that supports this. It was agreed that some care homes will already be achieving the care described in the quality standard but that this was not the case for a significant proportion of care homes.
026	51	Royal College of Nursing	General	The guidance indicators that are being made seem to assume that there is a problem with care homes not understanding and providing access. All of the standards suggest that if care homes understand the situation and flag up these to the appropriate agencies the quality will improve.	The QSAC discussed the issues surrounding access to healthcare services for people in care homes. They agreed that improving access to services for people in care homes needs to be addressed by a number of groups including care home staff, GPs, commissioners and local authorities. The section on <i>What the quality statement means for service providers, healthcare professionals, social care and public health practitioners, and commissioners</i> makes it clear that care home staff are not expected to implement the quality statements in isolation. The quality standard has been updated and links to a new SCIE Guide on services for older people living in residential care which describes the issue of access and proactive healthcare.
026	52	Royal College of Nursing	General	Much of the emphasis of the quality statements focus of care staff referring on. An issue that has not been mentioned is what happens to the referral. It is the view of care home providers that staff already understand the importance and record and promote dignity as aspired to within the standards. The barrier is not the care homes understanding the rights of individuals that live in care homes but the other professionals and agencies overlooking the right of the individuals to access support. Often referrals are not passed on. There is often misunderstanding about an individual's right to the support which is muddled by thinking that care homes are not providing an adequate service if they ask for the support outlined in the guidance.	The QSAC discussed the issues surrounding access to healthcare services for people in care homes. They agreed that improving access to services for people in care homes needs to be addressed by a number of groups including care home staff, GPs, commissioners and local authorities. The section on <i>What the quality statement means for organisations providing care, social care, health and public health practitioners, local authorities and other commissioning services</i> makes it clear that care home staff are not expected to implement the quality statements in isolation.
026	53	Royal College of Nursing	General	Many individuals once they are using the support of care homes have been needing general support for some time. It is difficult	Thank you for your comment.

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026	54	Royal College of Nursing	General	Older persons in a care home- can this be changed to Older persons living in a care home? Throughout the document.	The wording 'older people in care homes' cannot be changed as the populations covered by the quality standard include people who access day care and respite care. If the quality standard were to include the phrase 'living in a care home' this would exclude these groups.
026	55	Royal College of Nursing	General	There is no reference to nutrition. There really needs to be an acknowledgment of malnutrition and the risks that this will affect the wellbeing of the older person. There are lots of useful resources relating to this, on the malnutrition taskforce.org.uk web page.	Malnutrition is not included within the quality standard as it is specifically addressed by the CQC essential standards under outcome 5.
026	56	Royal College of Nursing	General	There is no mention of the older person having the right to maintain existing or to develop new relationships. This is important.	The quality standard has been amended to place greater emphasis on the maintenance and development of relationships.
026	57	Royal College of Nursing	General	The list of physical problems seems to be limited. We also think that the need to ensure comfort and pain control should be included. There is also nothing about end of life care?	The list of physical problems has been expanded. However, it is not intended that the quality standard will provide an exhaustive list of physical problems in the definitions section. It was not considered necessary to make specific reference to ensuring comfort and pain control as it is expected that this will be addressed by the implementation of statements 5 and 6. Additional text has been added to the equality and diversity considerations section for each statement regarding end of life care. The text highlights the importance of the needs and preferences of people who are approaching the end of their life. The End of life care quality standard is comprehensive, cross cutting and applicable across all settings. This quality standard has been added to the <i>Related Quality Standards</i> section.
029	58	OPENSspace Research Centre	General	The more types of residential outdoor space an older person has, whether private or shared, the greater their satisfaction. In terms of wellbeing, the smallest things can bring the biggest benefits, such as having one's own patio, space to socialise or simply a green view. See http://www.idgo.ac.uk/useful_resources/Presentations/LMIDG_O_KT_EQUAL_Edinburgh_19_March_2010.pdf	The definition of meaningful activity has been amended to include reference to using outdoor spaces.

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029	59	OPENspace Research Centre	General	Please insert each new comment in a new row. The importance of access to natural daylight and blue light regulation of mood, cognition and wellbeing is underlined by research such as the following: Schmoll C, Lascaratos G, Dhillon B, Skene D, Riha RL. The role of retinal regulation of sleep in health and disease. Sleep Med Rev 2011;15(2):107-13	Please respond to each comment. Thank you for your comment.
029	60	OPENspace Research Centre	General	The ability to get out and about in safe pleasant surroundings has obvious mental health benefits. If older people live in an environment that makes it easy and enjoyable for them to go outdoors, or within ten minutes' walk of a park, they are more likely to be physically active and satisfied with life and twice as likely to achieve the recommended levels of healthy walking. Physical activity is known to promote mental health and wellbeing especially in cases of mild depression, anxiety and stress. (See references cited above)	The definitions section of the quality statements about meaningful activity and personal identity have been amended to include reference to using outdoor spaces.
029	61	OPENspace Research Centre	General	The more types of residential outdoor space an older person has, whether private or shared, the greater their satisfaction. In terms of wellbeing, the smallest things can bring the biggest benefits, such as having one's own patio, space to socialise or simply a green view. The social interaction made possible by such places is known to address issues of depression and stress brought on by social isolation. (see references cited above)	The definitions section of the quality statements about meaningful activity and personal identity have been amended to include reference to using outdoor spaces.
029	62	OPENspace Research Centre	General	The pedestrian experience is vitally important to older people, who are most often on foot when out and about. For the many who find it difficult to get around, it is often due to the poor design, provision, installation or upkeep of neighbourhood features, especially footways.	It is not within the remit of NICE quality standards to comment on the design etc of public areas.
029	63	OPENspace Research Centre	General	Lesser-quality environments are often considered by older people to pose an increased falls risk, especially by those with vision, mobility or other impairments. They can heighten fears about crime, nuisance and traffic and make going outdoors less enticing; reinforcing feelings of loneliness or entrenching the challenges of socio-economic deprivation.	It is not within the remit of NICE quality standards to comment on the design etc of public areas.
031	64	Parkinson's UK and Lewy Body Society	General	Mental wellbeing for older people in care homes depends on the interplay of many factors including the environment, activities and relationships between everyone within and coming into the care home and the wider health and social care systems, as well	Thank you for your comment.

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				<p>Please insert each new comment in a new row.</p> <p>as the wider political and economic context. Impoverishment in any of these can undermine the physical, emotional, psychological and spiritual status of residents. Much has been written about how to improve the experience of older people, with and without mental health conditions, in residential settings and the best practice is applicable to the Parkinson's population.</p> <p>This joint response focuses on what is specifically applicable to the mental wellbeing of older people with Lewy body disorders - Parkinson's (PD), Parkinson's Dementia (PDD) and Dementia with Lewy Bodies (DLB) - living in a care home.</p> <p>Comments from family members of people with PDD or DLB who live or lived in care homes are shown in italic script.</p>	Please respond to each comment
031	65	Parkinson's UK and Lewy Body Society	General	<p>Prevalence of Parkinson's in the care home population Parkinson's is a progressive and fluctuating condition, with a range of motor and non-motor symptoms which can give rise to complex care requirements and impact on quality of life.⁴</p> <p>A recent study in the North East of England found that 14 per cent of people with Parkinson's were living in residential or nursing homes, representing 1.6 per cent of the total nursing / residential home population⁵. Those in care have been seen to be significantly older with later stage disease, poorer cognitive function and poorer functional ability. Psychiatric symptoms are more common among people with Parkinson's living in nursing homes compared with people with Parkinson's living at home and correlate with stage of disease and cognitive impairment, but not with age or duration of disease. In one study, 83 per</p>	Thank you for providing this information. The quality standard focuses on all older people living in care homes and therefore will not include statements about specific conditions such as Parkinson's. However, it is the aim of the quality standard to consider all conditions affecting older people in care homes by raising awareness via the equality and diversity considerations sections which are included with the quality statements.

⁴ Porter B, Macfarlane R, Unwin N, Walker R (2006) The prevalence of Parkinson's disease in an area of North Tyneside in the North-East of England. *Neuroepidemiology* 26(3):156-61.

⁵ Porter B, Henry SR, Gray WK, Walker RW. (2010). Care requirements of a prevalent population of people with idiopathic Parkinson's disease. *Age and Ageing* 39(1):57-61.

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				<p>cent of the nursing home population had at least one symptom present. Cognitive impairment is the most important risk factor for institutionalisation in Parkinson's disease and a prevalence of dementia may be as high as 90% among people with Parkinson's in nursing Homes.</p> <p>Outcomes for people with Parkinson's in residential care Outcomes for people with Parkinson's admitted to residential care are worse than for those who are able to stay at home, with a lack of knowledge and understanding of the condition by care home staff resulting in sub-optimal care⁶</p> <p>The reasons for such deficiencies are likely to be multi-factorial. Services for patients with Parkinson's in institutional care can be more difficult to access, particularly for those with cognitive impairment and for those without a family member able to contact services on their behalf, and staff in institutional care may be less experienced in dealing with the condition and less familiar with the medications and their side effects. Patients with later stage Parkinson's may be severely disabled for long periods and require considerable help with activities of daily living. They may no longer be guaranteed a consistent response to their dopaminergic medication. Moreover, this can result in the prescription of a large number of anti-Parkinsonian drugs with significant time spent balancing the effects of drugs against side effects. ^{7 8 9 10 11 12}</p>	

⁶ Barnes L, Cheek J, Nation RL, Gilbert A, Paradiso L, Ballantyne A. (2006) Making sure the residents get their tablets: medication administration in care homes for older people. *J Adv Nurs*. Oct;56(2):190-9.

⁷ Walker R, Sweeney W, Gray W, (2011) Access to care services for rural dwellers with idiopathic Parkinson's disease. *British Journal of Neuroscience Nursing* 7 (2) – (April/May) p494-496

⁸ Buchanan RJ, Wang S, Huang C, Simpson P, Manyam BV (2002) Analyses of nursing home residents with Parkinson's disease using the minimum data set. *Parkinsonism Relat Disord*. Jun;8(5):369-80

⁹ Cummings JL (1991) Behavioral complications of drug treatment of Parkinson's disease. *J Am Geriatr Soc* 39:708–16.

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031	66	Parkinson's UK and Lewy Body Society	General	<p>The draft quality standard could benefit from an altered and clarified definition of its focus.</p> <p>Wellbeing We suggest the quality standard should focus on 'Wellbeing', addressing whole person care for the individual, focusing on the definition in the briefing notes and concentrating more on the outcomes an excellent home would be delivering in terms of people's aspirations, identity and control. Entitling the standard 'mental wellbeing' and then addressing sensory and physical problems lacks clarity. The standards should talk in terms of identifying need and referring on to health professionals and health services in relation to mental health problems and sensory impairments.</p> <p>Setting It would be helpful if the standard addressed differences between a care home and a nursing home and set the boundaries towards what a care home can deliver and what other health services should be delivering – this is really important as most care staff are not trained to deliver health assessments and interventions; nor should they be expected to. The emphasis of these statements should be about improving quality in the care home and ensuring that activities, environment (in and out of the care home) and staff engagement, improve mental wellbeing. It is important for staff</p>	<p>Wellbeing – The department of health referred the topic of Mental wellbeing of older people in residential care for development as a quality standard. Whilst the QSAC agreed to make the amendment from 'residential care' to 'care homes' they did not feel it was necessary to change 'mental wellbeing'. As part of the development of quality standards areas are prioritised for development into statements following a stakeholder engagement exercise and discussion at the first meeting of the QSAC. The QSAC agreed that all of the topics identified as areas for quality improvement impact on mental wellbeing. The rationale sections of the statements on sensory impairment and physical problems have been amended in order to give greater clarity about how they link to mental wellbeing.</p> <p>Setting – The quality statements on mental health conditions and sensory impairment have been amended and no longer state that older people should be assessed. They now focus on the recognition of these conditions and impairments. An additional statement about access to the full range of health services has been added to the quality standard in order to ensure that assessments are undertaken by the most appropriate health professional or team.</p> <p>NICE quality standards describe high-priority areas for quality improvement in a defined care or service area.</p>

¹⁰ Thanvi B R, Munshi S K, Vijaykumar N, Lo T C N (2003) Neuropsychiatric non-motor aspects of Parkinson's disease *Postgrad Med J* 79:561–565

¹¹ Aarsland D et al (1999) Range of neuropsychiatric disturbances in patients with Parkinson's disease *J Neurol Neurosurg Psychiatry* 67:492–496

¹² Ibid

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				<p>in care homes to identify sensory impairments and mental health problems but they should not be held responsible for delivering things that the health service should provide.</p> <p>We query why a care home with or without nursing should assess someone for sensory issues. The care home is there to deliver whole person care with input and advice from appropriate services. Specialists should and must be involved in anything to do with a person’s mental, physical and sensory health.</p> <p>It is not clear whether the standard is designed to define what an excellent care home service should be doing or what all care homes should be doing and how it relates to the CQC standards of fundamental care. Some things are not addressed in the standard - like having good quality meals, or being able to bring your pet to live with you – both sources of huge pleasure to people. Are these things an excellent home would provide or should they all?</p> <p>Widening the focus to beyond the home This standard is focused on activities within the home. As the well-being of residents is often greatly enhanced by engagement outside the home and by people coming in from outside the home, and the provision of high quality healthcare depends on effective liaison with services based outside the home, we suggest that the standard should reflect this broader view.</p> <p>Focus on older people Parkinson’s UK and the Lewy Body Society have a concern that separating out the older population of care home residents, as opposed to all care home residents, may contribute to the inherent discrimination in services towards older people.</p>	<p>Areas prioritised for quality statement development are areas of care where there is evidence or consensus that there is variation in the delivery of care to patients or service users. Quality standards are a distinct and separate product from the CQC essential standards and do not necessarily make explicit links to the CQC standards of care.</p> <p>Widening the focus to beyond the home – The quality standard has been amended to include a focus on: the use of outdoor spaces; links with the community; and relationships and social inclusion.</p> <p>Focus on older people - The definition of older people (aged 65 years and over) is consistent with the public health guidance PH16. It is acknowledged that there is a population of people aged under 65 years, in care homes for older people, which will not be covered by this quality standard. The decision to define older people as aged 65</p>

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					years and over, in line with PH16, was made because the needs of older people in care homes are specific and therefore they must be considered as a discrete group.
032	67	Care Quality Commission	General	Some of the data sources are changing. We would suggest that NICE discuss with PSSRU and the NHS Information Centre on the latest plans regarding the data sources.	The quality standard is reviewed by the Health and Social Care Information Centre and the data sources will be the most up to date sources available at the time of publication.
032	68	Care Quality Commission	General	Reference is made to use of ASCOT as a tool for collecting local data but it is debatable how many councils use this. There may be other tools used within care homes that could be worth exploring, such as Dementia Care Mapping.	Examples of existing national data collection which may be relevant, in part at least, to the quality measure are referenced where appropriate. It is expected that local data sources and audits where appropriate will be considered in order to measure the quality statements in full. Reference to Dementia Care Mapping tools has been added to the equality and diversity considerations section for the statements on meaningful activity and personal identity.
032	69	Care Quality Commission	General	It would be interesting to see what evidence there is on the extent to which achieving these standards will lead to the outcomes that have been listed in length at the beginning of the document.	Thank you for your comment. The reference to national outcomes frameworks is included in order to provide additional context for the quality standard. The section is included to highlight the potential contribution the quality standard, alongside the development sources it is based on, may make to the improvements in the outcomes framework which have been highlighted as being potentially relevant. We appreciate that the broad selection of improvement areas from the frameworks reflects the cross cutting nature of the topic and some may be judged to be more direct than others.
032	70	Care Quality Commission	General	Whether or not data within the outcomes frameworks can be collected at a care home level poses an interesting but challenging question. CQC has undertaken a feasibility study on ASC surveys to consider the challenges in relation to that wider question. Collecting the information for the quality measures should be simpler but consideration needs to be given to if/how the information collected at a local level could be made available for the rest of the system (including commissioners, CQC and the public). Agreeing a common set of data, across the system, would help to avoid duplication. There remain some concerns about the validity and usefulness of local data	Examples of existing national data collection which may be relevant, in part at least, to the quality measure are referenced where appropriate. It is expected that local data sources and audits where appropriate will be considered in order to measure the quality statements in full. It is not within the remit of quality standards to comment specifically on how data systems should be set up and how data should be shared.

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				collections. These can be highly variable in quality and completeness.	
032	71	Care Quality Commission	General	The size of care home will have an impact on the reliability of indicators. Small numbers do not necessarily mean that the data is not useful, but it should influence how the information is used for improvement by the provider and how it is used by commissioners and CQC.	Thank you for your comment.
032	72	Care Quality Commission	General	Is there any evidence to support that the data sources referenced are an appropriate proxy for mental wellbeing? For example, the PSS survey. Even if they are viewed as an adequate proxy, there is a concern that a large proportion of people in care homes are unlikely to complete the questionnaire, would not be able to do so, or would have it completed by a third party, therefore weakening its relevance. It can be easy to miss capturing direct feedback from those who may lack capacity. As the Alzheimer's Society latest figures suggest that 80% of people living in care homes have some form of dementia, this is a very real issue for gathering data in this way.	Examples of existing national data collection which may be relevant, in part at least, to the quality measure are referenced where appropriate. It is expected that local data sources and audits where appropriate will be considered in order to measure the quality statements in full. Reference to Dementia Care Mapping tools has been added to the equality and diversity considerations section for the statements on meaningful activity and personal identity in order to consider older people who find it difficult or are unable to provide feedback.
032	73	Care Quality Commission	General	<p>There is no reference to mental capacity or the deprivation of liberty safeguards. The quality standard therefore runs the risk of conflating mental capacity and mental health into one issue. However, there are important distinctions in how and when decisions may need to be made on behalf of the person using the service. The below definitions help to understand this distinction, and highlight the risks of thinking of both issues as one:</p> <ul style="list-style-type: none"> • A person may lack capacity to make particular decisions at particular times, or they may be able to make decisions about some aspects of their life and not others at all times. • A person with mental health problems may be unable to make decisions when they are unwell, but able to 	The Mental Capacity Act (2005) has now been added to the quality standard under the overarching Diversity, equality and language section as the most appropriate place to recognise the need for care homes to understand these statutory principles. The QSAC did not feel that it was appropriate to include mental capacity as an additional stand alone statement. The group held the view that as the Mental Capacity Act is UK legislation, it was not a suitable area for development as a quality statement, as it would describe a legal requirement rather than high quality care.

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				<p>make them when they are well.</p> <p>Consideration could be given to including mental capacity and the potential implications for mental wellbeing more specifically. From CQC's perspective, in exploring how to use NICE quality standards within a new framework of performance ratings, it is questionable whether a high quality rating, such as outstanding, could be evidenced by a provider of social care that does not have a strong understanding of the Mental Capacity Act, and more specifically the Deprivation of Liberty Safeguards contained within the Act. There should be some recognition of the Mental Capacity Act included within the quality statements. This could be most easily achievable through an amendment to statement 2 that recognises capacity alongside mental health. Although, from a purely mental capacity perspective it might be better to have an entirely separate statement that captures the guiding principles of the Act: 'Older people in care homes...are assumed to have capacity unless it is established that they lack capacity' is a rephrase of the 1st statutory principle.</p>	
032	74	Care Quality Commission	General	Other organisations, such as Skills for Care, could contribute towards measures about training, if they have not already been approached.	Links have already been made with Skills for Care and the quality standard now includes reference to the Code of Conduct for Healthcare Support Workers and Adult Social Care Workers in England.
032	75	Care Quality Commission	General	Some of what is proposed appears to falls within the boundaries of public health. It would be helpful to have Public Health England's perspective on this, to help determine how much of this might be carried out, at what geographical level and by whom.	One of the evidence sources for the quality standard is NICE Public Health guidance 16 Mental wellbeing and older people. It is not within the remit of NICE quality standards to engage with specific organisations about how the quality standard may be implemented.
004	76	Alzheimer's Society	General	<p>Alzheimer's Society welcomes the list of quality statements. Each of these statements could potentially improve the quality of life for people with dementia living in care homes. Alzheimer's Society's Low Expectations report (Alzheimer's Society, 2013a) found that 41% of family members thought that the quality of life of a person with dementia in care homes was good, but 28% said it was poor. By contrast, 68% of respondents said the quality of care was good.</p> <p>There is a degree of crossover between the statements, so it</p>	It is expected that the quality standard will be considered as a whole. However, NICE quality standards are not mandated and it is therefore not possible for NICE to specify that all statements in the quality standard must be implemented.

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				important to emphasise to care home staff that they cannot be applied individually, but should be considered as a whole while assessing a person living in the care home.	
007	77	Life Story Network CiC	General	Whilst training of staff is referred to explicitly within quality statement 3, it needs to form part of the quality measures under all statements. Whilst there may be a recognition that staff should have sufficient and appropriate training and competences, our experience is that providing high quality compassionate 'person – centred' care and support remains a challenge for many staff. It is much more about a way of 'being' person centred rather than 'doing' person –centred 'tasks'! The focus of the training need to be value driven and enabling staff to recognise the core human values in themselves as much as the people that they care for.	<p>The statements on mental health conditions, sensory impairment and physical problems all include measures relating to training staff. The QSAC agreed that the measures developed for the statements were appropriate.</p> <p>The Code of Conduct and the National Minimum Training Standards for Healthcare Support Workers and Adult Social Care Workers in England has been added to the Training and Competencies section of the quality standard. This offers more information on values, behaviour and attitudes of staff.</p>
019	78	Research into Practice for Adults	General	<p>F: Involvement of Families</p> <p>The background document stated that the involvement of families is not covered by relevant NICE guidelines. However, family involvement (and the maintenance of relationships more generally) is integral to the delivery of Standards 1 and 5. It should also be a theme throughout Standards 2, 3 and 4 as the literature points to the value of involving families in care (Bradford Dementia Group 2007; Department of Health 2010). It is recommended that all Standards therefore reflect this area for quality improvement.</p> <p>While NICE guidance does not specifically cover family involvement, it is a core component of the delivery of standards 1 and 5, and should be a theme through 2, 3 and 4. As it is core to those elements, and the literature points to the value of involving families perhaps it should be at least referenced. Useful guidance on this area of work with specific reference to care homes can be found as outlined below.</p>	The quality standard has been amended to place greater emphasis on the involvement of families and carers and the maintenance and development of relationships in general.
003	79	Dementia Pathfinders Community Interest	Additional statement	The Draft Standard cover very important areas, central to the wellbeing of older people in care settings. There is no separate	The QSAC agreed that a separate statement on relationships is not required. However, it was agreed that

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		Company		statement covering relationships, however, and this is fundamental to mental health. Relationship factors are covered in statements 1 and 5 on activities and identity, but the focus throughout tends to be on individual choice and fulfilment. Would it be possible to have a statement on relationships or emphasise this more strongly within existing statements.	Please respond to each comment the quality standard required a stronger focus on relationships throughout the document. Text has been added to the quality standard to ensure that relationships have been adequately addressed.
005	80	Rotherham Doncaster and South Humber NHS Foundation Trust	Additional statement	Comment about environment: we would like to see a separate quality statement related to and reflecting the importance of the care home environment and how this supports mental well-being. There is a wealth of evidence about the importance of daily environments to mental well-being, particularly for people with sensory and/ or cognitive problems, including use of colour, signage to support orientation and way-finding, lighting, ability to control noise, temperature etc. Access to outdoor space access to kitchens, room design and layout are also key components of this.	The QSAC agreed that a separate statement on environment is not required. However, it was agreed that the quality standard required a stronger focus on environment throughout the document. Text has been added to the quality standard to ensure that environment has been adequately addressed.
005	81	Rotherham Doncaster and South Humber NHS Foundation Trust	Additional statement	Comment about communication problems: we would like to see a separate statement related to the assessment and provision of support for residents with communication problems. A high proportion of older people living in care homes have significant problems in understanding and being understood (for a wide range of reasons including dementia, stroke etc) they are consequently vulnerable to having unmet needs, becoming socially isolated etc with consequent serious impact of this on their mental well-being and relationships. In our service we have seen the difference made and the improvement in mental well-being there is if communication difficulties and needs are properly assessed and attended to (by speech and language therapy staff or suitably trained care staff). A quality statement related to this is imperative.	The QSAC agreed that a separate statement on communication problems is not required. However, they agreed that the quality standard required a stronger focus on this issue. Therefore, text has been added to the equality and diversity sections to ensure that communication problems have been highlighted.
005	82	Rotherham Doncaster and South Humber NHS Foundation Trust	Additional statement	General comments otherwise: we would like to see more emphasis throughout the statements about the need and the right to be cared for by staff with the right skills, qualities and qualifications. Also, whilst importance of dignity and privacy is implicit in an overarching way, we would prefer there to be a separate statement related to privacy, dignity and the right to be involved in decisions regarding care.	The Code of Conduct and the National Minimum Training Standards for Healthcare Support Workers and Adult Social Care Workers in England has been added to the Training and Competencies section of the quality standard. This offers more information on values, behaviour and attitudes of staff. The QSAC agreed that a separate statement on privacy,

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					dignity and the right to be involved in decisions regarding care is not required. However, they agreed that the quality standard required a stronger focus on these issues and the quality standard has been amended in order to address this.
006	83	Empowerment Matters	Additional statement	<p>Quality statements These generally capture the key areas for quality improvement but in our view there are some omissions that need to be considered.</p> <p>The independence aspect could be linked to choice and control and is also about people having the opportunity to express their views. If you live in an environment where nobody asks you what you think about things or takes time to find out what you choose and then acts upon what you say not only is it very disempowering but the effect on mental wellbeing is potentially very significant.</p>	The quality standard has been amended to give a greater focus on choice and control for older people and involvement in decisions.
009	84	College of Occupational Therapists	Additional statement	<p>The existing quality statements do not reflect the importance of social interaction/ inclusion/ maintenance and development of relationships both within and outside the care home setting. This is recognised within the Care Homes for Older People National Minimum standards and the Care Homes Regulations 2001. (DH, 2003) in particular within Standard 13.</p> <p>This could be achieved by an additional Quality Statement for example: Older people in care homes are supported to engage with the community within and outside of the care home setting.</p> <p>Alternatively, this element could be incorporated with Quality Statement 1. For example: Older people in care homes have opportunities and support during their day to participate in meaningful activities that promote health and mental wellbeing and to engage with their community within and outside of the care home setting.</p>	The QSAC agreed that a separate statement on social interaction and relationships is not required. However, it was agreed that the quality standard required a stronger focus on these issues throughout the document. Text has been added to the quality standard to ensure that social inclusion and relationships have been adequately addressed.
012	85	British Association of Behavioural and Cognitive	Additional statement	It is very surprising to see dementia included in the list of 'common mental health conditions'. Of course, as argued previously, with a prevalence of 70%, it clearly is a common	Thank you for your comment. Statement 3 has been amended and now states 'mental health conditions' rather than 'common mental health conditions'.

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		Psychotherapies		Please insert each new comment in a new row. condition in this context. But, this phrase has come to be used more typically (by NICE) without including dementia, and to include dementia here does not do it justice. An additional quality statement on assessment for dementia should be considered, again with a clear link to appropriate evidence-based interventions.	Please respond to each comment The Mental wellbeing of older people in care homes quality standard addresses a wider population than people who have dementia. The quality statements therefore need to be applicable to all older people in care homes rather than groups of older people with specific conditions. NICE has produced two quality standards specifically addressing the topic of dementia. These are: Dementia (quality standard 1); and Supporting people to live well with dementia (quality standard 30).
017	86	St Christopher's Hospice	Additional statement	Please ADD a further statement, namely: STATEMENT 6 – older people in care homes are supported to make decisions and plan for their end of life care	The QSAC agreed that an additional statement on end of life care was not required. Additional text has been added to the equality and diversity considerations section for each statement regarding end of life care. The text highlights the importance of the needs and preferences of people who are approaching the end of their life. The End of life care quality standard is comprehensive, cross cutting and applicable across all settings. This quality standard has been added to the <i>Related Quality Standards</i> section.
019	87	Research into Practice for Adults	Additional statement	G: Environmental Factors The standards are currently focussed on the 'individual' (e.g. their physical and mental health needs) and do not reflect the possible impact of the external environment on mental wellbeing. The available evidence suggests that a person's environment can have a significant impact on their quality of life (Barnes 2002; Parker 2004; Curtis 2010). It is therefore recommended that an additional standard is developed to address this area for quality improvement. The standards currently focus on the 'individual' (e.g. their physical and mental health needs) and do not reflect G (the importance of the environment, including design of the living space, access to outside space). The available evidence asserts the importance of the physical environment in mental well-	The QSAC agreed that a separate statement on environment is not required. However, it was agreed that the quality standard required a stronger focus on environment throughout the document. Text has been added to the quality standard to ensure that environment has been adequately addressed.

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001	88	Amore Care – Part of the Priory Group	QS 1	Vital to understand the person’s life – Life Story work essential for understanding and knowing the person before their dementia. Knowledge of routines, habits, interests, work life and emotional experiences to be able to rationalise changes in reactions and responses.	Thank you for your comment.
001	89	Amore Care – Part of the Priory Group	QS 1	Guidance would be useful that provides tools to engage people with dementia and their families in regular feedback during the day. Checking in with the person, knowing their state of wellbeing and ill-being at any one time. Asking the question ‘why’ and reflecting on practice.	A link to the Dementia Care Mapping tool has been added to the quality standard.
001	90	Amore Care – Part of the Priory Group	QS 1	Some description on how contracts could be improved to provide a balance between the ‘task’ and the ability of the person with dementia to ‘live life’ within the care home as they would in their street, road, sheltered accommodation, extra care etc and a focus on how this can be replicated within the care home setting?	The quality standard is for all older people living in care homes. As this suggestion relates only to people with dementia it has not been added to the quality standard.
003	91	Dementia Pathfinders Community Interest Company	QS 1	The use of the work activities, rather than activity, implies a more formal, structured way of spending time. Would it be possible to talk about meaningful activity?	Quality statement 1 has been updated to state ‘meaningful activity’.
003	92	Dementia Pathfinders Community Interest Company	QS 1	Examples listed of what activities may provide (emotional, creative, intellectual and spiritual stimulation) could also include sensory and social stimulation – these are important particularly in the later stages of dementia. For many residents, maintaining mental health is about having regular meaningful conversations (with visitors, staff and other residents). Many residents would prioritise this as a meaningful activity and it might be worth listing it in the definition given.	Conversation has been included within the definition of meaningful activity.
003	93	Dementia Pathfinders Community Interest Company	QS 1	An aspect of diversity important to reflect in supporting meaningful activity is personality – an example might be the diverse needs and wishes of extroverts and introverts living in a group setting. Supporting quiet activity a person enjoys in their room is just as important as offering group activities in communal areas.	The definition of meaningful activity has been amended to include more emphasis on the needs of the individual and the rationale section now emphasises the importance of older people being involved in choosing and defining activities.
004	94	Alzheimer’s Society	QS 1	General Alzheimer’s Society welcomes the quality statement on participation in meaningful activities. The Society thinks that	Thank you for your comment.

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				<p>this quality statement has the potential to be positive for people with dementia. The provision of meaningful occupation for people in care homes with dementia is an important tool to ensure both quality of life and good care. Too often Alzheimer's Society hears that people with dementia do to have enough to do in care homes. The Society further welcomes emphasis on meaningful activities, rather than just activities. People need to have activities and occupation personalised around them rather than rigidly scheduled group activities. A survey among care home staff for the Low Expectations report (Alzheimer's Society, 2013a) found that reminiscence and life history work are common practice – 82% of respondents said this took place in the home. However, among people with dementia who responded to the survey, 15% said they did not have lots of things to keep them busy. This suggests that the provision of activities and occupation in care homes remains an issue.</p> <p>Alzheimer's Society would like to draw attention to potential barriers to collecting data for this quality measure – this is detailed in the following box.</p>	
004	95	Alzheimer's Society	QS 1	<p>Outcome</p> <p>Alzheimer's Society recognises the importance of feedback from older people in care homes on whether they have been offered opportunities to take part in activities that are meaningful to them. When collecting data on this, the needs of people in the later stages of dementia who may have difficulties with communicating must be considered.</p>	<p>The quality standard has been updated to include reference to: tools that help enable people with dementia to provide feedback; and the involvement of families and carers in providing feedback.</p>
004	96	Alzheimer's Society	QS 1	<p>What this quality statement means for organisations</p> <p>The Care Quality Commission already has responsibility for inspecting meaningful activities in care homes and is currently changing the way they inspect services. Information on all elements of these standards must be shared with the CQC to inform their work. It should be further shared with local Healthwatch who have powers to enter and view care homes in their areas, as well as safeguarding teams in the local authorities.</p>	<p>NICE has a partnership agreement with the CQC which sets out: how the two organisations work together; and how NICE guidance and quality standards are used in the development of CQC inspection frameworks and thematic reviews. NICE is having discussions with Healthwatch England at a national level in order to ascertain how information will be disseminated to local Healthwatch.</p>
006	97	Empowerment Matters	QS 1	<p>Quality statement 1</p> <p>Important quality statement but could it go further to suggest</p>	<p>The rationale section for statement 1 has been updated to include greater emphasis on involving older people in</p>

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				<p>that older people are actually defining some of the activities they want to participate in and taking a more active role in choosing/defining 'meaningful' activities?</p> <p>It needs to be clear that accessing the community is an important part of this – whether enabling people to take part in activities of their choice outside of the care home or the 'community' coming into the care home. There are too many 'closed' care homes where older people are not given the opportunity to interact with their local community in any way. For many people who may have previously enjoyed an active life in their community, this can have a severe impact on their sense of belonging, identity, wellbeing, and purpose.</p>	<p>defining and choosing activities that are meaningful to them.</p>
007	98	Life Story Network CiC	QS 1	<p>The quality statement should include references which mitigate against social isolation and loneliness and place an emphasis on ensuring that the individual is an 'active citizen' and remains connected with the local community within which they live. It is more than meaningful 'activities', it is meaningful 'lives'. The emphasis should be on identifying what matters specifically to each individual so 'meaningful' activities are tailored to their needs not generic.</p>	<p>The QSAC agreed that the quality standard required a stronger focus on these issues throughout the document. The quality standard has been amended to ensure that social inclusion, links with the community and relationships have been adequately addressed.</p> <p>The quality standard clearly states that activities should be tailored to the needs and preferences of the individual.</p>
007	99	Life Story Network CiC	QS 1	<p>Capturing, using and embedding life story approaches has been shown to facilitate better relationships between care staff and individuals living in the home, which then enable staff to find out what really matters to the individuals. This intelligence should then inform what activities individuals would like to get involved with and how they want to be enabled to live more meaningful lives. This should not be just 'blocks' of activities e.g. music afternoons, quiz evenings etc. It needs to continually connect with what really matters to the individuals and their identity.</p> <p>Regarding measuring for this quality statement it should not be a quantitative measure of the number of life stories written or captured, but more about the improvements in the individuals quality of life and wellbeing as a result of this process and the nature of the relationships resulting from this, which in themselves contribute and promote one's sense of self esteem and wellbeing.</p>	<p>The NICE Support for Commissioning document provides a list of useful resources and tools for commissioners. However, it is not possible for NICE to compile an exhaustive list of tools that are applicable to this topic area and therefore this framework may not be included.</p>

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				It would be helpful to reference the use of the 5 Ways To Well Being as framework http://www.neweconomics.org/publications/entry/five-ways-to-wellbeing	
008	100	English Community Care Association	QS 1	This is a fundamental part of care home life for residents and is welcomed. This standard could be enhanced with reference to activity and engagement with the widest community and underpinned with evidence from recorded life stories of individuals being delivered within homes. Observational and documented evidence will be needed to capture experience of residents who are unable to express themselves verbally.	The quality standard has been amended to include a greater focus on links with the wider community. It is not within the remit of the quality standard to provide the type of evidence that is described here. The quality standard has also been amended to include reference to the use of tools such as Dementia Care Mapping for people who are unable or find it difficult to give feedback verbally.
009	101	College of Occupational Therapists	QS 1	<p>It is important to provide opportunities but older people may also need some sort of support to make choices and to engage in activities. We suggest changing to: 'Older people in care homes have opportunities and support during their day to.....'</p> <p>Suggestions: Quality Measures Structure –insert: '...that older people in care homes have opportunities and support to' Outcome – Local audit to measure:</p> <ol style="list-style-type: none"> 1. How staff are supporting a person to engage in day-to-day activities of their choice through documentation in care plans. 2. Processes – how do local policies and procedures support day-to-day activity, choice, dignity. 3. Resident's and relative's experience. <p>Organisations providing care ensure that older people in care homes have opportunities during their day to participate in meaningful activities that promote health and mental wellbeing. Health and social care practitioners ensure that older people in care homes are supported to make choices and participate in meaningful activities that promote health and mental wellbeing.</p> <p>The College of Occupational Therapists has developed an</p>	Thank you for your comments. The definitions and the equality and diversity considerations sections which underpin the statement on meaningful activity make it clear that activities should be tailored to the needs and preferences of the individual. This will include providing support where it is needed. The quality standard now references the Living Well through Activity in Care Homes: the Toolkit.

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				Enabling Activity Audit, available in Living Well through Activity in Care Homes: the Toolkit. (COT 2013). (Please contact COT for further details about the toolkit.)	
011	102	British Geriatrics Society	QS 1	Comments: Measurement- clearly difficult for people with dementia to self complete forms- also not easy for some people with anxiety/ depression. Carers can help but if they are care home staff (may be the case especially for those who have no near/ close family) that may be a confounder in results obtained. Should specify that shouldn't be care home staff who complete for patients- family/ friends can help. This does not mean shouldn't use self reports, but given possible barrers (sensory loss as well as mental health conditions etc), but what about engaging local volunteer sector to report on their knowledge/ engagement with local care homes as a measure here? We would expect good homes providing meaningful stimulation/ activities for their residents to be well linked to their local older people's voluntary groups	The quality standard has been amended to include reference to the use of tools such as Dementia Care Mapping and feedback from family members, carers or an advocate for people who find it difficult or are unable to give feedback verbally. The quality standard has been updated to emphasise the importance of links with the community. This specific suggestion has not been incorporated into the quality standard as the expectation is that quality statements and measures will be used and adapted at a local level.
012	103	British Association of Behavioural and Cognitive Psychotherapies	QS 1	The situation of people with severe dementia related cognitive impairment is not really addressed here. How will activities be adapted / offered for such people? How will they give feedback (Outcome)?	The equality and diversity considerations section states that staff should be aware of cognitive impairments when tailoring activities to the needs of the older person. It is expected that activities will be tailored for individuals at a local level as it is not possible for NICE to provide an exhaustive list of how to adapt activities for the wide range of abilities and needs that individual older people in care homes will have. The quality standard has been amended to include reference to the use of tools such as Dementia Care Mapping and feedback from family members, carers or an advocate for people who find it difficult or are unable to give feedback verbally.
015	104	The National LGB&T Partnership and The Lesbian & Gay Foundation	QS 1	We are pleased to note that the Equality & Diversity Considerations includes reference to sexuality, however, gender identity must be added to the list of equality groups which may lead to the specific needs of older people. Gender identity and sexual orientation are both protected characteristics under the Equality Act 2010 and as such all public sector organisations should be paying due regard to them. It is still extremely helpful however for guidance such as NICE Quality Standards to specify	Gender identity is now referenced under the Equality and diversity considerations section. All groups, including lesbian, gay, bisexual and transgender groups, are included under the Equality and diversity considerations section. It is felt that sufficient emphasis is given to the equality groups identified.

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				inclusion of all equalities groups. The needs of trans older people (those whose gender identity now is different to the gender identity they were assigned at birth) and of lesbian, gay and bisexual older people, often remain invisible and both groups are at risk of discrimination and homo-, bi- and transphobia. It is important to recognise that while lesbian, gay, bisexual and trans (LGB&T) groups may share similar fears about coming out and being at risk of discrimination in a care home environment, the needs of these groups are distinct. We would like to see a strengthening of the E&D Considerations to include supporting LGB&T people (and indeed, all those with protected characteristics) to engage in meaningful activities which positively reinforce their LGB&T identities.	
015	105	The National LGB&T Partnership and The Lesbian & Gay Foundation	QS 1	All data sources specified should collect demographic monitoring data, including sexual orientation and gender identity, in order to assess the needs and experiences of LGB&T people.	It is expected that the specific data collected will be decided at a local level.
016	106	Social Care Institute for Excellence	QS 1	The draft Guide considers that the relationship between the home and the residents' GPs is critical to their health and wellbeing	Thank you for your comment.
017	107	St Christopher's Hospice	QS 1	Statement 1 – should say opportunities throughout not during the day	The QSAC felt that the wording of the statement is appropriate and it has therefore not been amended.
017	108	St Christopher's Hospice	QS 1	Feedback is important but 80% of residents have dementia or a severe memory problem – any feedback needs to take account of this.	The quality standard has been amended to include reference to the use of tools such as Dementia Care Mapping and feedback from family members, carers or an advocate for people who find it difficult or are unable to give feedback verbally.
017	109	St Christopher's Hospice	QS 1	Source guidance – Namaste Care programme (Simard, 2013)	Thank you for your suggestion for additional source guidance. For quality standards source guidance must be accredited by NICE Evidence. As this source is not accredited we are unable to use it.
017	110	St Christopher's Hospice	QS 1	would like to stress the 'meaningfulness' of this activity. Many people with advanced dementia are unable to communicate orally and meaningful activity is through the appropriate stimulation of the senses (massage, taste, touch, sight and smell)	Thank you for your comment.
017	111	St Christopher's Hospice	QS 1	Should finish with...'They should have the skills to provide meaningful activities for their residents throughout their day to	The current wording is considered appropriate for this statement and it is not felt that the suggested wording will

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				Please insert each new comment in a new row. ensure their mental wellbeing.' It is not enough to include them in decision making.	Please respond to each comment enhance the statement.
019	112	Research into Practice for Adults	QS 1	<p>A: Participation in meaningful activity</p> <p>This area for quality improvement is reflected in Standard 1. However, while the background document emphasises that social participation and engagement are not covered by relevant NICE guidelines, evidence suggests that these are key components of meaningful activity with particular reference to maintaining mental well-being. For example, in a recent review by the Institute for Public Policy Research on 'Older People and Wellbeing', Allen states:</p> <p>“The most important factors underlying older people’s mental health and wellbeing are social and community participation. There is a sizeable body of research evidence linking the strength and quality of social relationships and community engagement to health, well-being and quality of life for older people [see review by Surr et al. 2005]” (Allen 2008: 27).</p> <p>And:</p> <p>“Continued participation in neighbourhood, family life and social life are seen as particularly important in protecting emotional wellbeing in later life. In fact, the impact of poor physical health is often mainly felt through the resulting impact on social and community participation” (Allen 2008: 37).</p> <p>It is therefore recommended that social participation and engagement are incorporated in to the discussion of 'meaningful activity'.</p> <p>D: Individualised Care</p> <p>While this area for improvement is implicit throughout</p>	The quality standard has been updated to include a greater emphasis on social inclusion, links with the community and relationships. The emphasis on individualised care is considered to be addressed adequately throughout the quality standard.

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				discussion on each of the standards, it could be emphasised more clearly. This is particularly relevant to the provision of 'meaningful activity' (where the activity should be based around what is meaningful to the person) and interventions in relation to mental health, sensory impairment and physical problems. In addition, individualised care should be a core component of Standard 5 and the maintenance of personal identity.	
023	113	Optical Confederation	QS 1	It is important that, where possible, individuals are able to engage in everyday activities, as mentioned above, independently. For example, it may seem that spectacles will be of little help to a person, however they may enable that person to see the food on their plate and thus eat independently, or can assist in seeing facial expressions or understanding their environment. Spectacles may enable a person to move more independently around the home. Key to this would be management of spectacle wearing in the home (correct fitting, engraving them to ensure distance or near spectacles are worn for specific tasks, etc).	Thank you for your comment.
028	114	Campaign to End Loneliness	QS 1	We agree that meaningful social activities are vital if we are to promote good mental wellbeing for older adults in care homes, and that this should be included in the rationale and first quality statement. Research demonstrates that loneliness is harmful to both our physical and mental health, equivalent to smoking 15 cigarettes a day as a risk factor for early mortality (Holt-Lunstad, 2010). Lonely individuals are at greater risk of depression (Cacioppo et al, 2006) (Green et al, 1992) and cognitive decline (James et al, 2011). One Dutch study found that lonely people have a 64% increased chance of developing clinical dementia (Holwerda et al, 2012). Loneliness and low social interaction are predictive of suicide in older age (O'Connell et al, 2007) (Koponen, 2007).	The quality statement makes reference to meaningful activity whereas the detail around what meaningful activity should involve, including the social aspects of it, is included within the definitions section.

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028	115	Campaign to End Loneliness	QS 1	<p>There is inadequate research into the prevalence of loneliness in care homes. However, a recent Norwegian study estimated 56% of nursing home residents without cognitive impairment were lonely (Drageset et al, 2011). This compares to up to 31% over 65s living in the community who reported feeling lonely “sometimes” (Victor et al, 2005).</p> <p>In light of this, and the significant evidence base demonstrating the link between loneliness and poor mental health, we believe it is important that quality statement’s structure and outcomes clearly state that ‘meaningful activities’ should incorporate social activities. The ASCOF measure 1I and the PHOF measure 1.18 will allow care providers and commissioners to evidence their progress in helping older adults in care homes feel connected and have as much social contact as they need.</p>	<p>The quality statement and measures makes reference to meaningful activity whereas the detail around what meaningful activity should involve, including the social aspects of it, is included within the definitions section. It is expected that the specific information collected to evidence the measures will be decided locally.</p>
028	116	Campaign to End Loneliness	QS 1	<p>We suggest that the Social Care Institute for Excellence (SCIE) Briefing 39 ‘Preventing loneliness and social isolation: interventions and outcomes’ also be recommended as source guidance for this quality statement.</p>	<p>Thank you for your suggestion for additional source guidance. For quality standards source guidance must be accredited by NICE Evidence. As this source is not accredited we are unable to use it.</p>
029	117	OPENspace Research Centre	QS 1	<p>When planning to ensure that older people in care homes have opportunities to participate in meaningful activities that promote health and wellbeing we would encourage carers not to neglect the outdoor environment in that planning. A well planned and inclusively designed built environment can enhance physical health and wellbeing.</p> <p>It is important to pay attention not only to the design of the environment in this regard but also how it is managed and access is controlled. Ideally all care home residents have the freedom to go out into a safe and attractive outdoor space whenever they wish, and find it easy to move between indoors and outdoors without barriers, locked doors, or lack of support from carers.</p> <p>From our research we know that the desire to get out and about</p>	<p>The definition of meaningful activity has been amended to include reference to using outdoor spaces.</p>

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				<p>does not diminish in older age, nor does the variety of activities people like to do outdoors.</p> <p>Our research has shown that, if older people live in an environment that makes it easy and enjoyable for them to go outdoors, or within ten minutes' walk of a park, they are more likely to be physically active and satisfied with life and twice as likely to achieve the recommended levels of healthy walking. In our research, older participants living in sheltered accommodation or care homes were found to be three times less likely to get outdoors for more than 5 hours per week.</p> <p>For evidence, see our publications on older people's access outdoors and quality of life at http://www.idgo.ac.uk/useful_resources/publications.htm especially</p> <p>Ward Thompson, C. & Aspinall, P. 2011. Natural environments and their impact on activity, health and quality of life. <i>Applied Psychology: Health and Well-Being</i>, 3 (3), 230-260.</p> <p>Sugiyama, T., Ward Thompson, C. and Alves, S. 2009. Associations between neighbourhood open space attributes and quality of life for older people in Britain. <i>Environment and Behavior</i>, 41(1), 3-21</p> <p>Sugiyama, T. & Ward Thompson, C. 2008. Associations between characteristics of neighbourhood open space and older people's walking. <i>Urban Forestry & Urban Greening</i> 7(1), 41-51.</p> <p>Sugiyama, T. and Ward Thompson, C. 2007. Outdoor environments, activity and the well-being of older people: conceptualising environmental support. <i>Environment and Planning A</i>, 39, 1943-1960.</p> <p>Sugiyama, T., and Ward Thompson, C. 2007. Older people's health, outdoor activity and supportiveness of neighbourhood environments. <i>Landscape and Urban Planning</i>, 83, 168-175.</p> <p>Sugiyama, T, & Ward Thompson, C. 2006. Is Older People's Perception of Neighbourhood Open Space Associated with Patterns of Outdoor Activity? Presented at the 1st International</p>	

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				Please insert each new comment in a new row. Symposium on Environment, Behaviour and Society, University of Sydney, 2006. Available at URL: www.idgo.ac.uk/useful_resources/publications.htm	Please respond to each comment
030	118	SCA Hygiene Products UK LTD	QS 1	SCA would like to highlight the relationship between ensuring the correct identification and physical conditions (Quality Statement 1) and care home staffs' ability to ensure continued 'Participation in meaningful activities' (Quality Statement 1). Physical conditions such as incontinence not only directly affect the mental wellbeing of individuals directly but also impair social participation. Inadequate or inefficient continence care, for example, can extend the time individuals require care such as an increase in the number of pad changes to tackle incontinence. In contrast, a recent SCA care home evaluation found that personal care plans that promote continence enabled over two hours more social interaction between staff and residents. This created a more rewarding atmosphere for residents and enabled them to actively participate in meaningful care home activities. As such, the rationale for Quality Statement 1 should include reference to the indirect impact that physical conditions, such as incontinence, have on mental wellbeing, by reducing individuals' available time to actively participate within the care home.	Physical problems are addressed by the statement on this subject. The definitions section of the statement on meaningful activity states that activities should be tailored to the needs of the individual which will include considering any physical conditions or problems.
031	119	Parkinson's UK and Lewy Body Society	QS 1	Structure and flexibility in the care regime and activities Whilst it is good practice for care homes to match an older person's preferred way of life and routines in general, homes need to be additionally flexible due to the physical and mental fluctuations experienced by people with Lewy body disorders. As many people with a Lewy body dementia are sleepy during the day and wakeful at night, the Quality Statement should be restated along the lines: Older people in care homes have opportunities during their waking hours to participate in meaningful activities that promote health and wellbeing. Food should be available 24 hours a day and the home's regime should be able to 'go with the flow' of the resident's rhythm,	The QSAC agreed that by stating 'their day' it is clear that this is when the older person is awake. As no timeframe or specific time of day is referred to it is considered implicit that the activity is offered when older people are awake. The definitions section of the quality standard clearly states that activities should be tailored to the needs and preferences of the individual. This section has been updated to include examples of activities of daily living and reference to access to outdoor spaces. The rationale for this statement has been updated to emphasise the importance of involving family, friends and carers in activity.

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				<p>whilst working towards good sleep hygiene. 13 14 15</p> <p>“Because of sleeplessness, my husband would appear in the lounge in the middle of the night saying, ‘Where’s breakfast?’ They gave him some toast...”</p> <p>Staff will need to adapt activities given the unpredictability of the ‘on / off’ physical and mental abilities of the resident with PD, PDD or DLB, maximising available skills and independence, building on and helping to maintain and restore strengths and adapting for deficits.</p> <p>Memory loss tends to be less of a problem for people with DLB than with Alzheimer’s, and people will retain lucid periods. Slowness of thinking (someone may take 20 minutes to respond to a question because of difficulties retrieving information) should not be confused with total loss of cognitive skill. People with DLB are not always well served by activities pitched for people with severe memory loss.</p> <p>Given the loss of executive function that this group of residents are likely to experience, the home should offer regular group and/or individual sessions to encourage older people to identify, construct, rehearse and carry out daily routines and activities that help to maintain or improve their health and wellbeing, involving older people as experts and partners in maintaining or improving their quality of life. The opportunities for residents to</p>	

¹³ College of Occupational Therapists and National Association for Providers of Activities for Older People (2007) Activity provision: benchmarking good practice in care homes for older people. London: College of Occupational Therapists

¹⁴ Care and Social Services Inspectorate Wales (2009) Older people with dementia

¹⁵ Nursing Standard (2009) Living well with dementia in a care home: a guide to implementing the National Dementia Strategy.

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				<p>Please insert each new comment in a new row.</p> <p>engage in personal daily living tasks should be integrated into daily care. 1617</p> <p>Homes should enable experience of the world outside the home, with access to fresh air and nature and opportunities to take part in gardening activities.¹⁸ Residents who live on upper floors and who have serious mobility problems should have equal access to fresh air, daylight and outdoor activity. Just because hoisting/wheeling someone to gain access takes time and effort, it should not disbar residents from social contact and contact with nature.</p> <p>“Mum had Parkinson’s and was very rigid. They had to use a sling to move her into a special chair. She would often be in bed when I made unannounced visits and spent most of her time eating on her own, which wasn’t what she wanted.”</p> <p>DLB often presents with gradual development of visuospatial dysfunction (e.g. diminishing sense of direction, becoming lost in familiar environments) which makes it particularly important for homes to have design that orients residents and supports wayfinding and moving around. Visuospatial problems can cause problems with movement, for example when patterns in floor coverings appear like holes and people are afraid of stepping on</p>	<p>Please respond to each comment</p>

¹⁶ [Online] Alzheimer’s Australia (2013) Relate, Motivate, Appreciate - A Montessori Resource: Promoting positive interaction with people with dementia http://qualitydementiacare.org.au/wp-content/uploads/AlzheimersAustralia_Montessori_Resource_WEB.pdf (last accessed 2 August 2013)

¹⁷ College of Occupational Therapists and National Association for Providers of Activities for Older People (2007) Activity provision: benchmarking good practice in care homes for older people. London: College of Occupational Therapists

¹⁸ Chalfont G [and] Walker A. (2013). Dementia green care handbook of therapeutic design and practice. Sheffield: *Safehouse Books*

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				<p>Please insert each new comment in a new row.</p> <p>them or when they misinterpret reflections in mirrors which become a source of fear. 19</p> <p>“The design of Mum’s care home was like H-Block. Every time I went there, I got lost. Every corridor was cream; they all looked the same.”</p> <p>Depression and apathy are a feature of PD and DLB, so staff should recognise and cater for those who have no wish to be active or sociable, but not assume this is a permanent state and give up offering opportunities to be involved. As people with Parkinson’s may develop a blank, mask-like facial expression, staff should pay particular attention to finding out how people are and how they feel about any activity. Staff need to gauge an individual’s need for the opportunity to be private and/or quiet, whilst ensuring that they are not left in a state of isolation or loneliness.²⁰</p> <p>Carers and family members have often built up considerable expertise in supporting their loved one and dealing with the fluctuations in their condition. Staff should recognise the value of including carers/significant others and make families feel welcome and at home. They should enable the involvement of families and significant others in the care, social life and activities of the resident.</p>	Please respond to each comment
032	120	Care Quality Commission	QS 1	Suggestion for additional statement or amendments made to existing statements 1&5 - ‘older people in care homes are supported to maintain and develop relationships of importance to them’.	The quality standard has been amended to include a greater focus on the importance of existing and new relationships.

¹⁹ CIH Scotland and the Dementia Services Development Centre (DSDC) (2013) Improving Housing and Housing Services for People with Dementia

²⁰ Care and Social Services Inspectorate Wales (2009) Older people with dementia

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				Please insert each new comment in a new row. This is not really covered explicitly by 'meaningful activities' or 'developing personal identity' but either of these current key areas could potentially be reworded to make this more explicit. The definition of 'meaningful activities' is more task/activity related than relationship related but most people get as much, if not more, meaning and sense of wellbeing from human relationships than 'activities'. Similarly, the 'personal identity' statement talks about 'social networks' but not meaningful relationships with other individuals. This means that care homes could mistakenly think that they are fulfilling this through enabling people to access shared social networks for everyone living in the care home, rather than maintaining the important relationships that people had before they moved into the care home.	Please respond to each comment
032	121	Care Quality Commission	QS 1	The content of statement 1, in particular, would benefit from input from nationally recognised organisations that work in this field, such as NAPA (National Association for Provision of Activities for Older People). We would recommend wider views be sought, if not done so already.	The College of Occupational Therapists new publication: <i>Living well through activity in care homes: the toolkit</i> has been added to this statement as a data source.
032	122	Care Quality Commission	QS 1	This section could be further strengthened. You might consider replacing the following sentence – 'Health and social care staff should identify and address the specific needs of older people arising from diversity, including gender, sexuality, ethnicity, age and religion' – with – 'Health and social care services and staff should identify and address the specific and diverse needs of older people arising from their gender, sexual orientation, ethnicity, age, and religion and belief, disability, and gender identity'. It is usual practice to reword such a list in alphabetical order but we have left it this way for easier comparison with the original. There might need to be some further definitions of these terms. For example, to make it clear that beliefs include ethical beliefs, such as vegetarianism, and to explain the terms sexual orientation and gender identity. The guidance could then signpost people to good practice around these areas. We have suggested some additional resources below under the 'personal identity' section.	The Equality and diversity considerations section has been updated to include gender identity. It is expected that providers will decide locally which guidance they would like to access in relation to these areas.
032	123	Care Quality Commission	QS 1	The paragraph at the bottom of this section contains a vital	The quality standard has been amended to include greater

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				<p>point about choice and control but potentially gets lost being included in one paragraph related to equality and diversity and participation in meaningful activities: ‘When tailoring activities to the needs and preferences of older people, staff should be aware of any learning disabilities or acquired cognitive impairments. Staff should have the necessary skills to include people with cognitive or communication difficulties in decision-making (from Dignity in care [SCIE guide 15]: Choice and control)’.</p> <p>There is the opportunity to make a more specific reference to issues around capacity rather than specifically stating ‘learning disabilities or acquired cognitive impairments’.</p> <p>Other than this paragraph, and the links between personal identity and choice and control in statement 5, there is little recognition in the quality standard as a whole that maintaining, or improving, choice and control can be a major factor in mental wellbeing. The importance of real choice and control in relation to physical and mental health, and the importance of good communication by care staff to enable choice and control, can have a huge impact on mental wellbeing, as demonstrated consistently through observational tools such as SOFI and dementia care mapping, for example. This may be worth adding as a statement in its own right, or weaving more about choice and control (a key human rights principle) throughout the other statements.</p>	<p>emphasis on choice and control in the statements on meaningful activity and personal identity.</p>
032	124	Care Quality Commission	QS 1	<p>The need for activities to take account of people with sensory impairments, as well as cognitive and communication impairments, is important in relation to disability equality. So is the need for activities to take account of ethnicity, sexual orientation, religion and belief. For example, some common activities in care homes, such as group reminiscence, can be</p>	<p>The quality standard addresses the issue of diversity when taking part in group activities by stating that ‘activities should take place in an environment that is appropriate to the needs and preferences of the individual’. This addresses both the physical and social environment that activities take place in.</p>

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				Please insert each new comment in a new row. difficult for older lesbian, gay and bisexual people or older people from Black and minority ethnic communities because they may not have a shared past with others in the care home and could fear that contribution of their reminiscences could lead to prejudice being expressed by others. Arguably, this statement should reflect both the need to be aware of the individual needs of people in relation to diversity, and the need to be aware of diversity when planning group activities. At the moment the statement does the former, but the latter only in relation to disability rather than all the equality characteristics.	Please respond to each comment
002	125	Nottinghamshire Healthcare NHS Trust	QS 1	Emphasis should be made on meaningful activities individually tailored to residents assessed needs, rather than putting a set activity on and expecting the resident to attend or not. Comprehensive ,holistic assessments need to be made on each resident and a care plan formulated to meet assessed needs	The quality statement clearly states that activities should be tailored to the needs and preferences of the individual. How needs and preferences are assessed should be decided locally.
003	126	Dementia Pathfinders Community Interest Company	QS 1	Linked with the above comment, being part of the local community is also beneficial to mental health and wellbeing, but does not receive detailed mention – this again could be covered in statements 1 and 5.	The quality standard has been updated to place greater emphasis on the importance of involvement with the community.
005	127	Rotherham Doncaster and South Humber NHS Foundation Trust	QS 1	Comment about quality statement 1 (Older people in care homes have opportunities during their day to participate in meaningful activities that promote health and mental wellbeing) Add “and daily life routines”, so statement reads “Older people in care homes have opportunities during their day to participate in meaningful activities and daily life routines that promote health and mental wellbeing”. Why do we suggest this? Whilst ‘routines’ are mentioned in the rationale the absence of this from the actual statement is felt to be a significant omission as it misses an opportunity to give this status and importance - this is felt to be an important point as in our experience (as a group of clinicians and service leads who deliver services into care homes) the opportunities for residents to stay involved in the gentle rhythms and routines of daily life appear to be overly restricted and the impact of this can be	The QSAC felt that the wording of the quality statement is appropriate and has the required level of detail. The quality statement seeks to address a broad area and it would be inappropriate to specify a particular type of activity in it as this may lead to other types of activity being considered as less important. Examples of activities of daily living have been added to the definitions section in order to give clarity about what this includes and emphasise their importance. It is expected that the type of data that is collected to evidence the measures will be decided locally. It is not within the remit of quality standards to specify minimum standards of care.

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				<p>significant, such as loss of role, loss of identity, increased disorientation and detachment from everyday life and relationships. Opportunities (and facilities) to enable residents (with help as needed) to continue with their daily life routines - such as helping to prepare meals, being involved in domestic and household tasks, doing laundry and so on – should be provided as routine and this in itself should be specifically measured.</p> <p>Comment about quality statement 1 – regarding measurement; we would like to see some measurement which captures and reflects that there is a high level of expectation with regards to the amount (time-wise) and range of activity being offered and that the actual resources available to support this are also quantified/ measured. In our experience many care homes will have activity timetables- but all too often the reality is that they allocate insufficient resources to deliver these and staff often have only limited time, funding and skills to deliver them. Many residents miss out or only can participate if they are able to join in in large groups (an outdated approach particularly for people with dementia), we would like to see some minimum standards related to provision of activity co-ordinators posts (or similar) and also some minimum standards related to how much time each resident is able to be engaged by staff in activities/ routines</p>	
009	128	College of Occupational Therapists	QS 1	<p>The existing quality statements do not reflect the importance of social interaction/ inclusion/ maintenance and development of relationships both within and outside the care home setting. This is recognised within the Care Homes for Older People National Minimum standards and the Care Homes Regulations 2001. (DH, 2003) in particular within Standard 13.</p> <p>This could be achieved by an additional Quality Statement for example: Older people in care homes are supported to engage with the community within and outside of the care home setting.</p> <p>Alternatively, this element could be incorporated with Quality Statement 1. For example:</p>	The quality standard has been updated to include greater emphasis on the importance of social inclusion, involvement with the community and the development and maintenance of relationships. The QSAC did not feel that a separate statement on this area was required.

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				Older people in care homes have opportunities and support during their day to participate in meaningful activities that promote health and mental wellbeing and to engage with their community within and outside of the care home setting.	
026	129	Royal College of Nursing	QS 1	There is no reference to the fact that some people will not want to participate in any of the activities or be referred. It should be noted that if offered and declined that this is an individual's choice rather than a failing of the care home.	One of the outcome measure for this statement is: Feedback from older people in care homes that they are offered opportunities during their day to take part in activities during their day. The use of 'offered' in this measure ensures that care homes will not be considered as not achieving the statement merely because some older people do not wish to take part in activities.
001	130	Amore Care – Part of the Priory Group	QS 2	Statistics may help set the context. We know that around 40% of people with dementia experience depression and people with dementia are at higher risk of delirium. The 'Lets Respect' campaign circa 2006 was implemented for the care home setting. This was an excellent tool for increasing knowledge and awareness.	It is not within the remit of this quality standard to provide an exhaustive list of resources for care homes. The most relevant sources have been selected for inclusion in the quality standard.
001	131	Amore Care – Part of the Priory Group	QS 2	Information about mental health and wellbeing should be shared between agencies. Social work assessments need to gather this information which is then shared with the care home. This part of the process could be much improved in some areas with a consequence of being able to deliver individualised care and support e.g. driving up quality. Often other mental health conditions can mimic some of the signs and symptoms of dementia. Care staff need to be highly attuned in picking up changes in mood, recording and referring this on where appropriate.	Thank you for your comment.
003	132	Dementia Pathfinders Community Interest Company	QS 2	Could this mention that people may experience multiple mental health conditions (e.g. depression and dementia) and that some residents may have enduring mental health problems, such as a history of depression or schizophrenia.	The definition of mental health conditions has been amended to state that people may experience multiple mental health conditions.
003	133	Dementia Pathfinders Community Interest Company	QS 2	Could emphasise the needs of those who have enduring mental health and cognitive problems alongside those diagnosed in later life.	The definitions section of this statement has been updated to include reference to staff being aware of existing mental health conditions.

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004	134	Alzheimer's Society	QS 2	<p>General</p> <p>Alzheimer's Society welcomes this quality statement to assess older people in care homes for common mental health conditions. The Society believes it is important that staff are trained to recognise mental health conditions and are aware of the referral process if they suspect a person has dementia. Evidence suggests that in excess of 80% of people living in care homes have dementia or significant memory problems (Alzheimer's Society, 2013a). Currently, only 46% of people receive a formal diagnosis (Alzheimer's Society, 2013b) and diagnosis often takes place late in a person's progression of the condition. This means that a person with dementia often enters a care home at a time of crisis, but still without a diagnosis.</p> <p>If the systems and structures were available, it should be possible to collect the data for this quality standard. Alzheimer's Society recommends that the CQC should be responsible for ensuring that care homes are collecting this data and that they make the necessary referrals.</p>	Thank you for your comment. It is not within the remit of NICE quality standards to advise the CQC on the data they collect.
004	135	Alzheimer's Society	QS 2	<p>Equality and diversity considerations</p> <p>Although communication barriers are recognised as a consideration when assessing older people for common mental health conditions, sensory impairment has not been mentioned and should be. The assessment for dementia is reliant on a person having useful vision and hearing, so it important that care home staff are aware of this to avoid missing that a person could have dementia.</p>	Sensory impairment has been added to the equality and diversity considerations for this statement.
007	136	Life Story Network CiC	QS 2	<p>It would be helpful if this quality measure made the necessary links to the NICE Guidance on Depression and Delirium. There is no reference to delirium in this quality standard. There is a huge gap in the recognition of mental conditions in older people living in care homes.</p>	The quality statement has been updated and now includes links to the NICE guidance on depression and delirium.
007	137	Life Story Network CiC	QS 2	<p>Given the plethora of measure of mental health and wellbeing that exist, there needs to be careful consideration as to which ones are used and how the evidence is collated.</p>	The NICE quality standard contains the measures that are considered most relevant and appropriate for each statement. It is expected that decisions about how evidence is collated will be made at a local level.
008	138	English Community Care Association	QS 2	<p>This is a much needed focus for improving detection rates within care homes of mental illness. With regard to quality measures</p>	The QSAC agreed that the focus of this statement should be changed to the recognition of mental health conditions

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				<p>Please insert each new comment in a new row.</p> <p>and evidence of protocols in homes, this in itself will not provide impact and outcome measures of their use with individuals and therefore the quality of resident experience both in terms of detection and intervention of mental illness will be missed. An intervention itself such as awareness raising is just that, the impact is the critical aspect.</p> <p>Measures will need to include recorded assessments and evidence of impact of training. This should include a range of common conditions as highlighted in the definitions of common illness, but we note this does not include delirium and this is an omission, in light of this cohort of vulnerable older adults with multiple co morbidities to which this standard applies.</p>	<p>Please respond to each comment</p> <p>and that assessment should be removed from the statement. A new statement has been added regarding access to the full range of healthcare services. It is expected that implementation of the new statement will lead to referrals being made to the most appropriate services and that the issues of assessment and management will be addressed by these services.</p>
009	139	College of Occupational Therapists	QS 2	<p>We are making the assumption that assessment refers to intervention also if there is an identified need. This is not explicit and probably needs to be. The wording in statement 3 could fit around 2 and make it more robust.</p> <p>Suggestion: Data Source: Local data collection c) Evidence of local arrangements to access multidisciplinary expertise from AHPs as well as medical provision.</p>	<p>The QSAC agreed that the focus of this statement should be changed to the recognition of mental health conditions and that assessment should be removed from the statement. A new statement has been added regarding access to the full range of healthcare services. It is expected that implementation of the new statement will lead to referrals being made to the most appropriate services and that the issues of assessment and management will be addressed by these services.</p>
010	140	Department of health	QS 2	<p>Older people in care homes are assessed for common mental health conditions, including dementia</p>	<p>The Mental wellbeing of older people in care homes quality standard addresses a wider population than just people who have dementia. Dementia is specified as one of a number of mental health conditions in the definitions section for this statement.</p> <p>NICE has produced two quality standards specifically addressing the topic of dementia. These are: Dementia (quality standard 1); and Supporting people to live well with dementia (quality standard 30).</p>
011	141	British Geriatrics Society	QS 2	<p>As well as trying to train all the non professional care home carers (a very big job) commissioners should be encouraged to look at the contact their community nursing and other health and social care services (general and specialist mental health) have with care homes and the role of these staff in identifying mental health problems. They should specifically ensure that</p>	<p>A new statement regarding access to the full range of healthcare services has been added to the quality standard to address the issue of older people in care homes having difficulty getting access and onward referral to the services they need.</p>

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				their local primary care mental health services accept referrals for people who live in care homes and those who are unable to travel to GP practices	
012	142	British Association of Behavioural and Cognitive Psychotherapies	QS 2	Levels of anxiety and depression are high in residential care homes, and yet access to evidence-based psychological therapies is poor for older people in general and especially so for those in care homes. Anxiety and depression lead to significantly reduced mental well-being and excess disability. Levels are high on and before admission to a care home, and are not simply a reaction to the care home environment (although this serves to maintain low mood in many cases). The quality statement does not go far enough. Assessment (even assessment and reporting to GP) is an insufficient response. Practitioners should ensure that evidence-based psychological therapies, as recommended in NICE guidelines on common mental health conditions, should be made readily available in the care home context. It is not enough to state that older people in care homes are protected by the NHS Constitution. For reasons of stigma or therapeutic helplessness or ageism, care home residents do not receive the psychological support they could benefit from in coping with anxiety and depression, often co-morbid with multiple physical problems, and in this context with cognitive impairment. Evidence-based therapies such as cognitive behaviour therapy have now been shown to be feasible in this context, and this statement would be much improved by recognising the need for assessment and intervention, and specific access to psychological therapies.	A new statement regarding access to the full range of healthcare services has been added to the quality standard to address the issue of older people in care homes having difficulty getting access and onward referral to the services they need. This statement covers all types of health services including mental health services.
012	143	British Association of Behavioural and Cognitive Psychotherapies	QS 2	It is very surprising to see dementia included in the list of 'common mental health conditions'. Of course, as argued previously, with a prevalence of 70%, it clearly is a common condition in this context. But, this phrase has come to be used more typically (by NICE) without including dementia, and to include dementia here does not do it justice. An additional quality statement on assessment for dementia should be considered, again with a clear link to appropriate evidence-based interventions.	<p>The wording of the statement has been updated to state 'mental health conditions' rather than 'common mental health conditions'.</p> <p>The Mental wellbeing of older people in care homes quality standard addresses a wider population than just people who have dementia. Therefore, the QSAC did not consider it appropriate to include a statement specifically about dementia.</p> <p>NICE has produced two quality standards specifically</p>

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					addressing the topic of dementia. These are: Dementia (quality standard 1); and Supporting people to live well with dementia (quality standard 30).
015	144	The National LGB&T Partnership and The Lesbian & Gay Foundation	QS 2	The Equality & Diversity Considerations must make reference to the needs of LGB&T people, and acknowledge that sexual orientation and gender identity can have an impact on the prevalence of common mental health conditions. A wealth of evidence shows that LGB&T are more likely to experience poor mental health compared to the general population; given that older people in general are more likely to experience poor mental health too, it is likely that older LGB&T are even further at risk of common mental health conditions. The Quality Statement should recommend that care home providers implement sexual orientation and gender identity monitoring for all patients, in order to assess and understand their needs. It should be recognised that there will be sensitivities for older LGB&T people around monitoring and around coming out, but these should be a spur to develop inclusive and supporting services rather than a barrier to addressing need. Guidance on sexual orientation monitoring, commissioned by NHS North West can be found here www.lgf.org.uk/som and on monitoring gender identity here www.gires.org.uk/assets/Workplace/Monitoring.pdf .	Gender identity is now referenced under the Equality and diversity considerations section. All groups, including lesbian, gay, bisexual and transgender groups, are included under the Equality and diversity considerations section. It is felt that sufficient emphasis is given to the equality groups identified.
015	145	The National LGB&T Partnership and The Lesbian & Gay Foundation	QS 2	All data sources specified should collect demographic monitoring data, including sexual orientation and gender identity, in order to assess the needs and experiences of LGB&T people.	It is expected that the specific data collected will be decided at a local level.
016	146	Social Care Institute for Excellence	QS 2	The draft Guide notes the impact of existing long-term conditions on the physical and mental health and intellectual capacity of older people, which needs to be understood in arrangements for access to health care assessment and treatment	Thank you for your comment.
017	147	St Christopher's Hospice	QS 2	Statement 2 - older people in care homes need to HAVE mental health conditions ASSESSED and MANAGED by the appropriate health care professional – including older people psychiatrists	The QSAC agreed that the focus of this statement should be changed to the recognition of mental health conditions and that assessment should be removed from the statement. A new statement has been added regarding access to the full range of healthcare services. It is expected that implementation of the new statement will

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					lead to referrals being made to the most appropriate services and that the issues of assessment and management will be addressed by these services.
019	148	Research into Practice for Adults	QS 2	<p>B: Access to services</p> <p>The importance of access to services is highlighted in Standard 3, which refers to assessment, recording a need and then addressing it. However, Standard 2 only highlights assessment and Standard 4 only highlights the identification and recording of problems. Each of these standards needs to reflect the framework in Standard 3, where “addressing” the difficulty is emphasised. These standards could then include more specific discussion of how needs are addressed, referencing the need for interventions to be evidence-informed and timely.</p>	The QSAC agreed that the focus of the statements on mental health conditions, sensory impairment and physical problems should be changed to recognition and that assessment should be removed from the statements. A new statement has been added regarding access to the full range of healthcare services. It is expected that implementation of the new statement will lead to referrals being made to the most appropriate services and that the issues of assessment and management will be addressed by these services.
020	149	Royal College of Psychiatrists	QS 2	<p>Standard 2 is about diagnosing mental illnesses in residents, most of who will have been fully assessed on admission.</p> <p>However there is no measurement of mental wellbeing, nor any acknowledgement that most people, of all ages, who need to be cared for in residential care will have compromised mental capacity and decision making skills.</p>	<p>The QSAC agreed that the focus of the statement should be changed to the recognition of mental health conditions and that assessment should be removed from the statement.</p> <p>The rationale section of the statement has been updated to make the link between mental health conditions and mental wellbeing clearer. The measures identified were reviewed and agreed by the QSAC as the most appropriate for inclusion for this statement. The quality standard has been updated to make reference to the Mental Capacity Act and also to state that older people in care homes should have access to an advocate if needed.</p>
028	150	Campaign to End Loneliness	QS 2	This quality statement could recognise that loneliness, alongside significant long-term disability, is a causal factor in poor mental health and wellbeing, and that care home staff should try to identify if an individual is in need of more social contact and companionship.	The statements on meaningful activity and personal identity emphasise the importance of social inclusion and relationships. The focus of the statement has changed to recognition of the symptoms and signs of mental health conditions. It is expected that the specific symptoms and signs staff need to be aware of will be decided locally.
029	151	OPENspace Research Centre	QS 2	When planning to ensure that older people in care homes are assessed for common mental health conditions, we would	The focus of the statement has changed to recognition of the symptoms and signs of mental health conditions. It

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				encourage carers not to neglect the outdoor environment in that planning. A well planned and inclusively designed built environment can enhance mental health and wellbeing.	was not considered feasible to address all issues that affect mental health within this statement. The quality standard has been updated to include reference to access to outdoor spaces in the statements on meaningful activity and personal identity.
031	152	Parkinson's UK and Lewy Body Society	QS 2	<p>We are concerned that the wording of quality statement 2 might lead to under- qualified care staff having to take on responsibilities that should be undertaken by health professionals. This statement should be strengthened, along the lines of:</p> <p>‘Older people in care homes are referred on to be assessed for common mental health conditions and have their mental health needs met, with access to the necessary services equal to older people living in the community’.</p> <p>“I believe it was more isolating having the physical symptoms on top of the dementia, since Mum was bedbound for the last 15 months of her life in the care home, and was lucid sometimes, so was frustrated at being stuck in her room. Then, when she was less lucid and sometimes aggressive, that upset the staff, who only saw the physical symptoms and didn't know or realise there was dementia. She was diagnosed with the dementia a long time after the Parkinson's, but the staff didn't know how to handle the double symptoms, nor were they particularly aware that it could occur like this. It is just not well known nor communicated.”</p> <p>“The care workers in the home were brilliant from a physical point of view and they were well versed in Alzheimer's, which is more of a</p>	The QSAC agreed that the focus of the statement on mental health conditions should be changed to recognition and that assessment should be removed from the statement. A new statement has been added regarding access to the full range of healthcare services. It is expected that implementation of the new statement will lead to referrals being made to the most appropriate services and that the issues of assessment and management will be addressed by these services.

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				<p>consistent thing, so they can gauge how someone is over time. But they didn't grasp how Mum could fluctuate so much. Sometimes she would be completely lucid and then within an hour or two she would manifest anger, upset and terror."</p> <p>The importance of non-motor symptoms of Parkinson's Whilst Parkinson's is often recognised as a motor disease, there are several non-motor aspects of the disease that impact on mental wellbeing: depression, dementia, anxiety, hallucinations, delusions, psychosis, weight loss, sleep disturbances, autonomic disturbance (causing a wide range of problems including orthostatic hypotension, continence issues, swallowing problems, choking and drooling), sexual dysfunction and apathy and within the context of care homes, these symptoms should be considered as common mental health conditions / risk factors for undermining mental wellbeing. Staff should be trained to understand the fluctuating nature of the non-motor symptoms and modify their supportive approaches according to how able the resident is at any time.</p> <p>Best practice in accurately identifying and managing Parkinson's non-motor symptoms, which will be expressed differently from individual to individual and which often involve trade-offs between achieving good physical or mental functioning, requires a multi-disciplinary assessment and approach to treatment and support that should involve a wide range of practitioners working together with the older person. Whilst input from mental health services to care homes is currently generally on an ad hoc basis, or reactive with referrals at times of crisis, a care home with a resident with a Lewy body disorder will need good working arrangements with liaison psychiatrist and psychogeriatrician, OT, physio, SLT. 21 22 23</p>	

²¹ Nursing Standard (2009) Living well with dementia in a care home: a guide to implementing the National Dementia Strategy

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				<p>Mental health problems can be hard to spot and to treat Mental health problems can be missed unless looked for—for example, depression can be difficult to diagnose in a patient with a mask-like face and bradyphrenia (slowness of thought). Use of special scales for assessment of depression, cognitive impairment, sleep disturbance, etc is often required.</p> <p>Depression There is often an element of depression in Parkinson's, which in an older adult can masquerade as confusion or dementia. Prevalence of 31% was reported in a recent meta-analysis. Depression has been strongly related to the people's quality of life.</p> <p>Mood fluctuations can accompany motor fluctuations of "on-off" states. Depression increases in the "off" state and improves in the "on" state. Controlling for severity of depression, PD patients report more fearfulness, helplessness, a preference to stay at home and diminished energy than AD patients. ²⁴</p> <p>Severe depression in Parkinson's may anticipate the development of intellectual impairment. Depression may also present as pseudodementia that resolves with effective treatment of the depression.</p> <p>Cognitive impairment</p>	

²² Heath H, *Health and healthcare services*. In Help the Aged (2007). My Home Life: Quality of life in care homes: A review of the literature. Help the Aged, London

²³ British Geriatrics Society (2012). Failing the frail: A chaotic approach to commissioning healthcare services for care homes. Available at: http://www.bgs.org.uk/index.php?option=com_content&view=article&id=1907:cqc-report-too-many-failing-hospitals&catid=6:prindex&Itemid=99 [Accessed 29 July 2013]

²⁴ Weintraub D, Xie S, Karlawish, J. [et al]. (2007). Differences in depression symptoms in patients with Alzheimer's and Parkinson's diseases: evidence from the 15-item Geriatric Depression Scale GDS-15). *International Journal of Geriatric Psychiatry*, 22(10), 1025-1030

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				<p>Most people with Parkinson’s show slowness in thinking and have word finding difficulties.</p> <p>Dementia People with Parkinson’s may have a sixfold increase in the risk of developing dementia in patients compared to controls.^{25 26} A recent US study found that close to half of nursing home residents with PD may have PDD at any given time and they remain undiagnosed and largely undertreated, with PDD remaining an unrecognised entity in the nursing home setting.²⁷ Reports from family members of people with PDD and DLB indicate this is also true in the UK. Progression from Parkinson’s to Parkinson’s dementia is common [50 per cent of people with PD after eight years, 80 per cent after 20 years].</p> <p>Given the risk for all older residents with normal cognition of developing dementia, and especially the increased risk of developing dementia for people with Parkinson’s, it is important for staff to be vigilant for signs of this. Services for expert assessment, early diagnosis and intervention, should be available to care home residents.^{28 29}.</p>	

²⁵ Reid WG, Hely MA, Morris JG, Loy C, Halliday GM (2011) [Dementia in Parkinson's disease: a 20-year neuropsychological study \(Sydney Multicentre Study\)](#). *J Neurol Neurosurg Psychiatry*. Sep;82(9):1033-7

²⁶ Aarsland D, Larsen JP, Tandberg E, Laake K (2000) Predictors of nursing home placement in Parkinson’s disease: a population based prospective study. *J Am Geriatr Soc*. 48(8):938-42

²⁷ Hoegh M, Ibrahim AK, Chibnall J, Zaidi B, Grossberg GT (2013) [Prevalence of Parkinson disease and Parkinson disease dementia in community nursing homes](#). *Am J Geriatr Psychiatry*. 21(6):529-35

²⁸ Thanvi B R, Munshi S K, Vijaykumar N, Lo T C N (2003) Neuropsychiatric non-motor aspects of Parkinson’s disease *Postgrad Med J* 79:561–565

²⁹ Aarsland D, Andersen K, Larsen JP, *et al.* (2001) Risk of dementia in Parkinson’s disease: a community based prospective study. *Neurology* 56:730–6.

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				<p>Dementia in Parkinson's often takes the form of memory difficulties that respond to external cues, difficulty with planning, distractibility, slowed thinking, lack of motivation and visuospatial deficits. Where non-motor symptoms precede or occur at the same time as parkinsonism, people are diagnosed as having dementia with Lewy bodies (DLB).</p> <p>Dementia in Parkinson's disease can also be due to concurrent Alzheimer's disease or a cerebrovascular disease as these conditions are common in the older population.</p> <p>Anxiety Symptoms of anxiety are common in Parkinson's disease, reported in some studies to be around 30 per cent. The anxiety disorders in people with Parkinson's can manifest as panic attacks, phobia, and/or as generalised anxiety disorder. Anxiety in Parkinson's can be a part of depression and thus may respond to antidepressants with sedative effects. It can also be a manifestation of the cognitive impairment, a side effect of the dopaminergic medications, or a part of the mood swings noted in patients with on-off periods. It is, therefore, important to take a detailed history from the patient or the carer.</p> <p>Psychosis Psychosis affects nearly one third of patients with Parkinson's disease. Parkinson's medications and polypharmacy have both been identified as risk factors for psychosis in Parkinson's, which usually manifests as vivid dreams, hallucinations, delusions, and in severe cases as confusional psychosis. On average, PD patients manifest psychotic symptoms ten or more years after the initial diagnosis.³⁰</p> <p>Hallucinations Hallucinations in people whose Parkinson's started after the age</p>	

³⁰ Zahodne LB [and] Fernandez HH (2008). Course, prognosis, and management of psychosis in Parkinson's disease: Are current treatments really effective? *CNS Spectrums*, 13(3 SUPPL. 4), 26-33

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				<p>of 65 are usually associated with cognitive impairment. People who have had dopaminergic therapy for some years can gradually develop hallucinations that are usually visual in content and without marked agitation or confusion. Some people with Parkinson’s develop hallucinations as a complication of medical illness because of infection, dehydration or drug toxicity. These patients usually are confused and agitated in the midst of their hallucinations.</p> <p>Often hallucinations occur in low light situations (sundowning), and when the individual is going from one state of consciousness to another, such as waking from sleep. Someone might “see” a relative in the bedroom upon awakening, but then realise the person is not really present. Something may be seen darting out of the corner of the eye, or crawling bugs will be seen in patterned wall coverings or floor tiles. Seeing small people (lilliputian figures), children, and animals are common hallucinations. As hallucinations become more vivid, insight into the unreality of the perception is lost, and the patient may be unable to distinguish real from hallucinatory experiences.</p> <p>Staff should be trained to reassure both the resident with PD/PDD/DLB and other residents, staff and visitors when hallucinations are an issue. Hallucinations such as flies on food can have a direct effect on both physical and mental wellbeing, so staff need to be good at the deflection techniques and clarification of feelings in good dementia care.</p> <p>Disrupted sleep Sleep disturbances can affect more than 70 per cent of people with Parkinson’s. Night terrors, Restless Legs Syndrome, REM behaviour disorder (RBD), Periodic Limb Movement Disorder and excessive daytime sleepiness are recognised features of Lewy body disorders. Some medication used in the treatment of Parkinson’s disease and depression can also impair sleep or cause nightmares.³¹</p>	

³¹ Thanvi B R, Munshi S K, Vijaykumar N, Lo T C N (2003) Neuropsychiatric non-motor aspects of Parkinson’s disease *Postgrad Med J* 79:561–565

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				<p>The sleep of long-term care residents in general is distributed across the 24-hour day rather than being consolidated to the night time hours. Residents are rarely asleep or awake for a continuous hour during the day or night. Some of the consequences of poor sleep, such as irritability, poor concentration and memory, slower reaction time, decreased performance may all be assumed to be part of dementia. Short sleep at night, low per cent of the night spent asleep and increased napping during the day are all associated with increased risk of falls as well as increased risk of shorter survival.</p> <p>Residents with RBD can fall out of bed or engage in dangerous behaviour during the night as a result of acting out dream-related behaviours while asleep. The resident should be reviewed for medication to control the condition and care home staff should secure the sleep environment to ensure safety.</p> <p>Exposure to bright light is the strongest synchronizer and stabilizer of circadian rhythms, and daytime light levels in long-term care facilities are quite low, with residents seldom taken outdoors. Typically, long-term care residents are exposed to only a few minutes of bright light each day, the strongest known time cue in humans. Long-term care residents, notably those with movement problems like parkinsonism, also spend extended periods in bed and are physically inactive during the daytime.</p> <p>Staff should enable residents to be exposed to sufficient daylight and also do enough exercise to help maintain their circadian rhythms .32</p> <p>Other Parkinson’s-related mental health problems Confusion and paranoid delusions can also occur.</p>	

³² Martin, J.L. [and] Ancoli-Israel, S. (2008). Sleep disturbances in long-term care. *Clinics in Geriatric Medicine*, 24(1), 39-50, vi.

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				<p>Impulsive and compulsive behaviour is a possible side effect of some Parkinson's drugs (dopamine agonists and other Parkinson's drugs, particularly levodopa). Although only a relatively small number of people experience this behaviour, it can have a significant impact on the person affected and those around them. Behaviours can include: binge eating, hypersexuality, compulsive hobbyism (collecting, sorting or continually handling objects), a deep fascination with taking things apart without always knowing how to put them back together again, hoarding things, pointless walking and talking in long monologues without any real content.³³</p> <p>Staff need to understand that these problems are directly related to a resident's PD/DLB and seek expert advice and assistance when necessary.</p> <p>Alternatives to antipsychotic medication There is a growing acceptance that so-called 'challenging behaviour' in dementia is a 'distressed reaction': a manifestation of disorientation, misperception, distress or suffering in the person, or distress in the caregiver. According to this definition, challenging behaviour can be seen as an active attempt by the person to meet or express a physiological or psychological need. It is important to recognise that because the behaviours are not the inevitable consequences of a disease, we need to be careful not to treat them as if they are – particularly if this involves using problematic drugs. Extreme caution in the use of antipsychotic drugs is critical for people with dementia with Lewy bodies, about half of whom have a potentially fatal neuroleptic sensitivity. ^{34 35 36 37 38}</p>	

³³ [Online] Parkinson's UK <http://www.parkinsons.org.uk/content/parkinsons-drugs-and-impulsive-and-compulsive-behaviour> [last accessed 1 August 2013]

³⁴ Brechin D, Murphy G, James IA [et al] (2013). *Alternatives to antipsychotic medication: psychological approaches in managing psychological and behavioural distress in people with dementia*. Leicester: British Psychological Society; Faculty of the Psychology of Older People (FPOP)

³⁵ Care and Social Services Inspectorate Wales (2009) Older people with dementia.

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				<p>“My husband had been in an NHS Assessment Unit where they sedated him because they didn’t know what to do with him. He was briefly in another home for emergency respite but they were not able to cope with him either. He got suddenly very bad. They were not able to cope with that level of aggression and anxiety. At the eventual home where my husband went, their aim was to reduce medication. He was on antipsychotics and they reduced them. He [started] very sleepy and gradually he became more alert.”</p> <p>Crucially, staff must understand the resident as well as possible, through talking with them and life history work. Service users with a Lewy body dementia may well have periods of lucidity which offer a ‘window of opportunity to understand what lies behind the distressed reaction and discuss support approaches and treatment options, including medication and consent. In addition, helpful approaches to avoid/reduce medication could include dementia awareness training for staff, dance, movement and exercise, art, Cognitive Stimulation Therapy, reminiscence, light therapy, doll therapy, access to nature, access to animals to pet, ‘green exercise’, multi-sensory activities/stimulation, use of memory and activity boxes, participation in chores and having</p>	

³⁶ Moniz Cook ED, Swift K, James I [et al]. Functional analysis-based interventions for challenging behaviour in dementia. Cochrane Database of Systematic Reviews (Online). February 15th 2012; Issue 2: No.CD006929.

³⁷ Stokes G. (2000) *Challenging behaviour in dementia: A person centred approach*. Bicester: Winslow Press

³⁸ [Baskys A](#) (2004) Lewy body dementia: the litmus test for neuroleptic sensitivity and extrapyramidal symptoms *J Clin Psychiatry* 65 Suppl 11:16-22

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				<p>responsibility for an element of life in the home, social interaction, changes to the physical environment, and listening to and making music. 3940</p> <p>Care homes should be honest with the families of prospective residents about the level of care they can provide. It is not uncommon for relatives of people with a Lewy body dementia to struggle to find a home that can cope with their neuropsychological symptoms. In some cases, where homes oversell their competencies, the placement can fail quite quickly, leading to the resident moving out of the home, with greater disruption, confusion and distress caused to them and their family.</p> <p>It is essential that any behaviours regarded as difficult are identified as part of the individual's plan of care and are regularly reviewed. Staff should try, with advice from family members and healthcare professionals, to understand both what triggers the behaviour (e.g. pain, medical illness, medications, drug interactions, loneliness, fear, boredom or environmental stress) and how best to manage it. Where the individual or others are put at risk through a particular behaviour, a proper risk assessment should be carried out. 41</p> <p>Because various commonly-prescribed agents (e.g. narcotics, hypnotics, antidepressants, and anxiolytics) can contribute to the development of psychotic symptoms, it is important for the clinician to consider the patient's complete pharmacological regimen when combating PD psychosis. The potential benefits</p>	

³⁹ [Online] Alzheimer's Australia (2013) Relate, Motivate, Appreciate - A Montessori Resource: Promoting positive interaction with people with dementia http://qualitydementiacare.org.au/wp-content/uploads/AlzheimersAustralia_Montessori_Resource_WEB.pdf (last accessed 2 August 2013)

⁴⁰ Brechin D, Murphy G, James IA [et al] (2013). *Alternatives to antipsychotic medication: psychological approaches in managing psychological and behavioural distress in people with dementia*. Leicester: British Psychological Society; Faculty of the Psychology of Older People (FPOP)

⁴¹ Care and Social Services Inspectorate Wales (2009) Older people with dementia.

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				Please insert each new comment in a new row. and risks of all clinical decisions should be shared with family members and their consent obtained (in writing if possible) This provides an opportunity to obtain proxy consent and discuss medications and their potential side effects. 42 43 Any use of restraint should be in line with best practice.44 45	Please respond to each comment
032	153	Care Quality Commission	QS 2	The statement could be strengthened further by including the need for parity between mental health and physical health.	It was not considered necessary to make this explicit within the statement. The quality standard includes statements on both mental and physical health.
032	154	Care Quality Commission	QS 2	Under 'definitions of terms used', there is reference to dementia and related guidance. There can be some disagreement as to whether dementia is referred to as a mental health condition, or whether it is preferable to refer to it in terms of mental capacity. Has the inclusion of dementia under this section on common mental health conditions been agreed by a range of stakeholders, so that it is understood and accepted by the social care audience this quality statement is aimed at?	The QSAC agreed that it was appropriate to include dementia under the definition of mental health conditions.
032	155	Care Quality Commission	QS 2	Under statements 3 & 4, sensory and physical needs should be assessed for and recorded in the care plan. However, under statement 2 it does not seem to be required that mental health needs should be recorded in the care plan. Consideration should be given to including this within statement 2, so that mental health needs are given parity in care planning alongside physical and sensory needs.	The statements were developed based on the evidence available for the individual topics they were addressing. Following the consultation period a new evidence source has become available and therefore the statements have been amended. The QSAC agreed that the focus of the statements on mental health conditions, sensory impairment and physical problems should be changed to

⁴² Salzman C, Jeste, DV, Meyer RE [et al]. (2008) Elderly patients with dementia-related symptoms of severe agitation and aggression: Consensus statement on treatment options, clinical trials methodology, and policy. *Journal of Clinical Psychiatry* 69(6), 889-898.

⁴³ Zahodne LB [and] Fernandez HH (2008). Course, prognosis, and management of psychosis in Parkinson's disease: Are current treatments really effective? *CNS Spectrums*, 13(3 SUPPL. 4), 26-33

⁴⁴ Qureshi, H (2009) Restraint in care homes for older people: a review of selected literature, Social Care Institute for Excellence (SCIE)

⁴⁵ Owen T, Meyer J, Meehan L and Cornell, M (2009) Minimising the use of 'restraint' in care homes: Challenges, dilemmas and positive approaches Social Care Institute for Excellence (SCIE)

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					recognition and that assessment should be removed from the statements.
026	156	Royal College of Nursing	QS 2	Not sure why we refer to 'common' mental health conditions. Is it expected that an older person will have these? We would suggest the removal of that term.	The use of the phrase 'common mental health conditions' was taken from the NICE guideline of the same name. However, as the conditions described are not all included within this guidance the term 'common' has been removed from the statement.
002	157	Nottinghamshire Healthcare NHS Trust	QS 2	Emphasis. needs to made on partnersip working with health care providers,secondary and primary health to determine if assessment has been made or to ensure they are in the future	The quality standard contains a section on Coordinated services which emphasises the importance of an integrated approach to providing services.
001	158	Amore Care – Part of the Priory Group	QS 3	This area is really important and the need for improved levels of consistency is vital. Care and support in this area can be patchy. Specific training in how to look after 'hearing aids' and glasses should be embedded into the development of care staff. Changing batteries, cleaning and replacing blocked tubes and regular cleaning of lenses will maintain well-being to some degree.	The definitions section of the statement on sensory impairment has been updated to give examples of what staff should do and these include cleaning glasses and changing hearing aid batteries.
001	159	Amore Care – Part of the Priory Group	QS 3	The Social Care Institute for excellence has recently commissioned a best practice film about dementia and sensory loss. In the near future, this will be accessible on SCIE TV.	Thank you for your comment.
001	160	Amore Care – Part of the Priory Group	QS 3	Important to note that tastes can change e.g. someone who never liked fruit or fruit drinks became a lover of both. In terms of good nutrition to be able to spot these changes and maximise things like to '5 a day' principle.	As part of the development of quality standards areas are prioritised for development into statements following a stakeholder engagement exercise and discussion at the first meeting of the QSAC. The QSAC prioritised the areas of care they felt were most important for older people in care homes, based on the development sources listed. Areas of care were prioritised where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. Nutrition and food tastes were not prioritised as an area for quality improvement.
001	161	Amore Care – Part of the Priory Group	QS 3	Some guidance on changes of sensory perception in later/advanced stages of dementia. People tend to respond at a sensory level. This could be touch and preferred sounds rather than visual sensory stimulation. This is likely to change from person to person, hence taking account of spirituality, religion and culture is important.	The Mental wellbeing of older people in care homes quality standard addresses a wider population than just people who have dementia. Therefore, the QSAC did not consider it appropriate to include specific reference to dementia in this statement. The equality and diversity considerations section of this statement highlights the

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					needs of groups such as people with dementia. NICE has produced two quality standards specifically addressing the topic of dementia. These are: Dementia (quality standard 1); and Supporting people to live well with dementia (quality standard 30).
001	162	Amore Care – Part of the Priory Group	QS 3	Positive relationship building with health professionals will support good health care. Getting all primary care staff ‘on side’ can make a big difference. Holding a GP practice within the care home responds to the ‘dementia friendly community’ ethos and enables improved access.	A new statement which focuses on the issue of access to all healthcare services, including primary care, for people in care homes has been added to the quality standard.
003	163	Dementia Pathfinders Community Interest Company	QS 3	Under addressing needs, it might be important to consider how the physical environment impact on sight and hearing problems of the individual.	The QSAC agreed that the focus of the statements on mental health conditions, sensory impairment and physical problems should be changed to recognition and that assessment should be removed from the statements. A new statement has been added regarding access to the full range of healthcare services. It is expected that implementation of the new statement will lead to referrals being made to the most appropriate services and that the issues of assessment and management will be addressed by these services.
004	164	Alzheimer's Society	QS 3	General Alzheimer’s Society recognises the importance of assessing older people for sensory impairment in care homes. However, we the Society has concerns that, due to cognitive impairment, people with dementia may not be able to understand the assessment for sensory impairment. It is welcomed that this is mentioned in the equality and diversity considerations, but it is vital that care home staff are trained to assess a person who may have sensory impairment and dementia.	The QSAC agreed that the focus of the statements on mental health conditions, sensory impairment and physical problems should be changed to recognition and that assessment should be removed from the statements. A new statement has been added regarding access to the full range of healthcare services. It is expected that implementation of the new statement will lead to referrals being made to the most appropriate services and that the issues of assessment and management will be addressed by these services.
006	165	Empowerment Matters	QS 3	Quality statement 3 What the quality statement means for service users and carers It may seem obvious but nonetheless we feel that the statement ‘Older people in care homes have any physical problems identified and recorded in the care plan’ should have added to it ‘and the person is supported to access health professionals where appropriate’.	The QSAC agreed that the focus of the statements on mental health conditions, sensory impairment and physical problems should be changed to recognition and that assessment should be removed from the statements. A new statement has been added regarding access to the full range of healthcare services. It is expected that implementation of the new statement will lead to referrals

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008	166	English Community Care Association	QS 3	There is no specific action relating to appropriate environment which could enhance the resident experience and improve outcomes of care. Should this be included?	being made to the most appropriate services and that the issues of assessment and management will be addressed by these services. The focus of the statement has changed to recognition of the needs arising from sensory impairment. It was not considered feasible to address all issues that are related to sensory impairment within this statement. The quality standard highlights the importance of an appropriate environment in the definitions sections of the statements on meaningful activity and personal identity.
009	167	College of Occupational Therapists	QS 3	We would suggest a statement regarding the care home making reasonable adaptations to the environment to support individual needs. For example, 30% to 60% of older people in care homes are more likely to have a visual impairment than older people living in the community and lighting needs to be improved to reduce the impact of declining sight. Fletcher A, Evans J, Smeeth L (2009) Impact of sight loss in older people in Britain. (Research Findings No 22). London: Thomas Pocklington Trust. Available at: http://www.pocklington-trust.org.uk/research/publications/rf22op19	The focus of the statement has changed to recognition of the needs arising from sensory impairment. It was not considered feasible to address all issues that are related to sensory impairment within this statement.
011	168	British Geriatrics Society	QS 3	Those identifying standards need to be mindful of the evidence in quest for quality that most PCTs (as were) are not meaningfully commissioning services for care homes and thus there are real barriers to the identification of and action on sensory or physical health issues for care home residents. The guide should recommend measurement of commissioners' contracts with specific regard to care homes for provision of NHS services for this population. It is essential that contracts for services to people in care homes contain a response time so that a "waiting list" is not allowed to develop (which in some cases in the work which was done as part of the evidence building for Quest for Quality was longer than the average life expectancy for a care home resident). They should have regard to the building evidence that proactive	It is outside the remit of the quality standard to make specific recommendations for inclusion in contracts.

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				care from primary care (supported where necessary by specialists in medical and care of older people) can support residents more effectively, identify and appropriately manage sensory and physical health problems and avoid some acute hospital admissions (which clearly impacts very directly on quality of life and mental health)	
012	169	British Association of Behavioural and Cognitive Psychotherapies	QS 3	The emphasis on addressing needs is welcome under this statement, and the clearer statement on 'Trained staff' is also welcome. As well as recognising when a referral for management of the sensory impairment is required, staff may also need training to identify when specialist assessment is required. It may be difficult to assess sensory impairment in a person with severe cognitive impairment for example.	The QSAC agreed that the focus of the statements on mental health conditions, sensory impairment and physical problems should be changed to the recognition and that assessment should be removed from the statements. A new statement has been added regarding access to the full range of healthcare services. It is expected that implementation of the new statement will lead to referrals being made to the most appropriate services and that the issues of assessment and management will be addressed by these services.
014	170	The Royal College of Ophthalmologists	QS 3	a) Evidence of protocols to ensure that staff are trained to assess older people in care homes for sensory impairment - as stated in the "Rationale" - the best contribution that staff should make, rather than access training themselves in evaluating sensory impairment, would be to ensure that people in their care have taken up the existing NHS provision for sight tests. There is already a great breadth of duties that care home staff are expected to be competent in. Ensuring that staff are trained in testing people's vision may be unnecessary as the provision exists for specialist optometric assessment to be carried out, free to the user, on a bi-annual basis from age 60 upwards and annually from the age of 70. The same provision is not necessarily there for hearing impairment, so training in this might still be appropriate, but from the eye care perspective, it would not be possible for care home staff to deliver the same quality of examination that the NHS sight test performed by an optometrist would. We would be concerned that such training for care home staff would give a false sense of security; staff may feel that they have been trained to monitor patients vision, and thereby fail to ensure that annual sight tests are being accessed, thereby risking untreatable visual loss, primarily from conditions such as Glaucoma, which is the second most	Thank you for your comment. It was not the intention of the statement that care home staff would undertake sight examinations. However, the QSAC agreed that the focus of the statements on mental health conditions, sensory impairment and physical problems should be changed to recognition and that assessment should be removed from the statements. A new statement has been added regarding access to the full range of healthcare services. It is expected that implementation of the new statement will lead to referrals being made to the most appropriate services and that the issues of assessment and management will be addressed by these services.

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				prevalent cause of blindness on earth and is primarily a disease of older age and would not be picked up by non-specialist staff until the loss of sight was advanced and untreatable. Where an indicator of the training of staff would be appropriate, might be training in the access of sight tests and emergency eye care as needed. All staff should be aware of older people's entitlements to NHS sight tests, and the means by which care can be sought (eg domiciliary visits for the immobile)	
014	171	The Royal College of Ophthalmologists	QS 3	a) Numerator – the number of people in the denominator who are assessed for sensory impairment and have their needs recorded in a care plan - it would be important to define that for visual impairment, the assessment being referred to in this numerator is the NHS sight test at the prescribed interval, rather than testing by care home staff. Where there is reluctance by patients to access these sight tests because they may feel pressure to buy expensive glasses they can not afford, training for the staff to encourage people to access their entitled tests without feeling constraint would be an important part of the detail, and might such training might appear in the “structure” indicator for evidence of protocols to show that staff are appropriately trained as mentioned above.	The QSAC agreed that the focus of the statements on mental health conditions, sensory impairment and physical problems should be changed to recognition and that assessment should be removed from the statements. The process measure for the statement on sensory impairment has been updated to include a measure on the proportion of people who have regular sight tests. A new statement has been added regarding access to the full range of healthcare services. It is expected that implementation of the new statement will lead to referrals being made to the most appropriate services and that the issues of assessment and management will be addressed by these services.
014	172	The Royal College of Ophthalmologists	QS 3	b) Denominator – the number of older people in care homes - in this section, if the numerator is the number of people in the denominator who have their needs arising from sensory impairment addressed, should the denominator not be the number of people in care homes who are found to have sensory impairment. If the denominator is, as stated, all people in care homes, then carers of populations where there are a large number of people with remediable sensory impairments could appear to be doing as well as carers of populations where there is less pathology. Thus poor performance in certain populations (eg lower SES, higher proportion of BME - both populations in which higher proportions of sight threatening pathology is expected) would not be picked up. It is appreciated that defining the denominator is less easy, however if uptake of Diabetic Retinopathy Screening amongst diabetics, and NHS sight tests amongst the elderly are being monitored, then the denominator could be derived from the outcomes of those screening events	The QSAC agreed that the focus of the statements on mental health conditions, sensory impairment and physical problems should be changed to recognition and that assessment should be removed from the statements.. The process measure for the statement on sensory impairment has been updated to include a measure on the proportion of people who have regular sight tests. A new statement has been added regarding access to the full range of healthcare services. It is expected that implementation of the new statement will lead to referrals being made to the most appropriate services and that the issues of assessment and management will be addressed by these services.

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				Please insert each new comment in a new row. as the number of referrals that result would be known, and the numerator would be the number of patients who access the appointments that result from their referrals.	Please respond to each comment
015	173	The National LGB&T Partnership and The Lesbian & Gay Foundation	QS 3	All data sources specified should collect demographic monitoring data, including sexual orientation and gender identity, in order to assess the needs and experiences of LGB&T people.	It is expected that the specific data collected will be decided at a local level.
016	174	Social Care Institute for Excellence	QS 3	The draft Guide notes the impact of existing long-term conditions on the physical and mental health and intellectual capacity of older people, which needs to be understood in arrangements for access to health care assessment and treatment	Thank you for your comment.
017	175	St Christopher's Hospice	QS 3	Needs use of symptom assessment tools – in particular assessment tools for pain and depression. The research shows that 26% of residents in care homes experience daily pain – with up to 60% of residents being depressed. Appropriate behavioural tools of pain (DOLOPLUS-2) and depression (CORNELL) need to be standard assessment tools in care homes – with the training of care staff who know how to use them. This is possible as we do it!	The QSAC agreed that the focus of the statements on mental health conditions, sensory impairment and physical problems should be changed to recognition and that assessment should be removed from the statements. A new statement has been added regarding access to the full range of healthcare services. It is expected that implementation of the new statement will lead to referrals being made to the most appropriate services and that the issues of assessment and management will be addressed by these services.
019	176	Research into Practice for Adults	QS 3	C: Impact of physical conditions While standards 3 and 4 address this to some extent, it is unclear from the standards that staff should be trained in responding to and understanding the impact of specific physical conditions. Understanding the impact of specific conditions will enable staff to meet needs effectively through considering the appropriateness of their own practice, enabling empathic and compassionate care. It would also support staff to understand and recognise the impact of one person's condition on their peers within a Care Home setting.	The QSAC agreed that the focus of the statements on mental health conditions, sensory impairment and physical problems should be changed to recognition and that assessment should be removed from the statements. It is also not within the remit of NICE quality standards to define all aspects of training that will be required in order to achieve the care described by the quality statement.
021	177	Sense	QS 3	Sense strongly welcomes this quality standard and in particular statement 3. Sensory loss is common in older people, but often overlooked as it is seen as an inevitable part of the ageing	Thank you for your comments.

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				<p>process. Unaddressed sensory loss causes difficulties with communication and mobility, which will have a resulting negative impact on both physical and mental wellbeing. Failure to address needs resulting from sensory loss will also make it impossible to achieve some of the other statements in this quality standard, particularly statements 1 and 2.</p> <p>We welcome the reference to staff training in the statement. Whilst assessing sensory loss, particularly dual sensory loss, and the appropriate measures to address it is a specialist area. However, training staff to identify possible sensory loss so that they can refer appropriately is relatively straightforward and should be easily achievable by all care homes for older people.</p> <p>In the way it is worded we believe that measuring this statement should be possible, since care plans will demonstrate evidence of assessment of sensory needs and measures taken to address these.</p>	
028	178	Campaign to End Loneliness	QS 3	<p>We are pleased that this quality statement recognises that sensory impairment and loss can result in isolation, and therefore should be prevented or alleviated as far as possible. We support the recommendation to help care home staff make changes as a result of an individual's sensory impairment that will particularly boost mental wellbeing through social contact - such as holding conversations in well-lit areas.</p>	Thank you for your comment.
029	179	OPENSspace Research Centre	QS 3	<p>From our research we know that the built environment can play a large role in the health and wellbeing of an individual, especially where that individual has some sensory deprivation. We would urge those undertaking assessment of needs for those with sensory impairment to be aware of this fact and to include an assessment of the built environment into the care plan for individuals with sensory impairment.</p> <p>See http://www.idgo.ac.uk/useful_resources/Presentations/RNIDGO_KT_EQUAL_Edinburgh_19_March_2010_final.pdf</p>	The QSAC agreed that the focus of the statements on mental health conditions, sensory impairment and physical problems should be changed to recognition and that assessment should be removed from the statements. A new statement has been added regarding access to the full range of healthcare services. It is expected that implementation of the new statement will lead to referrals being made to the most appropriate services and that the issues of assessment and management will be addressed by these services.

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031	180	Parkinson's UK and Lewy Body Society	QS 3	<p>Please insert each new comment in a new row.</p> <p>We are concerned that the wording of quality statement 3 might lead to under-qualified care staff having to take on responsibilities that should be undertaken by health professionals. We would like the quality statement to reflect that the role of care workers in care homes really about 'referral' rather than 'assessment'. The statement should be strengthened to say that older people's needs will be 'met' rather than 'addressed'.</p> <p>DLB can cause functional blindness because of visual disturbances (visuospatial deficits, double vision) and it is important to distinguish between this problem and eye problems, to ensure residents get the most appropriate treatment. Visuo spatial disturbances can mask the symptoms of sight loss, so eye tests are still valuable for residents with PD/PDD/DLB.⁴⁶</p> <p>The resident's assessment should involve a shared approach between their PD/PDD/DLB practitioner and the optician/audiologist.^{47 48}</p> <p>While the loss of sight/hearing clearly adds to the potential for confusion and isolation for a resident with dementia, in the short term correcting an underlying problem is likely to be disorientating too and staff need to pay particular attention to enabling the resident.</p>	<p>Please respond to each comment</p> <p>The QSAC agreed that the focus of the statements on mental health conditions, sensory impairment and physical problems should be changed to recognition and that assessment should be removed from the statements. A new statement has been added regarding access to the full range of healthcare services. It is expected that implementation of the new statement will lead to referrals being made to the most appropriate services and that the issues of assessment and management will be addressed by these services.</p>
032	181	Care Quality Commission	QS 3	<p>The equality and diversity paragraph in statement 3 states: 'It is important that sensory impairment is not considered as normal for older people in care homes.'</p>	<p>The wording of the equality and diversity considerations section for this statement has been updated to state 'expected' feature of ageing rather than 'normal'. The definitions section of the statement has been updated to</p>

⁴⁶ [Online] <http://www.nib.org.uk/livingwithsightloss/otherconditions/Pages/dementia.aspx> Last accessed 1 August 2013

⁴⁷ [Online] <http://www.pocklington-trust.org.uk/Resources/Thomas%20Pocklington/Documents/PDF/Research%20Publications/OP16.pdf> Last accessed 1 August 2013

⁴⁸ [Online] <http://www.alzscot.org/assets/0000/0280/deafnessanddementia.pdf> Last accessed 1 August 2013

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				Please insert each new comment in a new row. The use of the phrase 'normal' is, arguably, not the most appropriate. The important point is not whether sensory impairment is "normal or not normal" but that services take action to mitigate the disabling impact of sensory impairment. This could be through ensuring that individuals have appropriate glasses, hearing aids, etc., or it could be through environmental adaptations, such as colour contrast or it could be through service adaptations, such as ensuring that communication with people with a hearing impairment takes place in areas in the care home with little background noise.	Please respond to each comment make reference to the importance of staff taking action such as cleaning glasses and changing hearing aid batteries.
001	182	Amore Care – Part of the Priory Group	QS 4	Other long term conditions may be referred to here. How we manage co-morbidities alongside dementia is integral to improved quality of care. Pain can be one single factor affecting wellbeing. Being able to read non-verbal communication is essential and responding immediately to changes is paramount. How are staff trained to do this? This is something that Amore has embedded in our Creative Minds program.	The list of physical problems provides examples only. It has now been expanded but is not intended to be an exhaustive list. This is made clear in the wording of the definition of physical problems. It is not within the remit of NICE quality standards to define all aspects of training that will be required in order to achieve the care described by the quality statement.
001	183	Amore Care – Part of the Priory Group	QS 4	For people in care homes without a diagnosis of dementia, some reference to how long term conditions such as diabetes can place people at higher risk of dementia should be made. How this condition is managed can have a huge impact in the medium to longer terms.	The QSAC did not consider it appropriate to include specific reference to the links between long term conditions and dementia in this statement. The equality and diversity considerations section of this statement highlights the needs of groups such as people with dementia. NICE has produced two quality standards specifically addressing the topic of dementia. These are: Dementia (quality standard 1); and Supporting people to live well with dementia (quality standard 30).
001	184	Amore Care – Part of the Priory Group	QS 4	Best practice at end of life should be included. Again, knowing whether the person has made an Advanced Plan stating their wishes is vital to providing the person with 'A Good Death'.	The QSAC did not consider it appropriate to include specific detail about end of life care within the statement. Additional text has been added to the equality and diversity considerations section for each statement regarding end of life care. The text highlights the importance of the needs and preferences of people who are approaching the end of their life. The End of life care quality standard is comprehensive, cross cutting and applicable across all settings. This quality standard has been added to the <i>Related Quality Standards</i> section.

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002	185	Nottinghamshire Healthcare NHS Trust	QS 4	Emphasis needs to be made on partnership working with health care providers, secondary and primary health to determine if assessment has been made or to ensure they are in the future	The QSAC agreed that the focus of the statements on mental health conditions, sensory impairment and physical problems should be changed to recognition and that assessment should be removed from the statements. A new statement has been added regarding access to the full range of healthcare services. It is expected that implementation of the new statement will lead to referrals being made to the most appropriate services and that the issues of assessment and management will be addressed by these services. The measures in these statements make reference to referral arrangements.
008	186	English Community Care Association	QS 4	This statement could be enhanced by being specific about physical health issues or functional health needs. Physical problems could relate to environment for example and is misleading. The evidence of training and recording attendance in itself do not provide evidence of intervention, impact and outcome on resident wellbeing. This needs to be captured to track evidence that intervention has occurred and wellbeing enhanced.	The QSAC were happy that the use of the term 'physical problems' was clear and therefore did not make any amendments to it. The QSAC agreed that the focus of the statements on mental health conditions, sensory impairment and physical problems should be changed to recognition and that assessment should be removed from the statements. The measures for these statements have been updated in line with the new focus.
009	187	College of Occupational Therapists	QS 4	The statement and the structure are slightly ambiguous. Suggestion: Structure: a) Evidence of protocols to ensure that staff are trained to recognise and identify physical problems and the needs of these older people are recorded in care plans. Data Source: Local data collection Evidence of falls prevention assessments and care plans in place, personalised risk management plans. Evidence of referrals and working with multi disciplinary teams for reablement.	Structure measure for this statement has been reworded in order to remove any ambiguity. The measures included are those considered to be appropriate, measureable and specifically attributable to the action stated in the statement.
011	188	British Geriatrics Society	QS 4	Those identifying standards need to be mindful of the evidence in quest for quality that most PCTs (as were) are not meaningfully commissioning services for care homes and thus there are real barriers to the identification of and action on sensory or physical health issues for care home residents.	It is not within the remit of quality standards to comment specifically on contracts developed by commissioners. The measures included are those considered to be appropriate, measureable and specifically attributable to the action stated in the statement. The NICE Support for

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				<p>The guide should recommend measurement of commissioners' contracts with specific regard to care homes for provision of NHS services for this population. It is essential that contracts for services to people in care homes contain a response time so that a "waiting list" is not allowed to develop (which in some cases in the work which was done as part of the evidence building for Quest for Quality was longer than the average life expectancy for a care home resident).</p> <p>They should have regard to the building evidence that proactive care from primary care (supported where necessary by specialists in medical and care of older people) can support residents more effectively, identify and appropriately manage sensory and physical health problems and avoid some acute hospital admissions (which clearly impacts very directly on quality of life and mental health)</p>	Commissioning document that will be published alongside the quality standard may make suggestions about how commissioners may want to work with other organisations.
012	189	British Association of Behavioural and Cognitive Psychotherapies	QS 4	<p>There is a lack of clarity here as to whether it is the physical problem that needs to be identified and recorded, as opposed to the person's needs in relation to physical problems. There are two issues here: if the person has a physical problem, they should receive a proper assessment, diagnosis and treatment; if there are needs arising, these should be met. There is a lack of emphasis on identifying conditions underlying physical problems and intervening, as opposed to arranging care around the physical limitation. Again the NHS Constitution is cited, but the reasons for this being an issue could benefit from being properly addressed.</p> <p>The interplay of physical health and mental well-being, and the role of psychological processes in adjustment to, coping with physical health problems would benefit from development here. Person-centred care requires working with the person on their understanding and appraisal of their condition, and how they can cope with its effects.</p> <p>In the context of severe dementia, it is well-established that inadequately treated pain is a major factor in 'agitation', and greater use of observational scales which pick up the non-verbal features of pain in people with limited communication ability is recommended.</p>	The QSAC agreed that the focus of the statements on mental health conditions, sensory impairment and physical problems should be changed to recognition and that assessment should be removed from the statements. The measures for this quality statement have been amended to ensure it is clear that the physical problem is what needs to be recognised rather than the needs arising from the physical problem. A new statement has been added regarding access to the full range of healthcare services. It is expected that implementation of the new statement will lead to referrals being made to the most appropriate services and that the issues of assessment, diagnosis and treatment will be addressed by these services.
013	190	Marie Curie Cancer Care	QS 4	I am pleased to be able to respond to the NICE quality standard	The QSAC did not consider it appropriate to include

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				<p>on the mental wellbeing of older people in care homes on behalf of Marie Curie Cancer Care. Marie Curie is a charitable provider of care to terminally ill people and their families and carers. We provide our care to people in their own homes and in our nine hospices across the UK. Through the Marie Curie Nursing Service (MCNS), we also provide care to patients in residential and nursing care homes.</p> <p>We welcome the NICE quality standard on the mental wellbeing of older people in care homes, but think it should better reflect that the majority of older people in care homes are approaching the end of their lives. In a 2011 report on the length of stay in care homes, half of residents from a sample of 305 Bupa care homes died within 462 days of first moving to their care home .</p> <p>Being able to prepare, plan, and record their wishes for the end of life is important to the mental wellbeing and peace of mind of older people. Many people who live in care homes will also wish to die there, because they see it as their home, and it is therefore essential that they are able to discuss their wishes and preferences for care at the end of life with care home staff.</p> <p>We would suggest that NICE broadens Quality Statement 4, which deals with care plans for physical problems, to deal not just with care plans that record a patient’s current physical problems, but also their preferences for care for when their physical condition deteriorates and for when they approach the end of life. This part of the mental wellbeing of older people in care homes quality standard should fully reflect the statement three of the end of life care quality standard, which states that:</p> <p>People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.</p> <p>We are keen to work closely with NICE in the development of</p>	<p>specific detail about end of life care within the statement. Additional text has been added to the equality and diversity considerations section for each statement regarding end of life care. The text highlights the importance of the needs and preferences of people who are approaching the end of their life. The End of life care quality standard is comprehensive, cross cutting and applicable across all settings. This quality standard has been added to the Related Quality Standards section.</p> <p>Thank you for the information you have provided and for the offer of working with NICE. Whilst we appreciate this offer we must follow a structured process and timeline when developing quality standards and therefore are unable to have discussions with you at this stage in the process.</p> <p>Please note the forward planner for NICE quality standards that is available to view on the NICE website. This document provides information on topics planned for development as quality standards including the date of engagement and consultation exercises which enable you to provide comments on individual topics. Please also see the NICE website for more detail about how you can get involved.</p>

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				the quality standard on the mental wellbeing of older people in care homes in order to ensure that it includes a focus on end of life care, and would be pleased to share more about our work with terminally ill people in care homes.	
015	191	The National LGB&T Partnership and The Lesbian & Gay Foundation	QS 4	All data sources specified should collect demographic monitoring data, including sexual orientation and gender identity, in order to assess the needs and experiences of LGB&T people.	It is expected that the specific data collected will be decided at a local level.
016	192	Social Care Institute for Excellence	QS 4	The draft Guide notes the impact of existing long-term conditions on the physical and mental health and intellectual capacity of older people, which needs to be understood in arrangements for access to health care assessment and treatment	Thank you for your comment. The SCIE guide on access to health services for older people in care homes has been added as source guidance for the quality standard.
017	193	St Christopher's Hospice	QS 4	Statement 4 – older people have their specific physical problems identified ASSESSED, recorded and MANAGED	The QSAC agreed that the focus of the statements on mental health conditions, sensory impairment and physical problems should be changed to recognition and that assessment should be removed from the statements. A new statement has been added regarding access to the full range of healthcare services. It is expected that implementation of the new statement will lead to referrals being made to the most appropriate services and that the issues of assessment and management will be addressed by these services.
017	194	St Christopher's Hospice	QS 4	Not enough to be trained to be aware of and recognise need to ALSO assess the physical problems	The QSAC agreed that the focus of the statements on mental health conditions, sensory impairment and physical problems should be changed to recognition and that assessment should be removed from the statements. A new statement has been added regarding access to the full range of healthcare services. It is expected that implementation of the new statement will lead to referrals being made to the most appropriate services and that the issues of assessment and management will be addressed by these services.
019	195	Research into Practice for Adults	QS 4	B: Access to services The importance of access to services is highlighted in Standard 3, which refers to assessment, recording a need and then addressing it. However, Standard 2 only highlights assessment	The QSAC agreed that the focus of the statements on mental health conditions, sensory impairment and physical problems should be changed to recognition and that assessment should be removed from the statements. A new statement has been added regarding access to the full

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				Please insert each new comment in a new row. and Standard 4 only highlights the identification and recording of problems. Each of these standards needs to reflect the framework in Standard 3, where “addressing” the difficulty is emphasised. These standards could then include more specific discussion of how needs are addressed, referencing the need for interventions to be evidence-informed and timely.	Please respond to each comment range of healthcare services. It is expected that implementation of the new statement will lead to referrals being made to the most appropriate services and that the issues of assessment and management will be addressed by these services.
019	196	Research into Practice for Adults	QS 4	C: Impact of physical conditions While standards 3 and 4 address this to some extent, it is unclear from the standards that staff should be trained in responding to and understanding the impact of specific physical conditions. Understanding the impact of specific conditions will enable staff to meet needs effectively through considering the appropriateness of their own practice, enabling empathic and compassionate care. It would also support staff to understand and recognise the impact of one person’s condition on their peers within a Care Home setting.	The QSAC agreed that the focus of the statements on mental health conditions, sensory impairment and physical problems should be changed to recognition and that assessment should be removed from the statements. It is also not within the remit of NICE quality standards to define all aspects of training that will be required in order to achieve the care described by the quality statement.
029	197	OPENspace Research Centre	QS 4	We have no comment to make on this statement.	Thank you for your response.
030	198	SCA Hygiene Products UK LTD	QS 4	SCA welcomes the inclusion of incontinence within Quality statement 4: Identification of physical conditions as a key priority for helping care homes support the mental wellbeing of vulnerable older people. The Quality Standard correctly recognises that incontinence is a serious condition that can affect older peoples’ mental as well as physical wellbeing in care homes. Incontinence numbers are highly concentrated in care settings and the National Audit of Continence Care has suggested that up to 71% of patients in nursing homes are incontinent but nearly a third of care homes said that the impact of symptoms on quality of life had not been recorded. This Quality Standard is particularly welcome when it is considered that only 15% of individuals entering a care home are given a rectal exam, despite this being an essential assessment for diagnosing for assessing faecal incontinence. SCA agrees that incontinence can not only cause physical	Thank you for your comments.

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				discomfort and seriously impact on an individuals' health but also undermine individuals' mental wellbeing. A failure to address continence issues with patient-centered care undermines individuals' independence and dignity, leading to emotional problems such as low self-esteem and depression. SCA believe that high quality continence care should take a patient-centered approach, tailored around the continence needs of the individual. Quality Statement 4 is therefore a welcome Standard to ensure that all care home residents are assessed for continence issues and supporting patient-centered care that protects residents' physical and mental wellbeing	
030	199	SCA Hygiene Products UK LTD	QS 4	<p>SCA recommends that Quality Statement 4 should also ensure that physical issues be adequately 'addressed' by clinical staff further to their identification. As such, 'be addressed' should be inserted through Quality Statement 4, in the same way that it is currently used in Quality Standard 3.</p> <p>Training standards for the care of physical conditions, and continence care in particular is highly variable, despite being a core function of care home staff. Even when clinical staff do record physical conditions in an individuals' care plan, too often continence care merely seeks to manage incontinence with one-size-fits-all care solutions rather than addressing a patients' particular needs. The result is that continence care limits independent living, and reduces quality of life.</p> <p>In contrast, SCA supports a patient-centered care approach with intelligent care programmes that respond to individuals' case histories and personal needs. Promoting continence with individual toileting plans can lead to greater independence and restore confidence in the individuals' ability to self-manage their condition with appropriate products. Focussing on continence promotion using an intelligent care model also improves residents' dignity and independence, by reducing the number of intrusive interventions that are required. In this way, care home staff can support positive mental wellbeing through the improvement, rather than mere maintenance and management of the physical condition, without the need for referral.</p> <p>Studies have also shown that patient-centered care is more cost effective, reducing costs by up to 30% through savings in staff</p>	The QSAC agreed that the focus of the statements on mental health conditions, sensory impairment and physical problems should be changed to recognition and that assessment should be removed from the statements. A new statement has been added regarding access to the full range of healthcare services. It is expected that implementation of the new statement will lead to referrals being made to the most appropriate services and that the issues of assessment and management will be addressed by these services.

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				<p>time and resources. This enables greater staff time to be spent directly on patient wellbeing and is especially important given the current strain on resources in the care support system. A Quality Statement for physical problems should therefore make clear that care home staff should not only identify physical problems as a fixed issue but ensure that staff know to address the physical condition directly, when appropriate, to ensure that positive improvements are made. In this way, it is essential that trained staff assess older people in care for physical conditions on an ongoing basis and take steps to address these needs directly. In this way, care home staff can support the improvement of mental wellbeing in the same way set out in Quality Statement 3.</p>	
031	200	Parkinson's UK and Lewy Body Society	QS 4	<p>The quality statement should be strengthened along the lines of: 'Older people in care homes have their specific physical problems identified, as they change over time, recorded in a care plan that is kept up to date and met through access to community and specialist healthcare services'</p> <p style="padding-left: 40px;">"Once every nine months, a nurse updates his care plan frantically at the last minute. She brings his care plan up-to-date by asking me or looking at other people's absolutely frugal notes that tell you nothing about him."</p> <p style="padding-left: 40px;">"All the residents had quite complex needs but there was a good proportion of registered nurses, not just a token one or two. They gave him his medication well and were able to manage his Parkinson's. They encouraged him to move about even if it was a case that he might fall over and they tried to encourage him to eat independently. The staff were all well trained."</p> <p>We have already noted the complex combination of symptoms affecting the care home population who have a Lewy body disorder and the fact that symptoms will change and worsen over time as a result of neurodegeneration. Whilst care homes have historically been disadvantaged in terms of their access to the full range of NHS-funded health services, particularly podiatry, dentistry, dietetics, specialist medicine and specialist</p>	<p>The QSAC agreed that the focus of the statements on mental health conditions, sensory impairment and physical problems should be changed to recognition and that assessment should be removed from the statements. A new statement has been added regarding access to the full range of healthcare services. It is expected that implementation of the new statement will lead to referrals being made to the most appropriate services and that the issues of assessment and management will be addressed by these services.</p> <p>Managing medicines in care homes is in the core library of quality standards planned for development. Therefore, it was not appropriate to develop a statement in this area as it will be addressed by the quality standard on this topic.</p>

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				<p>nursing, it is vital for the physical care of people with PD/PDD/DLB that they have timely and sufficient access to the healthcare professionals they need to see. Commissioners of health services must ensure that care home residents have equal access to healthcare services as those living in the community.</p> <p>Care assessment and planning must be conducted between health and care services, and should include regular review. The work of all the healthcare specialisms should be co-ordinated and knowledge shared. Care home staff need to fulfil their duty of care to look out for changes in the resident's condition, record them and respond appropriately, by raising concerns with healthcare colleagues. When health practitioners change a resident's treatment regime, the care staff should act accordingly. ⁴⁹ ⁵⁰</p> <p>OTs brought stuff in but the care staff didn't use it.</p> <p>"The doctor changed Mum's Parkinson's drug which gave her involuntary movements so severe she fell out of bed onto the floor.</p> <p>The nurses and carers ignored this and just said, 'It's what's written up for her, it's not for us to question.' How are they monitoring changes in medication?"</p> <p>Medicines management Effective medicines management is of critical importance to people with Parkinson's. If they do not get their medication on time, their ability to manage their symptoms may be lost. For example they may suddenly not be able to move, get out of bed or walk down a corridor. In the complex advanced stages of the illness, medicines management may be particularly complex,</p>	

⁴⁹ Nursing Standard (2009) Living well with dementia in a care home: a guide to implementing the National Dementia Strategy

⁵⁰ My Home Life (2007) *Quality of Life in Care Homes. A Review of the Literature*. Help the Aged, London.

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				<p>especially if the person with Parkinson's has several other health conditions.⁵¹</p> <p>Nutrition The progressive nature of dementia, with its significant changes in daily living activities, behaviour, appetite and eating habits, can put people living with dementia at an increased risk of physical health problems and mean they become increasingly dependent on health services and care staff.⁵²</p> <p>Swallowing and choking problems are common in advanced Parkinson's and people with Lewy body dementia can lose of recognition of what food is and how to eat it, so staff need to be particularly supportive in maintaining good nutrition and hydration.</p> <p>Falls The incidence of falls in advanced Parkinson's is high, even when patients are optimally medicated. Falls lead to injuries and fracture that further reduce independence. Patients with previous falls often develop fear of falling which further limits their mobility, contributing to increased weakness and deterioration. The design of the home should reduce gait and trip hazards and staff should be trained in enabling residents with Parkinson's to move when 'frozen', turn safely and make safe transitions from different positions. ⁵³</p> <p>Pain Pain is under-recognised in dementia care. Typically, on nursing</p>	

⁵¹ [Online] <http://www.parkinsons.org.uk/content/transcript-get-it-time-medicine-management-residents-parkinsons> [last accessed 31 July 2013]

⁵² Four Seasons Health Care (2013). *PEARL specialised dementia service: phase 2 report*. Wilmslow: Four Seasons Health Care

⁵³ Varanese S, Birnbaum Z, Rossi R and Di Rocco A (2010) Treatment of Parkinson's Disease *Parkinsons Dis.* 2010: 480260 Published online 2011 February 7. doi: [10.4061/2010/480260](https://doi.org/10.4061/2010/480260)

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				<p>Please insert each new comment in a new row.</p> <p>units, 40 per cent of residents are taking analgesic medication. By contrast on typical dementia units, with a similar population profile, 0-10 per cent of residents are taking analgesics.⁵⁴</p> <p>Residents with DLB or PD may not be able to express their need for pain relief in words and their pain-related distress may be attributed to another cause. Pain is positively correlated with aggression and agitation, so effective pain management may help to reduce these distress reactions and promote mobility in people with dementia.⁵⁵</p> <p>“At Christmas, the GP wanted to put Mum on mogadon and an antipsychotic because she was pulling faces. He thought she was hallucinating. But she wouldn’t want her mouth opened, so I thought she had toothache. It turned out she was in pain and needed a dentist.”</p> <p>Physiotherapy Physiotherapists with PD expertise can provide specific interventions, such as cueing strategies to overcome freezing of gait. Care home residents with dementia and impaired mobility often have limited access to physical therapies, despite the potential benefits. Several clinical trials have suggested that physiotherapy might substantially enhance both motor performance and quality of life (Keus, Munneke et al. 2009). .⁵⁶ 57</p>	<p>Please respond to each comment</p>

⁵⁴ Four Seasons Health Care (2013). *PEARL specialised dementia service: phase 2 report*. Wilmslow: Four Seasons Health Care

⁵⁵ Ahn H, Horgas A (2013) The relationship between pain and disruptive behaviors in nursing home residents with dementia. *BMC Geriatrics*, Vol.13(14), pp.1-7

⁵⁶ LLeemrijse CJ, de Boer ME, et al. (2007). Factors associated with physiotherapy provision in a population of elderly nursing home residents; a cross sectional study. *BMC Geriatr* 7:7

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032	201	Care Quality Commission	QS 4	The use of the phrase 'physical problems' seems a little unusual, given the list of issues given in this statement as examples. Consideration could be given to using 'physical health issues', unless there has already been discussion on terminology and a consensus agreed with the use of 'physical problems'. Another very common example which could be added to the list provided, of things which may affect a person's mental wellbeing, is urinary tract infection.	The QSAC agreed that the 'physical problems' is the most appropriate phrasing for this statement. Urinary tract infection has been added to the list of examples of physical problems.
026	202	Royal College of Nursing	QS 4	The list of physical problems seems to be limited. We also think that the need to ensure comfort and pain control should be included. There is also nothing about end of life care?	The list of physical problems provides examples only. It has now been expanded but is not intended to be an exhaustive list. This is made clear in the wording of the definition of physical problems. Additional text has been added to the equality and diversity considerations section for each statement regarding end of life care. The text highlights the importance of the needs and preferences of people who are approaching the end of their life. The End of life care quality standard is comprehensive, cross cutting and applicable across all settings. This quality standard has been added to the <i>Related Quality Standards</i> section.
001	203	Amore Care – Part of the Priory Group	QS 5	Clearer detail her about the person with dementia waking up each day with a purpose, feeling valued, having a sense of belonging and increasing their self esteem and feeling of worth must be the key aim to holding on to personal identity.	The wording of the definition has been amended to include reference to having a purpose in life, feeling valued, having a sense of belonging and feeling of worth.
001	204	Amore Care – Part of the Priory Group	QS 5	Creating a dementia friendly environment will also support identity. Contrasting colours to support 3D images, having choice of door colour and being supported to develop something that identifies the person room to them. Clear signage with route finding and way marking will support independence in orientating around the care home. Reference to the Kings Fund and Dementia Services Development Centre at	The Mental wellbeing of older people in care homes quality standard addresses a wider population than people who have dementia. Therefore, the QSAC did not consider it appropriate to include specific reference to dementia in this statement. NICE has produced two quality standards specifically addressing the topic of dementia. These are: Dementia (quality standard 1); and Supporting people to

⁵⁷ Keus SH, Munneke M, Nijkrake MJ, Kwakkel G, Bloem BR. (2009) Physical therapy in Parkinson's disease: evolution and future challenges *Mov Disord.* Jan 15;24(1):1-14

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				Please insert each new comment in a new row. the University of Stirling would be helpful.	Please respond to each comment live well with dementia (quality standard 30).
003	205	Dementia Pathfinders Community Interest Company	QS 5	Linked with the above comment, being part of the local community is also beneficial to mental health and wellbeing, but does not receive detailed mention – this again could be covered in statements 1 and 5.	The QSAC agreed that the quality standard required a stronger focus on being part of the local community. The statements on meaningful activity and personal identity have been amended to ensure that social inclusion, links with the community and relationships have been adequately addressed.
004	206	Alzheimer's Society	QS 5	General Alzheimer's Society welcomes this quality statement as recognition of the vital role of choice in care. Alzheimer's Society's report Home from home (Alzheimer's Society, 2008) found that people with dementia were often not given a choice over their day-to-day lives, such as when to have a drink, what to wear or when to go to bed. In a survey for Dementia 2013 (Alzheimer's Society, 2013b) 52% of people with dementia living in care homes reported that they did not have a choice about their day-to-day life. A significant proportion of people with dementia living in care homes who responded to the survey reported feeling lonely and they even reported feeling anxious or depressed. Care homes should be encouraged to use tools, such Alzheimer's Society's This is me booklet, which support staff to deliver personalised care.	Thank you for your comment. The introduction of the quality standard has been updated to include reference to the findings of the Alzheimer's Society report Home from Home.
004	207	Alzheimer's Society	QS 5	Outcome Alzheimer's Society recognises the importance of feedback from older people in care homes on whether they have been enabled to maintain and develop their personal identity. When collecting data on this, the needs of people in the later stages of dementia who may have difficulties with communicating must be considered.	Text has been added to the Equality and diversity considerations sections of the statements on meaningful activity and personal identity suggesting that tools such as Dementia Care Mapping should be used to capture the experiences of people who find it difficult to provide feedback.
006	208	Empowerment Matters	QS 5	Quality statements These generally capture the key areas for quality improvement but in our view there are some omissions that need to be considered. Statement 4 is not clear. Does this mean 'physical' in the sense of disability or does it mean 'health' issues? If it means the former, then enabling older people to maintain physical health is	The definition of mental wellbeing has been updated to include reference to independence. The QSAC agreed that a separate statement about independence was not required. The issue of independence has been addressed in the statement on personal identity by adding reference to the involvement of older people in decision making to the rationale section. The definitions section of this

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				<p>Please insert each new comment in a new row.</p> <p>missing and vice versa. If it is about physical health it needs to say more about enabling older people to access healthcare services.</p> <p>Statement 5 – Could ‘maintain and develop their identity’ also include ‘independence’? Or perhaps this needs a separate quality statement to deal with enabling older people to maintain a level of independence. We feel this is important because often in care homes everything is done ‘to’ or ‘for’ older people without considering how the older person can be supported to do things for themselves which could impact significantly on their mental wellbeing.</p> <p>The independence aspect could be linked to choice and control and is also about people having the opportunity to express their views. If you live in an environment where nobody asks you what you think about things or takes time to find out what you choose and then acts upon what you say not only is it very disempowering but the effect on mental wellbeing is potentially very significant.</p>	<p>Please respond to each comment</p> <p>statement has also been updated to give examples of how older people can exercise choice and control and therefore maintain their independence.</p>
006	209	Empowerment Matters	QS 5	<p>Personal identity</p> <p>It is important that older people have a ‘voice’ and are supported and enabled to express who they are, want they want and to make their own decisions and choices wherever possible. Could something to this effect be included in the Rationale section?</p> <p>There needs to be something in this section about supporting older people in care homes to express what is important to them and about care staff taking action to explore and understand the uniqueness of every individual.</p>	The wording of the rationale has been amended to convey what is being said in the suggested wording.
007	210	Life Story Network CiC	QS 5	The way in which the quality statement is articulated is positive in that it emphasises that that the individual not only is enabled to maintain their identity but also develop it; they have a present and a future, not just a past.	Thank you for your comments.
007	211	Life Story Network CiC	QS 5	Whilst retaining control and choice is a necessary aspect of part of describing / defining personal identity; it is not sufficient. A greater emphasis needs to be placed on the importance of identify in the context of positive and meaningful relationships.	A greater emphasis has been placed on relationships in this statement.
007	212	Life Story Network CiC	QS 5	Definition of ‘Enabled’ - Whilst we agree with the definition and the emphasis on using life story approaches to facilitate social	The QSAC agreed that the quality standard required a stronger focus on social inclusion throughout the

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				inclusion, our learning from the DH funded 'Your Community Matters' programme indicates that this remains a challenge for many care homes given the staffing levels, austerity measures and current dependency levels. More innovative and creative approaches are required to promote and facilitate social inclusion, including working in partnership with family carers, friends and volunteers, seeing them as a conduit to the wider community.	document. The quality standard has been amended to ensure that social inclusion, involvement of family, friends and carers and links with the community have been adequately addressed. A link to the College of Occupational Therapists (2013) Living well through activity in care homes: the toolkit has been added to the <i>Definitions and data sources for the quality measures</i> section. This provides suggestions for what care home staff can do in terms of offering the opportunity for activity to older people if they have very little or no spare time.
007	213	Life Story Network CiC	QS 5	Definition of 'Personal identity' - Whilst the definition is taken from the 'personalisation' agenda, there is a need to ensure and emphasise the importance of enabling the person's identity to be seen in the context of their relationship with others, including family, friends, colleagues, staff and other residents in the care home.	The QSAC agreed that a greater emphasis on relationships was required in the quality standard. The statement on personal identity has been updated to include greater emphasis on the importance of social inclusion, involvement with the community and the development and maintenance of relationships.
007	214	Life Story Network CiC	QS 5	Equality and diversity section - The need for affection, intimacy and relationships for people in care homes has too often been ignored and side-lined in policy and practice. The focus should not only be on 'identifying the specific needs of older people arising from diversity, including gender, sexuality, spirituality, culture, age and religion', these are integral and core to one's identity and as such should be explored, promoted and celebrated within a relational approach to identify and well being. Within this context, individuals should be offered opportunities to live the lifestyle that supports and reinforces their identity and relationships. http://www.ilcuk.org.uk/index.php/publications/publication_details/the_last_taboo_a_guide_to_dementia_sexuality_intimacy_and_sexual_behaviour	The QSAC agreed that a greater emphasis on relationships was required in the quality standard. The statement on personal identity has been updated to include greater emphasis on the importance of social inclusion, involvement with the community and the development and maintenance of relationships. It was not considered necessary to make specific reference to relationships within the equality and diversity considerations section.
008	215	English Community Care Association	QS 5	How can residents who are unable to express themselves verbally be captured in the proposed outcome? There needs to be throughout an ability to capture local data which reflects the carers or families knowledge of the person in such cases. Use of life story work in identifying past history and personal life journey could be linked to care plans as well as observational	Text has been added to the Equality and diversity considerations sections of the statements about meaningful activity and personal identity suggesting that tools such as Dementia Care Mapping and feedback from people considered suitable to represent the views of the older person should be used to capture the experiences of

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				Please insert each new comment in a new row. recording that residents daily routines and preferences are adhered to.	Please respond to each comment people who find it difficult to provide feedback.
009	216	College of Occupational Therapists	QS 5	This statement could be stronger and mention dignity – this is a huge issue in care. Enabled definition – We would like to see something in there about ‘human interactions’. Outcome- every resident has a life history highlighting interests, personal preferences, likes and dislikes, sexual orientation, beliefs, etc.	The rationale for this statement has been updated to include reference to dignity. The definition of enabled has been updated to give greater emphasis to social inclusion and relationships, The NICE quality standard contains the measures that are considered most relevant and appropriate for each statement. It is expected that decisions about what specific evidence is collected will be made at a local level.
012	217	British Association of Behavioural and Cognitive Psychotherapies	QS 5	Control and choice are important in personal identity, but are not the only aspects that should be considered. Relationships and interactions are also crucial. The physical environment (privacy, own space, possessions) is also relevant.	The QSAC agreed that a greater emphasis on relationships was required in the quality standard. The statement on personal identity has been updated to include greater emphasis on the importance of social inclusion, involvement with the community and the development and maintenance of relationships. The definitions section has been updated to include reference to adapting the older person’s environment.
012	218	British Association of Behavioural and Cognitive Psychotherapies	QS 5	‘Enabled’ should reference evidence-based life review approaches, which have been shown to be also helpful in the context of dementia (Subramaniam, P., & Woods, B. (2012). The impact of individual reminiscence therapy for people with dementia: systematic review. Expert Reviews in Neurotherapeutics, 12 (5), 545-555.) Older people in care homes are likely to benefit from a therapeutic relationship which assists them in constructing their life story, or, if dementia is more severe, family members may well be in a good position to produce a life story book for the person.	It is expected that approaches to achieving the care outlined in the quality statement will be decided locally. The Mental wellbeing of older people in care homes quality standard addresses a wider population than people who have dementia. NICE has produced two quality standards specifically addressing the topic of dementia. These are: Dementia (quality standard 1); and Supporting people to live well with dementia (quality standard 30).
012	219	British Association of Behavioural and Cognitive Psychotherapies	QS 5	Interestingly cognitive impairment does not feature in the ‘Equality and diversity considerations’ for this statement, although it is dementia that perhaps poses the greatest threat to personal identity in this context. Staff need skills and competence to recognize and support personal identity, and work with the person’s family and friends to uphold it.	Thank you for your comment. Cognitive impairment has been added to the Equality and diversity considerations section of this statement.
015	220	The National LGB&T Partnership and The Lesbian & Gay	QS 5	We are pleased to note that the Equality & Diversity Considerations includes reference to sexuality, however, gender identity must be added to the list of equality groups which may	Gender identity is now referenced under the Equality and diversity considerations section. All groups, including lesbian, gay, bisexual and transgender groups, are included

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		Foundation		Please insert each new comment in a new row. lead to the specific needs of older people. Gender identity and sexual orientation are both protected characteristics under the Equality Act 2010 and as such all public sector organisations should be paying due regard to them. It is still extremely helpful however for guidance such as NICE Quality Standards to specify inclusion of all equalities groups. The needs of trans older people (those whose gender identity now is different to the gender identity they were assigned at birth) and of lesbian, gay and bisexual older people, often remain invisible and both groups are at risk of discrimination and homo-, bi- and transphobia. It is important to recognise that while lesbian, gay, bisexual and trans (LGB&T) groups may share similar fears about coming out and being at risk of discrimination in a care home environment, the needs of these groups are distinct. We would like to see a strengthening of the E&D Considerations to include supporting LGB&T people (and indeed, all those with protected characteristics) to maintain and develop their personal identity in a way which positively reinforces their LGB&T identities.	Please respond to each comment under the Equality and diversity considerations section. It is felt that sufficient emphasis is given to the equality groups identified.
015	221	The National LGB&T Partnership and The Lesbian & Gay Foundation	QS 5	All data sources specified should collect demographic monitoring data, including sexual orientation and gender identity, in order to assess the needs and experiences of LGB&T people.	It is expected that the specific data collected will be decided at a local level.
017	222	St Christopher's Hospice	QS 5	Evidence of meaningful activity provided and time attended throughout the day	The NICE quality standard contains the measures that are considered most relevant and appropriate for each statement. It is expected that decisions about what specific evidence is collected will be made at a local level.
019	223	Research into Practice for Adults	QS 5	D: Individualised Care While this area for improvement is implicit throughout discussion on each of the standards, it could be emphasised more clearly. This is particularly relevant to the provision of 'meaningful activity' (where the activity should be based around what is meaningful to the person) and interventions in relation to mental health, sensory impairment and physical problems. In addition, individualised care should be a core component of Standard 5 and the maintenance of personal identity.	The quality standard has been updated to include a greater emphasis on social inclusion, links with the community and relationships. The emphasis on individualised care is considered to be addressed adequately throughout the quality standard. The rationale section of the statement on personal identity has been updated to emphasise the older person's involvement in decision making.

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019	224	Research into Practice for Adults	QS 5	<p>E: Personal Identity</p> <p>This is clearly stated in Standard 5. However, the discussion in relation to this standard oversimplifies personal identity, summarising it as individual choice and control while failing to recognise the importance of a 'view of life' built up over time (Westius et al. 2007) containing central values (Hitlin 2003). It also ignores the social construction of identity, where "close relationships...have a primary place in validating personal identity" (Day 1985: 495).</p> <p>It is therefore recommended that the discussion on personal identity clearly refers to these aspects.</p> <p>harnett t [PubMed] [Google Scholar]</p> <p>jönson h [PubMed] [Google Scholar]</p>	<p>The definition of personal identity has been expanded to include greater emphasis on relationships, feelings of worth and having a purpose in life.</p>
020	225	Royal College of Psychiatrists	QS 5	<p>Some outcome measures are clearly unachievable e.g. Standard 5. The outcome measure is "feedback from older people in care homes that they feel they have a sense of personal identity". This would be difficult to implement when a majority of residents lack mental capacity. Behavioural measures could be used but they are also unreliable.</p>	<p>Text has been added to the Equality and diversity considerations sections of the statements about meaningful activity and personal identity suggesting that tools such as Dementia Care Mapping and feedback from people considered suitable to represent the views of the older person should be used to capture the experiences of people who find it difficult to provide feedback.</p>
028	226	Campaign to End Loneliness	QS 5	<p>Definition of 'enabled' - We agree that staff in care homes facilitating social inclusion by promoting and supporting access to social networks will have a positive impact on both identity and mental wellbeing. Although there is insufficient research into this area, links can be drawn between loss and loneliness for people in residential care, as well as living in their own homes or supported living. Lonely individuals are more likely to focus on loss and lack confidence (Kirkevold et al, 2013). Therefore, care homes should ensure that their residents are enabled to maintain links with social networks they had outside</p>	<p>The QSAC agreed that the quality standard required a stronger focus on relationships throughout the document. The definition of enabled has been amended to ensure that social inclusion, links with the community and relationships have been adequately addressed.</p>

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				Please insert each new comment in a new row. the care home, including friends and family but also other community groups or structures, e.g. faith or interest-based groups.	Please respond to each comment
029	227	OPENSspace Research Centre	QS 5	Personal identity can be strongly related to place and activities associated with such places. For many people, being able to garden and to personalise a part of the garden space they have access to is an important part of their identity. This should be considered in the design and management of care home outdoor spaces. See http://www.idgo.ac.uk/useful_resources/Presentations/LMIDG_O_KT_EQUAL_Edinburgh_19_March_2010.pdf	The definitions section of the quality statement on personal identity has been amended to include reference to using outdoor spaces. It is not within the scope of the quality standard to comment on the design of care homes.
031	228	Parkinson's UK and Lewy Body Society	QS 5	The best practice in enabling the wider care home population, including people with dementia, to maintain and develop their personal identity applies to residents with PD, PDD and DLB.	Thank you for your comment.
032	229	Care Quality Commission	QS 5	Suggestion for additional statement or amendments made to existing statements 1&5 - 'older people in care homes are supported to maintain and develop relationships of importance to them'. This is not really covered explicitly by 'meaningful activities' or 'developing personal identity' but either of these current key areas could potentially be reworded to make this more explicit. The definition of 'meaningful activities' is more task/activity related than relationship related but most people get as much, if not more, meaning and sense of wellbeing from human relationships than 'activities'. Similarly, the 'personal identity' statement talks about 'social networks' but not meaningful relationships with other individuals. This means that care homes could mistakenly think that they are fulfilling this through enabling people to access shared social networks for everyone living in the care home, rather than maintaining the important relationships that people had before they moved into the care home.	The quality standard has been amended to include a greater focus on the importance of existing and new relationships.
032	230	Care Quality Commission	QS 5	We welcome that maintaining personal identity is a quality statement in its own right, because it is so important to people's	The Equality and diversity considerations section has been updated to include gender identity. It is expected that

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				<p>Please insert each new comment in a new row.</p> <p>wellbeing. To strengthen this further, the current equality and diversity considerations could be reworded from:</p> <p>‘Care home staff should identify the specific needs of older people arising from diversity, including gender, sexuality, ethnicity, spirituality, culture, age and religion’ – to – ‘Health and social care services and staff should identify and address the specific and diverse needs in relation to maintaining and developing the personal identity of older people arising from their gender, sexual orientation, ethnicity, age, and religion and belief disability and gender identity’.</p> <p>An additional point could be added about discrimination. It is clear from the work that CQC is currently doing with Age UK and Stonewall that fear of discrimination is a key factor in older lesbian, gay and bisexual people in care homes not being able to ‘come out’ and therefore not being able to express an important aspect of their personal identity. It is also clear that this has a major impact on people’s mental wellbeing. Consideration could be given to adding:</p> <p>‘In order for older people to share and express some aspects of their personal identity, such as their sexual orientation if they are lesbian, gay or bisexual, older people need to be confident that they will receive a positive response to their sexual orientation from care home staff and be protected from any discrimination by others using the service or others coming into the care home (such as other professionals). It is important that the care home is proactive in giving messages that indicate that they welcome lesbian, gay and bisexual people and that staff training covers all equality issues to enable a positive response from staff. It is also important that there is a culture in the care home where people are able to discuss their fears and anxieties so that people are able to raise any fear of or actual instances of discrimination and that the service takes steps to prevent and deal with discrimination. Older people from different religions, ethnic groups or transgender older people may also have similar concerns about sharing and expressing aspects of their personal</p>	<p>Please respond to each comment</p> <p>providers will decide locally which guidance they would like to access in relation to these areas.</p> <p>All groups, including lesbian, gay, bisexual and transgender groups, are included under the Equality and diversity considerations section. It is felt that sufficient emphasis is given to the equality groups identified.</p>

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				<p>identity'.</p> <p>Equality and diversity publications previously published by the Commission for Social Care Inspection (CSCI) would be helpful source materials to signpost to here. They are still widely used and are part of the Think Local Act Personal resources. Though some of the law has changed since the bulletins, the summaries and action point lists are still as relevant as ever.</p> <p>http://www.thinklocalactpersonal.org.uk/Browse/Co-production/Equalities/LGBT/?parent=8627&child=8113 (CSCI Putting people first: equality and diversity matters 1 – providing appropriate services for lesbian, gay and bisexual and transgender people)</p> <p>http://www.thinklocalactpersonal.org.uk/_library/Resources/Personalisation/Localmilestones/Putting_people_first_Equality_and_Diversity_Matters_2.pdf (CSCI Putting people first: equality and diversity matters 2 – providing appropriate services for black and minority ethnic people)</p> <p>http://www.thinklocalactpersonal.org.uk/Browse/Co-production/Equalities/Equalaccess/?parent=8626&child=8106 ((CSCI Putting people first: equality and diversity matters 3 – achieving disability equality in social care services)</p>	

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