

# **NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE**

## **HEALTH AND SOCIAL CARE DIRECTORATE**

### **QUALITY STANDARD CONSULTATION**

#### **SUMMARY REPORT**

## **1 Quality standard title**

Older people with social care needs and multiple long-term conditions

Date of Quality Standards Advisory Committee post-consultation meeting:

22 June 2016

## **2 Introduction**

The draft quality standard for older people with social care needs and multiple long-term conditions was made available on the NICE website for a 4-week public consultation period between 26 April and 24 May 2016. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 36 organisations, which included commissioners, service providers, national organisations, professional bodies and others.

This report provides the Quality Standards Advisory Committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the Committee as part of the final meeting where the Committee will consider consultation comments. Where appropriate the quality standard will be refined with input from the Committee.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the Committee should read this summary alongside the full set of consultation comments, which is provided in appendix 1.

### **3 Questions for consultation**

Stakeholders were invited to respond to the following general questions:

1. Does this draft quality standard accurately reflect the key areas for quality improvement?
2. Are local systems and structures in place to collect the data for the proposed quality measures? If not, how feasible would it be for these systems and structures to be put in place?
3. Do you have an example from practice of implementing the NICE guideline that underpins this quality standard? If so, please submit your example to the [NICE local practice collection](#) on the NICE website. Examples of using NICE quality standards can also be submitted.
4. Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resources that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

Stakeholders were also invited to respond to the following statement specific questions:

5. For draft quality statement 2: It is important that information and advice are given at every opportunity to help older people with multiple long-term conditions and social care needs to maintain their independence. This quality standard can drive improvement in particular areas. Are there any specific types of information for this group that need to be improved? Please explain.

## **4 General comments**

The following is a summary of general (non-statement-specific) comments on the quality standard.

- Stakeholders welcomed the quality standard and there was broad support for the areas identified for quality improvement.
- There were some concerns about the population in scope for the quality standard:
  - It was questioned why the quality standard does not apply to younger people. There was a request to clarify which younger people with complex needs the quality standard may be relevant to as per the Introduction.
  - Specifying that the person should have more than one long term condition will exclude people with one condition that causes multiple difficulties e.g. frailty.
  - It was suggested that the population should be identified on the basis of the impact of health morbidity or using the electronic frailty index (eFI) instead.
  - It needs to be clearer that the quality standard includes all older people, regardless of whether they are eligible for financial support for social care.
- In general, the wording needs to be more person-centred and there should be a more positive focus on improving quality of life.
- It was suggested that there should be more emphasis on identifying and addressing housing needs and the needs of carers.
- It needs to be clearer what a community care provider is.
- It would be helpful to link to the NHS England funded health and social care outcome measures that are due to be published by ICHOM soon.

### **Consultation comments on the introduction**

- It was suggested that the introduction should highlight:

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- the burden of hearing loss among older people
- the role of lifestyle choices in the onset of long-term conditions in older age
- the current lack of awareness of how to fund residential care and other housing and care options
- An additional outcome for 'independent living at home if this is the person's wish' was suggested.
- The training and competencies section needs to be clearer.

### **Consultation comments on data collection**

- Stakeholders generally agreed that it should be possible to collect the data if appropriate systems are in place.
- Currently, there are local systems and structures in place in some but not all areas. Those that exist may not collect all the data required and health and social care systems may not be well connected.
- Current inconsistencies in data sharing may mean that individuals are not identified as having multiple long term conditions.
- It is important for data collection to include feedback from older people and their carers. It was suggested that there is potential for the community and voluntary sector to gather this information more routinely.

### **Consultation comments on resource impact**

- There was a general concern that the quality standard may be ambitious in the context of current public finances and, in particular, funding for social care.
- It was questioned how well the quality standard fits within a wider context of care models that put an increasing emphasis on self-care and support from family carers and the voluntary sector.
- The quality standard could lead to cost savings if care is better integrated and may lead to reduced duplication and increased efficiency.

## **5 Summary of consultation feedback by draft statement**

### **5.1 Draft statement 1**

Older people with multiple long-term conditions having a social care needs assessment discuss their physical and mental health needs.

#### **Consultation comments**

Stakeholders made the following comments in relation to draft statement 1:

- Some stakeholders felt that the focus for the statement should be ensuring access to a social care needs assessment for people with multiple long term conditions.
- Identifying physical and mental health needs was supported but some felt specific needs should be identified including: housing, hearing, visual impairment, oral health and nutrition.
- There was a concern that a shortage of physical and mental health professionals including geriatricians may mean this statement is difficult to implement.
- It was suggested that the statement could support cost savings if assessments could be carried out by the voluntary sector e.g. dementia advisers, although it will be important to ensure staff are trained appropriately.
- Some concern that the measures do not ensure the quality of the assessment.
- The definition of multiple long term conditions should include hearing loss.
- The list of practitioners should include occupational therapists.
- It is important to identify that some people may need support with communication, or for an advocate to act on their behalf, during a social care needs assessment.

## **5.2      *Draft statement 2***

Older people with multiple long-term conditions having a social care needs assessment are given information about the services that can help them, the cost of these services and how they can be paid for.

### **Consultation comments**

Stakeholders made the following comments in relation to draft statement 2:

- The statement should include cost-free services provided by the voluntary sector.
- It is important to emphasise that older people should be supported to ensure they fully understand their care and support options and are not just given a leaflet.
- It was suggested that the outcome measure on 'ease of finding information and advice' does not match the intent of the statement and should be focused on the suitability of the information provided instead.
- More emphasis on the need for a joined-up, up-to-date and accessible (not just via the internet) information resource in local areas and to ensure older people and their families are aware of how they can find information.
- Stakeholders suggested that housing and related services should be included within the rationale and the definition of information about services that can help, in line with the Care Act.
- The list of practitioners should include occupational therapists.
- The descriptor for older people should be amended as having information will not help them to decide what they need, it will only help them to know what is available.

### **Consultation question 5**

Stakeholders made the following comments in relation to consultation question 5:

- Stakeholders highlighted a wide range of different types of information that older people and their families need as follows:
  - Writing a will and setting up Powers of Attorney
  - Dealing with abuse
  - Housing options including residential care

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- Caring
- Applying for welfare benefits
- Managing a long-term condition
- Diet and oral hygiene
- Advocacy
- Aids, equipment, adaptations and assistive technologies
- Home care (domiciliary care)
- Care assessments
- Community/personal alarms
- Dementia services
- Mental health services
- Paying for residential or nursing care
- Which services can be accessed for free, and which need to be paid for privately
- End of life care planning (advanced care planning)
- Finding a care home; the quality of care homes
- Local support groups and opportunities for social and physical activities and friendship
- Disability support groups
- Day care availability and accessibility
- It was emphasised that all organisations including the voluntary sector and local authority should play a role in providing information and advice to older people not just health and social care practitioners.
- It is important that information is not just about giving people leaflets. Older people may want the opportunity to discuss their options and to ensure they understand the information and what it may mean for them.
- It was suggested that the statement should focus on providing information about evidence based interventions to a more specific population group e.g. exercise based interventions for those with mild to moderate frailty.

### **5.3      *Draft statement 3***

Older people with multiple long-term conditions and social care needs have a named care coordinator.

#### **Consultation comments**

Stakeholders made the following comments in relation to draft statement 3:

- Some stakeholders were concerned about the potential resource impact of the statement while others felt there could be cost savings by reducing duplication.
- There was uncertainty about whether the statement applies only to those older people who are having a social care assessment or the ongoing support of all older people with multiple long term conditions and social care needs.
- The statement should ensure that the older person is involved in agreeing who their care coordinator is.
- The statement wording should be amended to identify that the care co-ordinator is part of a multi-disciplinary team.
- It needs to be clearer who can be a care co-ordinator e.g. health or social care practitioners, the voluntary or private sector or the older person and their carer.
- Care coordinators from the voluntary sector should be trained, and have access to appropriate information and support from practitioners.
- The role and responsibilities of the care co-ordinator need to be clear. Specific suggestions included:
  - Links to other care co-ordinators e.g. mental health care co-ordinators (Care Programme approach) and the discharge coordinator in the transition between inpatient hospital and community settings quality standard.
  - Liaising and supporting family carers.
  - Ensuring arrangements are clear if the coordinator is on holiday or sick and arranging handover if they leave.
- There was concern that the process measure will not be effective as older people may not be identified as having multiple long term conditions and social care needs until they have a care co-ordinator.
- The list of practitioners should include occupational therapists.



## **5.4 Draft statement 4**

Older people with multiple long-term conditions and social care needs have a jointly agreed health and social care plan that identifies how their personal priorities and outcomes will be met.

### **Consultation comments**

Stakeholders made the following comments in relation to draft statement 4:

- The wording should be amended to a 'health, social care and housing plan'.
- More emphasis needed on the importance of communication and shared decision making with older people and their carers in developing the care plan.
- Issues around ensuring health and social care plans are signed were raised:
  - A stakeholder felt this was excessively bureaucratic and could evoke suspicion.
  - It needs to be clear what would happen if the person did not want to sign it.
  - The original should be kept by the older person to ensure the plan is not seen as professionally driven.
- Care plans need to have a standard format nationally. Suggested that the definition of a joint health and social care plan should also include:
  - medicines management
  - issues addressed by a social care assessment as identified by the Care Act
  - emergency care plan if the carer is ill
  - support provided by a carer
  - dentistry
  - advance care planning
- Additional measures to assess the quality of care plan development (person-centredness) and to capture effectiveness prior to annual review were suggested.
- There were concerns that staff do not have the care planning skills required.
- The list of practitioners should include occupational therapists.
- Sensory loss should be spelt out as hearing loss and sight loss because hearing loss is often overlooked.

## **5.5      *Draft statement 5***

Older people with multiple long-term conditions and social care needs have a review of their personal health and social care plan at least annually.

### **Consultation comments**

Stakeholders made the following comments in relation to draft statement 5:

- The statement should emphasise the need for timing for the review to be responsive to individual needs.
- It needs to be clear whose responsibility it is to initiate the review – the provider or the local authority.
- The review should include a review of the carer's needs.
- It needs to be clear that the statement applies to all older people with multiple long term conditions as currently those living in residential care are less likely to have a review.
- An additional outcome for 'supporting older people and their carers to self-manage' was suggested.
- There was a concern about the resource impact of this statement.

## **6            Suggestions for additional statements**

The following is a summary of stakeholder suggestions for additional statements.

- Assessment for carers
- Access to a comprehensive geriatric assessment (CGA).

## Appendix 1: Quality standard consultation comments table – registered stakeholders

ID	Stakeholder	Statement number	Comments <sup>1</sup>
1	Dudley MBC. The Directorate of People Services	General	We will be reflecting on the above in joint discussions with local Health colleagues as well as with ADASS on the national factors that will further bear on the successful delivery of the quality statements.
2	Care and Repair England	General	<p>We note that in the Briefing Paper (Page 30) there is a further quality standard due on housing, which is to be welcomed. However we feel that all other guidance and quality standards should include housing factors where this is appropriate to ensure that they are addressed. In this instance this is because housing plays such a critical role in person centred planning for social care for people with long term conditions.</p> <p>Many of the chronic health conditions people face are exacerbated by poor and inappropriate housing and can be alleviated by improving and adapting people's homes.</p> <p>There is an expanding evidence base on the value of housing interventions to care and health planning and provision. Whilst we would not expect social care practitioners to deal with housing issues per se we would argue that housing needs to be considered in any social care assessment and that social care staff need to know about the common housing issues and who to contact locally to ensure that people's housing circumstances are addressed in so far as they impact on a persons' wellbeing.</p> <p>Unless there is collaboration strategically and operationally between health, care and housing it is doubtful that there will be commissioning of truly integrated services for people with long term conditions. Housing needs to be integrated with social care and health at both the strategic and individual assessment level</p>
3	British Thoracic Society	General	Whilst recognising this NICE statement is around elderly patients with multiple long term conditions there is a need to recognise that younger individuals may get multiple long term conditions and need even greater help in navigating the system".
4	National Pensioners Convention	General	Whilst NICE's quality standards of care are not able to comment on national issues such as the long-term funding arrangements for social care, in reality very few people would accept that such factors do not have a significant impact on the quality of the service delivered. Of course, the standards of care and outcomes that NICE proposes are in themselves, perfectly reasonable and appropriate to ensure decent care, but they are seriously undermined if the

<sup>1</sup>PLEASE NOTE: Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its staff or its advisory committees.

ID	Stakeholder	Statement number	Comments <sup>1</sup>
			resources are not available that will enable those providing the services to meet their obligations.
5	National Pensioners Convention	General	Most practitioners now favour keeping older people at home for as long as possible. However, the severe financial pressure faced by local social care services often means that there is insufficient support available to either help older people stay at home or enable them to be properly cared for when they are due to leave hospital. The latest evidence reveals around 1.8m older people no longer in receipt of social care in the community. This task largely falls onto family carers, many of whom are themselves older people, with their own health conditions. The drive towards “community self-sufficiency” effectively means individuals and their families having to cope, with very little support. Failing to put in this additional help then has two very obvious outcomes: firstly the carer’s health and wellbeing deteriorates and this secondly impacts on the individual for whom they are caring. In both cases, the cost of dealing with these health needs falls to the health service and ultimately represents a false economy.
6	Association of British Neurologists	General	The need for a person to have more than one long term condition is not helpful, particularly if it defined in terms of diagnosis. A young adult with MS may have poor vision, memory, concentration and attention problems, difficulties with dexterity and mobility, and double incontinence. They should be entitled to the same things as someone with hypertension and diabetes. Given the focus is on long term conditions we are also unclear why this has to be for older people.
7	RCGP	General	Essentially serviceable and helpful, it might be helpful for the impact of health morbidity to be scored rather than related to the number of conditions. Chronic hypertension well controlled, stable prostatic disease will have less impact than poorly controlled arthritis. (PS)
8	RCGP	General	There is a need to celebrate and help people to enjoy their health and empower them, the document seems to concentrate on the problems. Quality of life is most important, complex medication may make life more difficult and there are important trade-offs. (PS)
9	RCGP	General	Its important to be clear that this guidance applies to all - including people who are not eligible financially for support from social services. Giving such information to older people themselves and their families is vital. (DP)
10	RCGP	General	The language in this draft is not person-centred; patients are being encouraged to follow the plan. (DP)  It would be appropriate to remove the term ‘older people’ for ‘people aged over 65’. (DJ)
11	RCGP	General	NHS England has recently funded a project through ICHOM to develop some internationally valid health and social outcome measures for older people – they are due to be published in July 2016. Possibility of these being referenced?(DP)
12	Healthwatch Norfolk	General	Healthwatch Norfolk agrees with the key areas selected for consideration in the quality standards and the five quality statements. These quality statements resonate with the evidence we’ve been gathering from the public, patients and service users since 2013 but specifically in our findings on the needs of unpaid carers, experiences of dementia services, quality of dementia care in local care homes and more recent investigations into pressure ulcers, equipment and reablement services, advanced care planning for end of life and the provision of information and signposting to

ID	Stakeholder	Statement number	Comments <sup>1</sup>
			support for the 'living longer, living well' independence agenda.
13	National Community Hearing Association	General	<p>Moreover, the draft quality standard notes that "people with long-term conditions account for around 50% of all GP appointments" (p.2). Due to the prevalence of hearing loss in older people and level of unmet need a substantial part of these GP appointments are likely to be about hearing loss. It is important GPs (potential care coordinators) and social workers consider the impact hearing loss might have on care and wellbeing. For example a survey of 600 people with hearing loss found that after attending a GP appointment</p> <p>28% had been unclear about their diagnosis 26% had been unclear about the advice given 19% had been unclear about their medication[x]</p> <p>[x]NHS England and Department of Health (2015) Action Plan on Hearing Loss. p 11. <a href="http://www.england.nhs.uk/wp-content/uploads/2015/03/act-plan-hearing-loss-upd.pdf">http://www.england.nhs.uk/wp-content/uploads/2015/03/act-plan-hearing-loss-upd.pdf</a></p>
14	Arthritis Research UK	General	<p>I am writing in response to your consultation on the draft quality standard for older people with social care needs and multiple long term conditions. We have not submitted a full response to the consultation, instead I wanted to bring to your attention two pieces of work that we are doing, which could offer some useful insights into the draft quality standards.</p> <p>The first is a report on people living with multimorbidities and the impact it has on quality of life, particularly in regard to the health and social care system.</p> <p>The second is a policy project looking at aids and adaptations in the home for people with arthritis and looks at local authorities responsibilities for the provision of aids and adaptations.</p> <p>If you feel these would be useful, please let me know and I will send them through as soon as they are available.</p>
15	Royal College of Physicians	General	<p>The RCP is grateful for the opportunity to respond to the above consultation.</p> <p>We would like to formally endorse the response submitted by the British Thoracic Society</p>
16	British Geriatrics Society	General	<p>NHS England has just funded a project through ICHOM to develop some internationally valid health and social outcome measures for older people – they are due to be published in July – would be nice if these could be referenced.</p>
17	British Geriatrics Society	General	<p>Its also important to be clear that this guidance applies to all - even people who are not eligible financially for support from social services who often have to go it alone( despite what the Care Act 2015 says). Giving such information to older people themselves and their families is vital</p>
18	Department of Health	General	<p>I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.</p>
19	Northumbria Healthcare NHS Foundation Trust	General	<p>We distributed your email and have received no comments.</p>

ID	Stakeholder	Statement number	Comments <sup>1</sup>
20	Age UK	Introduction	It is noted that incidence of depression is 7 times higher amongst people with 2 or more long term conditions. It is not clear whether depression is regarded as a long term condition, or whether it would fall within the definition of a long term condition as lasting for more than a year, as it might be intermittent. If the person's needs are to be addressed holistically it is important that depression is included amongst those needs.
21	Stroke Association	Introduction	While stroke can affect people of any age, the chances of having a stroke increase with age and as such, three quarters of all strokes occur in people over the age of 65. In the briefing notes accompanying this consultation, there is mention of the focus of this quality standard and how it "is focussed on people over 65 but may also be relevant to some people under 65 with complex needs." We feel there should be greater clarity here. While we agree that large parts of this draft standard could be applied to those under 65, it would be helpful if NICE could set out what "complex needs" would constitute eligibility for this standard.
22	evidENT	Introduction	In this section it may be worth highlighting hearing loss as a major burden of disease in this patient population. 70% of people above the age of 70 have hearing loss in the UK. Further that age related hearing loss will be in the top ten disease burdens, above diabetes and cataracts by 2030. Age related hearing loss is also associated with other conditions including dementia and poor mental health. Evidence suggests that older people with hearing loss are 2.5 times more likely to develop depression and up to five times more likely to develop dementia.
23	Care and Repair England	Introduction	Why this Quality Standard is needed Paragraph 4 - Add people may not be aware how to fund residential care and other housing and care options if their conditions worsen.
24	Care and Repair England	Introduction	Why this Quality Standard is needed Paragraph 2 - Add the following outcome – independent living at home if this is the person's wish
25	Cochrane ENT	Introduction	In this section it may be worth highlighting hearing loss as a major burden of disease in this patient population. 70% of people above the age of 70 have hearing loss in the UK. Further that age related hearing loss will be in the top ten disease burdens, above diabetes and cataracts by 2030. Age related hearing loss is also associated with other conditions including dementia and poor mental health. Evidence suggests that older people with hearing loss are 2.5 times more likely to develop depression and up to five times more likely to develop dementia.
26	RCGP	Introduction	Table 1: The Adult Social Care Outcomes Framework 2015–16 Assessment of a person's experience of integrated care; Many patients may not know what to expect, and what GPs see as integrated is no different in what patients experience. (DP)
27	Royal College of Nursing	Introduction	"Does this draft quality standard accurately reflect the key areas for quality improvement?" Yes they do but commenting, on the Outcome measure on Table 1: 'People manage their own support as much as they wish, so they are in control of what, how and when support is delivered to match their needs' – we consider that some people may wish to manage their needs but not physically able - there needs to be a way of supporting people living with frailty and long term conditions in this scenario.
28	United Kingdom Homecare Association	Introduction	The use of the word 'wish' in the statement "People manage their own support as much as they wish, so they are in control of what, how and when support is delivered to match their needs" implies that every desire can be

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			accommodated which often is not the case. It may be that an expression such as “People manage their own support as much as they are able .....’ creates a more realistic frame of reference.
29	United Kingdom Homecare Association	Introduction	Expressions such as “Unplanned hospitalisation for chronic ambulatory care sensitive conditions” are jargon and could usefully be re-phrased in an unambiguous way: two Registered Nurses and someone with an MA in Political Theology have tried unsuccessfully to deconstruct this statement and determine the intended meaning. We do not understand what this means.
30	United Kingdom Homecare Association	Introduction	The paragraph headed “Training and Competencies” is not very focused and the explanation in the latter half of the paragraph is not concluded in a way that creates an understanding of why this has to be included. The last sentence is particularly opaque.
31	EPA UK/EU	Introduction	<p>The introduction states ‘the prevalence of long-term conditions is linked to ageing.’ And whilst it is true that some long-term conditions are linked to ageing, for example, sensory loss, hip/knee replacements and mobility, many other conditions have other root causes. New medicine and health models depend on partnerships between people, GPs, other health practitioners - both conventional and complementary - founded on self-care and self-responsibility for health from childhood, through to adulthood, middle and old age. It is important that health and potential health issues are addressed at any age, the earlier the better, rather than delaying until after the onset of illness and disease with the understanding that prevention is the way forward. This is particularly key with regard to lifestyle choices. There is a huge potential here for NICE in the introduction to this guidance to go further and make a clear distinction between preventable long-term ill-health (chronic) conditions so often related to lifestyle choices from those more directly related to ageing. This could be achieved by citing relevant research evidence. We know from the World Health Organisation that: ‘Chronic diseases, such as heart disease, stroke, cancer, chronic respiratory diseases and diabetes, are by far the leading cause of mortality in the world, representing 63 percent of all deaths. (i). According to the Kings fund: ‘Current lifestyles present a serious threat to population health, particularly for more disadvantaged groups’ (ii) and that ‘More than 60 per cent of the population have a negative or fatalistic attitude towards their own health, particularly in more disadvantaged groups. (ii). The Kings Fund additionally states ‘The ageing population and increased prevalence of chronic diseases require a strong re-orientation away from the current emphasis on acute and episodic care towards prevention, self-care, more consistent standards of primary care, and care that is well co-ordinated and integrated’. (iii). In the UK 3 million people are affected by diabetes. (iv)’ ‘People from a South Asian ethnic background, are known to have one of the highest rates of type 2 diabetes; four times the rate of the general population’ (iv). An example of preventative medicine in action is the East Midlands, the ‘Let’s Prevent” programme, which states that it ‘will lead to a best practice approach for reducing the risk of type 2 diabetes in South Asian communities’. (iv) Offering education programmes like this earlier in life could help reduce the multiplicity of ill-health conditions in old age and therefore the increasing cost burden on service provision. Including statistics like these in the introduction gives a fuller picture of true nature of the nation’s health and initiates a crucial educative and awareness-raising process. (i) Kings Fund ‘Healthy behaviours’ 2012 (ii) Kings Fund ‘Transforming our Health Care</p>

ID	Stakeholder	Statement number	Comments <sup>1</sup>
			Systems' 2015 (iii) World Health Organisation v)NHS National Institute for health research' Diabetes prevention pathway in a south Asian population'
32	EPA UK/EU	Introduction	<p>It is stated that 'Quality statements on staff training and competency are not usually included in quality standards' This omission weakens the quality standard considerably. Quality standard statements are clear, precise and clinical. What is missing is a standard on the human touch. The quality standard could be enhanced by including descriptors of required competencies (qualities) essential for social care practitioners working with older people. It is often assumed that people know how to relate to older people when providing a service. Detrimentially, this is not always the case. Social care practitioners are often more familiar with delivering transactional 'processes' than establishing caring relationships. It is important to make sensitivity, humaneness, love and compassion central to the care we give older people. NICE could take a lead by making clear that competencies based on these 'human qualities' are fundamental to providing truly caring and rewarding health and social care services. Training of social care practitioners rarely mentions the 'human qualities' of true care. This is an area that deserves careful consideration if the quality of care we give to older people is to be significantly raised beyond the current level of home and residential care. A Place to call Home' - A Review into the Quality of Life and Care of Older People living in Care Homes in Wales' recommends that social care providers offer 'high quality care' based on 'values-based training. The current mandatory training (Health and Safety, Moving and Handling, Food Safety and Hygiene) for front-line carers does not accurately reflect the complexity of the responsibility. Supporting 'emotionally vulnerable, cognitively impaired and frail older people is emotionally, mentally and physically challenging and demanding'' (i) and often underestimated. It is time quality of training provided reflects all aspects of the role. Ref: 'A Place to call Home' - A Review into the Quality of Life and Care of Older People living in Care Homes in Wales' 2014.</p>
33	EPA UK/EU	Introduction	<p>We agree and support this quality statement's recognition of 'the important role families and carers have in supporting older people with social care needs and multiple health conditions.' Family members (significant others or chosen friends) are often the ones who take the lead in guiding the older person through the process. It is essential that this group (or individual), with the consent of the older person, is involved from the start in 'the decision making process, about investigations, treatment and care'. In our experience, support for the families and carers is crucial if they are to remain a consistent and positive support for the older person.</p>
34	Age UK	Introduction	<p>The list of outcomes on page 3 refers to quality of life outcomes as being either 'social care related' or 'health related'. In order for these outcomes to encompass the most vital determinants of quality of life both of these concepts must be interpreted broadly. So the scope of 'social care related' quality of life should include those aspects of wellbeing set out in the Care Act which local authorities must take into account when considering care needs. These aspects of wellbeing include outcomes such as being able to maintain social roles and dignity, rather than just provision of care to enable people to carry out activities of daily living. It needs to be clear that 'social care related quality of life' is intended to be inclusive of these aspects of wellbeing. Aspects of wellbeing set out in the Care act are;</p>



ID	Stakeholder	Statement number	Comments <sup>1</sup>
			<ul style="list-style-type: none"> <li>-personal dignity (including treatment of the individual with respect);</li> <li>-physical and mental health and emotional well-being;</li> <li>-protection from abuse and neglect;</li> <li>-control by the individual over day-to-day life (including over care and support, or support, provided to the individual and the way in which it is provided);</li> <li>-participation in work, education, training or recreation;</li> <li>-social and economic well-being;</li> <li>-domestic, family and personal relationships;</li> <li>-suitability of living accommodation;</li> <li>-the individual's contribution to society.</li> </ul>
1	LondonADASS	Introduction	We support the content and structure of the introduction section.
35	RCGP	Questions for consultation - Question 1	<p>The draft quality standard reflects the key areas for quality improvement largely, although the guidance should apply to older people with frailty – even if that is their only LTC.</p> <p>Quality standards are appropriate and these are best delivered close to the patient and family/carers so as to be as responsive as possible. However this needs to support and augment current primary care (in its wider understanding) rather than place more burden on it. This requires a wider service model reconfiguration away from the GP gatekeeper model and adoption of the “Prudent“ model of shared goal setting and multifaceted team working. Central to this is patient and public acceptance that most solutions don't exist within statutory health or social care but they need to be involved in the delivery of a sustainable model. (DP)</p>
36	Parkinson's UK	Questions for consultation - Question 1	<p>Yes, we largely agree that the draft quality standard accurately reflects the key areas for quality improvement. However, we do not agree that the first quality statement is of most relevance. In our view, social care needs develop as a result of growing physical and mental health needs, which prevent individuals from managing daily tasks and activities and that a high-quality social care assessment should naturally examine these nuances. We therefore feel that a more pressing area for quality improvement is ensuring that people with multiple long-term conditions are offered social care assessments in the first instance. We discuss this further below</p>
37	British Dental Association	Questions for consultation - Question 1	To some extent.
38	Alzheimer's Society	Questions for consultation - Question 1	Alzheimer's Society welcomes these quality standards and believe they have included the main areas for improvement.
39	National Pensioners Convention	Questions for consultation -	There needs to be greater recognition of the way in which this practice now takes place. There are numerous examples, across the country, where older people are discharged from hospital at night/early morning without any

ID	Stakeholder	Statement number	Comments <sup>1</sup>
		Question 1	support in place. Those taking them home can in some cases simply drop them at their door. Without the necessary support at home, the individual can often find themselves being quickly readmitted to hospital. Given the increase in this problem, it is essential that the guidelines therefore reflect the need for there to be appropriate discharge times, alongside a confirmed package of support at home prior to someone leaving hospital.
40	National Pensioners Convention	Questions for consultation - Question 1	<p>The draft quality standard includes many of our own concerns and issues. In addition, we would like to see the following specific items considered:</p> <ul style="list-style-type: none"> <li>• Introducing a single point of contact for the coordination of all care</li> <li>• Having a personal care plan – covering health and social care - agreed between the individual, their family and services, including new preventative checks for vulnerable or frail older people to help spot risks and act before problems occur</li> <li>• The provision of the right to counselling and therapy as well as medication, as part of a new emphasis on social prescribing</li> <li>• Having the right to care where you want it, such as being in your own home at the end of your life with homecare provided on the NHS</li> <li>• A professional and skilled workforce that is treated properly, valued for their knowledge and commitment, and for all these things to be reflected in a career and grade structure that rewards them</li> </ul>
41	MHA (Methodist Homes)	Questions for consultation - Question 1	We agree that this draft quality standard accurately reflect the key areas for quality improvement. However a clearer definition of ‘community care providers’ is required. We have assumed it means care home providers but we are not sure.
42	Carers UK	Questions for consultation - Question 1	<p>This document does not adequately reflect the support needs of carers or outcomes for carers. This is integral to the support for older people with social care needs and multiple long term conditions, the vast majority of whom depend on the unpaid care provided by friends and relatives and many (and increasing numbers of)older people with their own long term conditions are also providing care for others.</p> <p>Without weaving the outcomes needed for carers throughout this quality standard, they will be invisible and this quality standard will be deeply flawed.</p> <p>The key areas for quality improvement explicitly refer to better outcomes for carers, including that carers feel they are respected as equal partners throughout the care process. However, none of the quality statements include carers and they are largely left out of the more detailed information on each quality standard statement.</p>
43	NHS England	Questions for consultation - Question 1	<p>The standard does reflect some but not all of the key areas for quality improvement. Importantly it does not take into account a number of important practical difficulties in ensuring that the standard could be deliverable.</p> <p>1) Identification: currently LTCs are identified in multiple sets of record systems which are not necessarily aligned into</p>

ID	Stakeholder	Statement number	Comments <sup>1</sup>
			<p>a common shared health and social care record. This includes Secondary care, General Practice, other Primary care systems (pharmacy, community dentistry, optometry for example), Social Care and Mental Health services. Not all of the host provider services sit within the public sector and there is no common shared community data set to capture all of the LTCs which a person may be affected by. There is currently national inconsistency in approach to data sharing agreements among organisations and providers to aggregate this data (much of which is still held in paper or incompatible electronic data set forms among multiple organisations).It is currently entirely possible that individuals with social care needs will not be identified as having physical and mental health needs, or that those needs may not be fully understood by the contact assessor.</p> <p>One potential solution to this is to re-frame older people with multiple LTCS as older people with frailty for which there is now a reliable screening tool available in primary care – though importantly this not yet in widespread use in the absence of meaningful interventions: <a href="https://ageing.oxfordjournals.org/content/45/3/328.full">https://ageing.oxfordjournals.org/content/45/3/328.full</a> The electronic frailty index (eFI) (<a href="http://ageing.oxfordjournals.org/content/45/3/353.short">http://ageing.oxfordjournals.org/content/45/3/353.short</a>) is widely available and provides a potential means by which older people with multiple LTCs leading to escalating health and social care needs could be consistently and reliably identified. It is suggested that using ‘frailty’ rather than ‘multiple LTCs’ as the index condition trigger for this Quality Standard is a more reliable and more likely to permit accurate measurement.</p> <p>2) Assessment: given that there is no robust system in place to systematically identify and share data about LTCs with social care needs assessors, there is a strong possibility that needs are inaccurately or incompletely assessed, or that there is unnecessary duplication of assessment. In addition the standard appears to assume that social care needs assessors are suitably trained and qualified to discuss physical and mental health needs, or that there are adequate physical and mental health professionals available to support such discussions which is unlikely to be the case. Currently there is a national recruitment shortage of qualified geriatricians and the majority of geriatricians work in secondary care settings not community care where it is anticipated the majority of the work necessary to meet the standard would be undertaken.</p> <p>The preferred methodology of comprehensive geriatric assessment (CGA) would capture the physical and mental health needs of older people with social care needs and has utility in improving outcomes: <a href="http://www.sciencedirect.com/science/article/pii/S1470204512702590">http://www.sciencedirect.com/science/article/pii/S1470204512702590</a>. CGA is not yet universally or consistently available in primary, secondary or social care settings for the target population identified in this standard. The utility of frailty screening can be significantly improved and interventions more accurately targeted using a CGA: for example <a href="http://www.sciencedirect.com/science/article/pii/S1470204512702590">http://www.sciencedirect.com/science/article/pii/S1470204512702590</a>. It is also feasible to develop the use of CGA in other settings which yield useful outputs likely to assist in the delivery of this standard.</p> <p>For example</p>

ID	Stakeholder	Statement number	Comments <sup>1</sup>
			<p><a href="http://journals.cambridge.org/action/displayAbstract?fromPage=online&amp;aid=9496558&amp;fileId=S1481803500003043">http://journals.cambridge.org/action/displayAbstract?fromPage=online&amp;aid=9496558&amp;fileId=S1481803500003043</a>; and <a href="http://www.nejm.org/doi/full/10.1056/nejm199511023331805">http://www.nejm.org/doi/full/10.1056/nejm199511023331805</a></p> <p>It is suggested that two areas for additional quality improvement which would align with the standard are therefore 1) Older people with multiple LTCs are systematically identified using a validated frailty screening tool; and 2) Older people with multiple LTCS (frailty) who are most likely to be in receipt of social care assessment undergo a CGA.</p>
44	EPA UK/EU	Questions for consultation - Question 1	<p>This quality standard does reflect key areas that need to be addressed. It re-confirms existing standards already adopted by many service providers and goes further since the 2014 Care Act to include older people and their carers. It is also a crucial acknowledgement that many older people with social care and multiple ill-health conditions require more integrated, responsive and humane services from social care and health providers. This is appreciated and long overdue. We support the notion of responding to the 'whole' person and not individual ill-health conditions. This sets a fundamental philosophy from which derives a standard that can be built on further. The guidance supports the integration of health and social care services in local areas and in so doing signals to local authorities, service providers and commissioning groups to work creatively to achieve this. The question throughout, with reductions in local authority social care budgets and disability benefits by government, is the ability to apply these standards in a meaningful and purposeful way. There is evidence of stated standards not currently being met. But also evidence of NICE guidelines applied fully and extended by one private sector social care provider.</p>
45	British Geriatrics Society	Questions for consultation - Question 1	<p>Largely although we would argue that the guidance should apply to older people with frailty – even if that is their only LTC.</p>
46	Foundations	Questions for consultation - Question 1	<p>Foundations welcomes the quality standard to NG22 and particularly the explicit attempt to ensure more person centred assessments, plans and reviews.</p> <p>However, a key area of quality improvement for services dealing with older people with social care needs and long term conditions is the extent to which people are enabled to discuss their home environment alongside their physical and social needs. While the quality standard touches on Telecare, adaptations and the ability to maintain a home at some points, a safe and appropriate home environment is essential to improve the resilience of older people with care needs and long term conditions. As such we should like to see greater emphasis throughout the quality standard on the assessment, options and support and review for the planning of future housing needs alongside physical and care needs.</p>
47	Stroke Association	Questions for consultation - Question1	<p>We would like to see a quality standard which specifically recognises the vitally important role that families and carers play in supporting older people with social care needs and multiple long term conditions. The quality standard should make clear that carers should be offered support, particularly given that – as NICE's own assessment has shown – fewer people involved in delivering social care are actually getting paid for it. This suggests that families and unpaid carers are playing an ever-increasing role in helping those with social care needs. According to our State of the</p>

ID	Stakeholder	Statement number	Comments <sup>1</sup>
			<p>Nation report, 1 in 5 stroke survivors in the UK are dependent on family and friends.[1] 41% of stroke survivors need help with activities of daily living when they are discharged, and they are often dependent upon their carers in this regard.[2]</p> <p>Currently, many families and carers do not feel prepared when a stroke survivor is discharged. According to our recent survey of stroke survivors, almost 40% did not feel that their carer had enough support when they returned home. 53% of carers either disagreed or strongly disagreed with the statement, "I felt prepared when the person I care for was discharged from hospital". This is an area where improvement is clearly needed and improving family and carers in discharge planning can help to make the transition from hospital to home smoother.</p> <p>[1] Stroke Association, 'State of the Nation', January 2016, <a href="https://www.stroke.org.uk/resources/state-nation-stroke-statistic">https://www.stroke.org.uk/resources/state-nation-stroke-statistic</a>  [2] Stroke Association, 'State of the Nation', January 2016, <a href="https://www.stroke.org.uk/sites/default/files/state_of_the_nation_2016_110116_0.pdf">https://www.stroke.org.uk/sites/default/files/state_of_the_nation_2016_110116_0.pdf</a></p>
48	RCGP	Questions for consultation - Question 2	It is unlikely that local systems and structures in place to collect the data for the proposed quality measures will always be possible – in some areas quality standards are only recently being introduced to recognise frailty. (DP)
49	Parkinson's UK	Questions for consultation - Question 2	Yes. However, data collection on the frequency with which individuals have had their social care needs reviewed may be difficult to obtain, as it will rely on individuals with care needs to self-report when they last had an assessment.
50	evidENT	Questions for consultation - Question 2	There is a paucity of data collection systems in place to collect data on older people with hearing loss.
51	British Dental Association	Questions for consultation - Question 2	It is proposed that most of the data collection would be done on a local basis. It would be a major task to analyse every assessment, and would involve numerous identical local processes. Perhaps the work could be done in one area each year and the results then scaled up.
52	National Pensioners Convention	Questions for consultation - Question 2	From our experience, in some areas there are local systems and structures in place to collect the data for the proposed quality measures. However, pilot programmes for achieving this are still running and so it is impossible at this stage to state whether or not the system is able to fulfil this requirement.
53	RCGP	Questions for consultation - Question 2	The GP patient survey provides only a limited contribution. The RCGP feels that it is important to be more skilful in national and local outcomes measures that are person-centred. (DP)
54	Healthwatch Norfolk	Questions for consultation -	There are already some well-established data collection systems in place to collect the type of data referenced in the quality standards. Healthwatch Norfolk has heard multiple local debates regarding connectivity between I.T/digital

ID	Stakeholder	Statement number	Comments <sup>1</sup>
		Question 2	systems and how health and social care systems can, or cannot, effectively communicate with each other or between different providers within the system. This may result in some incomplete data sets. Data sources: It is likely that the community and voluntary sectors, including local Healthwatch, may also be routinely gathering feedback on the quality of older people's care provision – for example, on information, signposting, advice, support networks, carers support, advocacy and complaints – that could contribute to the data collection. Asking the community and voluntary sector to contribute to data gathering is feasible so long as it was adequately resourced and supported.
55	OPAAL UK	Questions for consultation - Question 2	Data collection should be possible but should ideally involve feedback from those who have undergone needs assessments rather than in simply counting the numbers of those who have them and have signed their agreement. If it is a numerical count we suggest additional random face to face checks to ensure the older person understands what it is they have signed their agreement to. This will give a warning of any ongoing tick box practice.
56	Royal College of Nursing	Questions for consultation - Question 2	“Are local systems and structures in place to collect the data for the proposed quality measures? If not, how feasible would it be for these systems and structures to be put in place? “ We are not aware of local systems in place and which would cope with this. There are too many variations in information technology which may present a challenge to easily capture the relevant data.
57	NHS England	Questions for consultation - Question 2	No: there is no common or consistently held customer/patient level community data set which shares data about physical and mental health status or social care needs. This means that the denominator may not be reliable. The eFI described above is a reliable measure of frailty and is becoming widely available in primary care medical records systems. Its use as a screening tool is currently not recommended because of the lack of widely available interventions. However it is suggested that use of the eFI to direct targeted CGA among a population of people undergoing social care needs assessment is both feasible and measurable. This would align well with the Quality Standard outlined and improve its delivery feasibility and ability to be measured.
58	British Geriatrics Society	Questions for consultation - Question 2	We think it is unlikely that this will be possible – certainly in our area we are only now implementing a quality standard to recognise frailty for example.
59	Cochrane ENT	Questions for consultation - Question 2	There is a paucity of data collection systems in place to collect data on older people with hearing loss.
60	Parkinson's UK	Questions for consultation - Question 3	No
61	British Dental Association	Questions for consultation - Question 3	We do not have any examples.

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ID	Stakeholder	Statement number	Comments <sup>1</sup>
62	OPAAL UK	Questions for consultation - Question 3	No examples available
63	British Geriatrics Society	Questions for consultation - Question 3	HEE Wessex is funding a project within Southern Health NHS Foundation Trust to improve skills in care planning for community staff. Contact <a href="mailto:Abigail.barkham@southernhealth.nhs.uk">Abigail.barkham@southernhealth.nhs.uk</a>
64	Parkinson's UK	Questions for consultation - Question 4	Yes. However, we remain concerned that local authority social care services will struggle to ensure people with Parkinson's are offered regular assessments and annual reassessments, given the growing social care funding gap which is likely to put further pressure on social care provision. Although the Government announced in the 2015 Comprehensive Spending Review its intention to enable local authorities to increase council tax by up to 2% per financial year, the Care and Support Alliance estimates that even if every council introduced the maximum 2% precept allowed, this would still lead to a £1.4 billion gap in social care funding from April 2016, and £1.6 billion in April 2017.
65	Dudley MBC. The Directorate of People Services	Questions for consultation - Question 4	We welcome the opportunity to comment on the draft standards and are pleased with the overall aim of the standards in reducing variation in support and enabling local people to be apprised with what they should expect from services. In responding to the consultation we would wish to focus on Question 4 and the Quality Standards spotlighted below as we feel it is these that present the most challenge and debate.
66	British Dental Association	Questions for consultation - Question 4	The statements are ambitious given the current state of public finances, but they would also be very useful and helpful to ensure consistency of care. Although the percentage compliance is for local determination, perhaps some guidance or a minimum level could be given.
67	National Pensioners Convention	Questions for consultation - Question 4	Localities and services are fragmented and underfunded. CCGs currently set priorities based on the funding available, rather than the needs of the population in their area. Patients and the public are often ignored from these decisions and more and more local authorities are now developing care models that put a greater emphasis on the voluntary sector or family carers providing support that previously would have been carried out by professional care providers.
68	OPAAL UK	Questions for consultation - Question 4	See statement 3 above. OPAAL has reservations about capacity. Perhaps the under-utilisation of Care Act advocacy provision could be rectified and advocacy support used to help not only the older person but also help alleviate resource pressure on practitioners.
69	Royal College of Nursing	Questions for consultation - Question 4	<p>"Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them?"</p> <p>This is probably the most difficult area. Our members working in front line services inform us that social services are overwhelmed with their current workload which is hindered by workforce vacancies. Perhaps NICE could consider a more self-care model for this quality standard as first choice? Support should also be provided for those who have no</p>

ID	Stakeholder	Statement number	Comments <sup>1</sup>
			one else to support them or cannot self-manage.
70	MHA (Methodist Homes)	Questions for consultation - Question 4	We agree that the standards should be achievable, to ensure that quality care is delivered and as a requirement in the Care Act 2014.
71	MHA (Methodist Homes)	Questions for consultation - Question 4	Personal priorities and outcomes may be more ambitious than the funding available. We should be ambitious for older people and should ensure that they have similar opportunities as younger people with long term conditions, however we find the reality of social care funding to be quite different to this ambition.
72	NHS England	Questions for consultation - Question 4	As described above there eFI is becoming widely available within General Practice Record systems (System One and EMIS) and as a means of identifying the target population to whom this standard would apply (rather than the more imprecise term 'multiple LTCs' ) is available with little or no additional cost. However the introduction of systematic CGA triggered by social care need and defined levels of frailty would have resource impacts particularly the resources required to deliver a CGA which aligns with a social care needs assessment. However there is evidence that the costs of implementation of CGA in targeted risk populations are offset by the benefits of the intervention both in terms of patient outcome and better deployment of health and social care resources: see for example <a href="http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2009.02383.x/full">http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2009.02383.x/full</a> .
73	Parkinson's UK	Statement 1	<p>Parkinson's UK strongly supports the principle of the first quality statement, and the recognition that it is 'important to ensure that all their health and social care needs are considered'. However, in our understanding social care needs almost always derive from the impact of physical and mental health needs on a person's daily life.</p> <p>The wife of a person with advanced Parkinson's explains how her husband's care needs have developed as a result of his stiffness and muscle weakness: 'My husband is very rigid in the morning until the medication kicks in. Bending down can be difficult so I sometimes need to assist with socks and laces and also doing up buttons. My husband has tried to adjust his wardrobe to be able to be as independent as he can. He is unable to have button fly jeans and we have recently purchased both shorts and trousers with an elasticated waist band.'</p> <p>To this extent, we would already expect any properly conducted social care assessment to fully examine the impact of a person's physical and mental needs and how care needs therefore derive from these. We also note Care Act statutory guidance to local authorities explicitly states that 'an assessment must seek to establish the total extent of needs before the local authority considers the person's eligibility for care and support and what types of care and support can help to meet those needs. This must include looking at the impact of the adult's needs on their wellbeing and whether meeting these needs will help the adult achieve their desired outcomes.'*</p> <p>We therefore feel that this quality statement could more usefully be used to ensure that people with Parkinson's and other older people are offered social care assessments in the first place. A recent Parkinson's UK survey** of 244</p>



ID	Stakeholder	Statement number	Comments <sup>1</sup>
			<p>people with the condition found that 51% of respondents had never been assessed for their social care needs.</p> <p>Research commissioned by Parkinson's UK*** has also found that people with the condition are often unaware of social care and how to access it, until they reach crisis point. A person with Parkinson's explains: 'I liken it to a pinball machine that you sort of hit against this or that or, you know, you get your information by happenchance and bumping into people and speaking to people'.</p> <p>Recommendation: This quality statement is strengthened to ensure that people with care needs are identified as early as possible and are invited to undertake a needs assessment.</p> <p>*Department of Health, Care Act and Support Statutory Guidance - <a href="https://www.gov.uk/guidance/care-and-support-statutory-guidance/first-contact-and-identifying-needs">https://www.gov.uk/guidance/care-and-support-statutory-guidance/first-contact-and-identifying-needs</a></p> <p>** Parkinson's UK social care survey 2016</p> <p>*** Tod, Angela Mary et al (2016) Good-quality social care for people with Parkinson's disease: a qualitative study, BMJ Open 2016;6:2, available at: doi:10.1136/bmjopen-2014-006813</p>
74	Dudley MBC. The Directorate of People Services	Statement 1	<p>There is a strong expectation that all people with social care needs are supported and enabled to identify the outcomes they want/ need and are effectively supported by or are signposted to the services that can facilitate these outcomes. Evidencing this however, is an on-going challenge. In further developing our approach to asset-based service delivery we are currently reviewing our assessment forms to ensure they better enable practitioners to demonstrate this.</p>
75	Age UK	Statement 1	<p>This should be re-worded to be clear that people should have access to an assessment: 'Older people with multiple long term conditions receive a care assessment that includes discussion of physical and mental health needs'.</p>
76	Stroke Association	Statement 1	<p>We very much welcome this quality statement. It is absolutely critical that stroke survivors are assessed for their social care needs not only in hospital, but when they are ready to leave as well.</p> <p>We particularly welcome the focus on physical and mental health needs. Mental health needs are too often overlooked as a key area for support. A third of stroke survivors experience depression as a result of their stroke.[3] Stroke often occurs in people with existing medical conditions and stroke itself can lead to the onset of one or more associated long term conditions such as incontinence, dementia and mental health problems, as we have already mentioned. As quoted in this consultation's associated briefing document, the King's Fund found that depression is seven times more prevalent in those with two or more long term conditions or chronic health complaints.[4]</p>

ID	Stakeholder	Statement number	Comments <sup>1</sup>
			<p>[3] Stroke Association 'State of the Nation', January 2016, <a href="https://www.stroke.org.uk/sites/default/files/stroke_statistics_2015.pdf">https://www.stroke.org.uk/sites/default/files/stroke_statistics_2015.pdf</a></p> <p>4] Naylor et al (2012), 'Long term conditions and mental health: the cost of co-morbidities', the King's Fund, <a href="http://www.centreformentalhealth.org.uk/long-term-conditions">http://www.centreformentalhealth.org.uk/long-term-conditions</a></p>
77	evidENT	Statement 1	Considering that 70% of people above the age of 70 have hearing loss, it is also important to assess and consider their hearing needs (which can have major impact on independence and quality of life).
78	Care and Repair England	Statement 1	<p>Under the rationale for this statement we would propose that you add the following -</p> <p>'In order to identify any support they may need to improve their quality of life and maintain their independence it is important to ensure that all their health, social care and related housing needs are considered'</p> <p>This reflects the expectation in the Care Act that housing factors are a part of an integrated assessment.</p>
79	British Thoracic Society	Statement 1	Thoracic medical problems, e.g. COPD, asthma and other co-morbidities that may occur as a consequence of the treatment e.g. diabetes and osteoporosis will often occur in individuals who are not elderly but will have "social care needs" and mental health issues that need to be addressed (statement 1).
80	Cochrane ENT	Statement 1	Considering that 70% of people above the age of 70 have hearing loss, it is also important to assess and consider their hearing needs (which can have major impact on independence and quality of life).
81	British Dental Association	Statement 1	Assessment of physical needs should include oral health needs. This should be mentioned in the "what it means for service providers..." section of QS1 under both practitioners and commissioners. People on multiple/long-term medications might have oral health problems directly caused by the medications (sugar-free versions should be used where possible). They might also have particular problems with oral hygiene and/or nutrition (vicious cycle of sub-optimal diet leading to oral health problems and further difficulty with eating). This might best be expressed as nutritional needs.
82	Alzheimer's Society	Statement 1	People with dementia should be offered an advocate, if required, to act on their behalf during a social care needs assessment which is a right granted under the Care Act (QS 1).
83	RCGP	Statement 1	The RCGP wonders how this statement shall be measured. 'Local data collection' for this kind of indicator would risk it becoming a pointless box ticking exercise. (DJ)
84	OPAAL UK	Statement 1	OPAAL would like to see mention of timeframes and in addition, on the universality of care needs assessments for all older people with multiple long term conditions regardless of ability to pay for care. Our experience is that self-funding older people with multiple long term conditions are either not assessed at all because of "gate keeping" or are put at the end of long waiting lists prior to assessment of needs. The assumption seems to be that if they can afford to pay they can do that themselves and are therefore low priority. In addition, OPAAL believes that Care Act advocacy should be fully utilised in supporting older people with multiple long term conditions to get their voices heard in needs assessments and ensure that this is not an administrative tick box, paper exercise by service providers, practitioners

ID	Stakeholder	Statement number	Comments <sup>1</sup>
			and/or commissioners.
85	National Community Hearing Association	Statement 1	<p>This quality standard aims to cover the planning and delivery of coordinated care for people with long-term conditions.</p> <p>Suggested change:</p> <p>- hearing loss should be mentioned on pages 13 and 16 where the quality standard lists examples of long-term conditions. This is because hearing loss is one of the most common long-term conditions affecting older people and supporting this group is a fundamental requirement in order to achieve the outcomes listed in this quality standard</p>
86	National Community Hearing Association	Statement 1	<p>Detail/evidence to support suggested changes:                      The group for which this quality standard will apply have a higher prevalence of hearing loss than the general population. This is important because, in England hearing loss is a long term condition and the 6th leading cause of years lived with disability[i] approximately 60% of people aged 71-80[ii] and 93.4% of people aged 81+ have hearing loss[iii].</p> <p>This means that older people with other long term conditions are likely to have hearing loss which could impact on their care needs. In addition to this several NICE guidelines acknowledge and reference the importance of hearing loss and the management of hearing loss. Extracts from NICE guidelines that apply to the group covered by the quality standard are listed below:</p> <p>Delirium in adults – “tailored interventions to prevent delirium... ensuring that any hearing and visual aids are working and are used”</p> <p>Mental wellbeing of older people in care Homes – “hearing losses are a common feature of ageing and may go unnoticed for some time, but can have a serious effect on a person’s communication, confidence and independence. Older people in care homes are cared for by staff who recognise needs that occur because of sight or hearing problems and record these as part of their care plan”</p> <p>Older people: independence and mental Wellbeing – “ensure staff in contact with older people can identify those most at risk of a decline in their independence and mental wellbeing ... Others at risk includes those who: ... have an age-related disability. Age-related disability ... impairment associated with ageing, such as a reduction in, or loss of vision, hearing, mobility or cognitive ability”</p> <p>Managing medicines in care homes – “health and social care practitioners should identify and record anything that may hinder a resident giving informed consent. Things to look out for include mental health problems, lack of (mental) capacity to make decisions, health problems (such as problems with vision and hearing), difficulties with reading, speaking or understanding English and cultural differences. These should be taken into account when seeking</p>

ID	Stakeholder	Statement number	Comments <sup>1</sup>
			<p>informed consent and should be regularly reviewed”</p> <p>Medicines adherence: involving patients in decisions about prescribed medicines and supporting adherence – “consider any factors such as physical or learning disabilities, sight or hearing problems and difficulties with reading or speaking English, which may affect the patient’s involvement in the consultation”</p> <p>Mental wellbeing in over 65s: occupational therapy and physical activity interventions – “increase older people’s knowledge and awareness of where to get reliable information and advice on a broad range of topics, by providing information directly, inviting local advisers to give informal talks, or arranging trips and social activities. Topics covered should include: meeting or maintaining healthcare needs (for example, eye, hearing and foot care)”</p> <p>Older people with social care needs and multiple long-term conditions – “ensure health and social care practitioners are able to recognise, consider the impact of, and respond to: common conditions, such as dementia and hearing and sight loss”</p> <p>Patient experience in adult NHS services: improving the experience of care for people using adult NHS services – “ensure that factors such as physical or learning disabilities, sight, speech or hearing problems and difficulties with reading, understanding or speaking English are addressed so that the patient is able to participate as fully as possible in consultations and care”</p> <p>Rehabilitation after critical illness in Adults – “examples from the short clinical assessment that may indicate the patient is at risk of developing physical and non-physical morbidity [...]Changes in vision or hearing, pain, altered sensation”</p> <p>Stroke rehabilitation in adults – “perform a full medical assessment of the person with stroke, including cognition (attention, memory, spatial awareness, apraxia, perception), vision, hearing, tone, strength, sensation and balance”</p> <p>Dementia: independence and wellbeing – “examples of services that help maintain physical and mental health and wellbeing include: hearing therapists”</p> <p>Excess winter deaths and illness and the health risks associated with cold homes – “Health and Wellbeing Boards and their partners should ensure the local single-point-of-contact health and housing referral service provides access to tailored solutions to address identified needs, rather than an off-the-shelf approach. Solutions should take into account the language and reading ability of recipients, including any vision or hearing problems”</p> <p>Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services – “take into account communication needs, including those of people with learning disabilities, sight or hearing problems or language difficulties, and provide independent interpreters (that is, someone who does not have a relationship with the service user) or communication aids (such as using pictures, symbols, large print, Braille, different languages or sign language) if required”</p> <p>Autism in adults: diagnosis and Management – “on an individual basis, and using information from the comprehensive assessment and physical examination, and clinical judgement, consider further investigations, including: hearing or sight tests, hearing or visual impairment”</p>

ID	Stakeholder	Statement number	Comments <sup>1</sup>
			<p>Chest pain of recent onset: assessment and diagnosis – “address any physical or learning difficulties, sight or hearing problems and difficulties with speaking or reading English, which may affect people’s understanding of the information offered”.</p> <p>[i] Vos, T et al (2015), Global, regional, and national incidence, prevalence, and years lived with disability for 301 acute and chronic diseases and injuries in 188 countries 1990-2013: a systematic analysis for the Global Burden of Disease Study 2013. The Lancet</p> <p>[ii] Davis, Adrian (1995). “Table 2.4 page 24. The combined estimate of the mean and prevalence of hearing impairment in Great Britain, from all three component studies as a function of ear and age group. Hearing impairment is derived from the averaged threshold at 0.5, 1, 2 and 4 kHz.” Prevalence at ≥25dB HL in better ear. Hearing in Adults. The prevalence and distribution of hearing impairment and reported hearing disability in the MRC Institute Hearing Research’s National Study of Hearing, MRC Institute of Hearing Research, Whurr Publishers Limited, London</p> <p>[iii] Davis, Adrian (1995). Table 8.1. page 822. Prevalence at ≥25dB HL in better ear in people aged &gt;80. Hearing in Adults. The prevalence and distribution of hearing impairment and reported hearing disability in the MRC Institute Hearing Research’s National Study of Hearing, MRC Institute of Hearing Research, Whurr Publishers Limited, London.</p>
87	Optical Confederation and Local Optical Committee Support Unit	Statement 1	<p>The Optical Confederation and the Local Optical Committee Support Unit welcomes this quality standard. We fully support the aim to ensure that older people with social care needs and multiple long-term conditions are managed in a holistic way.</p> <p>Good sight can make an enormous difference to a person’s sense of wellbeing and independence. It is therefore our opinion that the quality standard could be made stronger by including a requirement to check that a patient, or their carer, is aware of the need to have regular sight tests is listed as an essential discussion point during the physical and mental health component of a social care needs assessment. Everyone aged 60 and over is entitled to an NHS-funded sight test, and it is important that health and social care professionals are made aware of this. In addition, those who are unable to leave the house due to a physical or mental disability or illness are entitled to an NHS-funded domiciliary sight test.</p> <p>Good eye care should be a part of everyone’s regular health routine and is particularly important in older age when eye health can be neglected because other health conditions are prioritised. It is also particularly important that elderly people at greater risk of dementia attend regular sight tests, as symptoms of dementia can mask symptoms of sight loss. Regular sight tests can lead to the detection of eye diseases, such as glaucoma, allowing early intervention and treatment which can reduce the risk of avoidable sight loss.</p>

ID	Stakeholder	Statement number	Comments <sup>1</sup>
			<p>Regular eye care ensuring a person has good sight has also been shown to help reduce the risk of falls. Older people with sight loss are 1.7 times more prone to falls than those with good vision. The College of Optometrists published a report, Focus On Falls, which makes several practical recommendations for falls services and the optometric sector. We welcome the fact that NICE guideline C161 on Falls includes an assessment of visual impairment as part of the multi-factoral assessment carried out during a hospital stay.</p>
88	Carers UK	Statement 1	This statement should also indicate that older people who are carers are also entitled to a Carer's Assessment
89	United Kingdom Homecare Association	Statement 1	The continued use of arcane formulae citing numerator and denominator are not helpful and a reversion to everyday language would be of value in improving comprehension
90	Housing LIN (Learning and Improvement Network)	Statement 1	This section makes no reference to housing and links to quality of life. The Care Act now includes the suitability of accommodation in meeting an individual's long term conditions and need for personal care and support at home. This could include home adaptations through access to Disabled Facilities Grants via local Better Care Fund arrangements or a move to specialist housing, such as extra care housing to prevent a move to residential or nursing care.
91	EPA UK/EU	Statement 1	We support the rationale that every older person has a social care needs assessment to discuss physical and mental needs. This quality statement seeks to see the whole person in terms of their multiple needs, naturally incorporating mental health alongside social care needs. Too often the opposite is the case: health conditions are treated in an isolated, disjointed way and with little regard for the whole person. Mental health conditions in particular, often kept hidden by families, are not picked up at the investigative stage. When applied, this quality standard has the potential to reduce the level of disruption and confusion for the older person and suggests a social care service that 'goes to the service user' and not the other way round. Since GPs are often the first port of call, it is essential that they are aware of their role to make referrals to social care providers. For this quality standard to be effective in practice requires all parties to work together to agree a process that ensures that all older people with social care needs and multiple health conditions are identified at an early stage.
92	EPA UK/EU	Statement 1	This quality standard does not include quality assurance measures. If social care assessments are to have a true value they must be more than a tick box exercise. Social Care Assessments are foundational to forming a true relationship with the older person, one based on equality, true listening and an unhurried manner to give service users time to assess, analyse and reflect fully on all their needs and for social care practitioners to have a comprehensive understanding of the whole situation and not just the symptoms. The dedication to the quality of the assessment is paramount if we are to ensure that precious resources are maximized as efficiently as possible for the full benefit of the service user and service providers.
93	Royal College of Speech and Language Therapists	Statement 1	Older people with multiple long term conditions may have communication problems which make it more difficult for them to discuss their physical and mental health needs. The provision of appropriate communication support, including speech and language therapy, should be provided where needed.

CONFIDENTIAL

ID	Stakeholder	Statement number	Comments <sup>1</sup>
2	LondonADASS	Statement 1	<p>We are mainly in agreement with this statement but note that the professional conducting the assessment needs to be skilled/have training in asking the right questions and prompts/follow up.</p> <p>Measure - We support this measure but note that IT systems would need to be reviewed and the costs of making adjustments considered.</p>
3	LondonADASS	Statement 1	<p>The resources that would be required include:</p> <ul style="list-style-type: none"> <li>• Appropriately trained individuals who can undertake a social care needs assessment and a process for recording when the assessments take place along with the outcome.</li> <li>• Joint information sharing with Health colleagues</li> </ul> <p>Potential cost savings or opportunities for disinvestment by implementing this statement include:</p> <ul style="list-style-type: none"> <li>• Utilising the voluntary sector to carry out assessments, in some instances they may be better placed to assess a person living with a certain condition. For instance a person living with dementia will have specific needs which may be better understood by a dementia support worker or dementia adviser.</li> <li>• Staff time spent trying to "piece" together what is happening with a client/patient to get a full picture of their services/needs would be minimised.</li> </ul>
4	College of Occupational Therapists	Statement 1	<p>The College would strongly recommend that occupational therapists are included the list of health and social care professionals.</p> <p>The statutory guidance of the Care Act 2014 recognises that occupational therapists, along with registered social workers, 'are considered to be two of the key professions in adult care and support. Local authorities should consider how adults who need care, carers, and assessors have access to registered social care practitioners, such as social workers or occupational therapists' (DH 2016, section 6.82).</p> <p>Occupational Therapists are also named in 'Older people with social care needs and multiple long-term conditions (2015) NICE guideline NG22, so for parity should also be named in the quality standard</p>
94	EPA UK/EU	Statement 2	<p>We accept and support that older people when having a social needs assessment are given all the information they need about services. Impact of guidance could be strengthened if service providers, social care practitioners and commissioners committed jointly to compile up-to-date, accessible information about local services, treatment options and care services and costs. This is often a bewildering time for older people, carers and families. Information is key, as is the quality, accuracy and accessibility of information given. There is still a very large group of older people who are not computer literate who need clarity and simplicity of accurate information relevant to them made readily available.</p> <p>Additional information that could be provided; Writing a will and setting up Powers of Attorney</p>

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			What to do if subjected to any form of abuse.
95	Parkinson's UK	Statement 2	<p>Parkinson's UK strongly agrees with the second quality statement. Our 2016 social care survey* found that 74% of respondents with Parkinson's (180) and 59% of carers (66) were unaware of their local authority's social care information service. The Sheffield Hallam research** also found that a model of 'Parkinson's aware' social care, which increases in-step with an individual's growing needs can prevent an individual and carer reaching 'crisis point'.</p> <p>A person with Parkinson's explains: "Right at the outset I'm sure lots of people don't get the...benefits of what is available. Because nobody's there to tell them, which is where I feel strongly about right at the outset, from the doctor's consultation at the time you've got Parkinson's. He ought to kick off a machine that will bring those benefits to you, and it doesn't seem to happen. It's left too much to chance, and I feel it shouldn't be left to chance.</p> <p>* Parkinson's UK social care survey 2016</p> <p>** Tod, Angela Mary et al (2016) Good-quality social care for people with Parkinson's disease: a qualitative study, BMJ Open 2016;6:2, available at: doi:10.1136/bmjopen-2014-006813</p>
96	Stroke Association	Statement 2	<p>We agree that there is a need for as much information as possible to be available about the services available to older people, including the costs involved. Cost is a major consideration for all those receiving social care, but it is particularly important to stroke survivors. People from the most economically deprived areas of the UK are around twice as likely to have a stroke than those from the least deprived areas, meaning more people are likely to be reliant on social care services. People from the most economically deprived areas are also three times more likely to die from a stroke than those from the least deprived areas and this is therefore a key inequality which needs to be addressed.[5]</p> <p>The way that information is communicated is particularly important for older stroke survivors. Many experience communication difficulties such as aphasia, and may have difficulty understanding a social care plan. A recent survey carried out by the Stroke Association reports that far fewer people had a care plan in place that the SSNAP statistics show – so it suggests that plans may not be adequately explained or communicated to stroke survivors and improvement in this area is needed. It is very important that the relevant professionals ensure that the stroke survivor understands what is being communicated to them.</p> <p>We would like to see the wording of this statement amended to include the cost-free services provided by voluntary groups as not all good-quality social care is delivered by paid provider.</p> <p>[5] Stroke Association 'State of the Nation', January 2016, <a href="https://www.stroke.org.uk/sites/default/files/stroke_statistics_2015.pdf">https://www.stroke.org.uk/sites/default/files/stroke_statistics_2015.pdf</a></p>



ID	Stakeholder	Statement number	Comments <sup>1</sup>
97	Care and Repair England	Statement 2	Under the rationale for this statement we would propose that you add the following – It will help them to choose care and support and housing options as appropriate to meet their needs and enable them to maintain their independence and quality of life.
98	Care and Repair England	Statement 2	We suggest the following addition to the definition of terms in the section entitled Information about services that can help them ‘information about how to obtain care, support and housing services’ we also suggest an addition to this list as follows ‘Information on adaptations, modifications to the home and community equipment that would support them’
99	British Thoracic Society	Statement 2	Such patients would need help in paying for services, especially if they are not elderly and may have difficulty in accessing funds (statement 2).
100	Association of British Neurologists	Statement 2	In section on page 16. What the quality statement means for service users and carers Older people with more than 1 long-term condition are given information about services that can help them, the cost of these services and how they can be paid for, when they have a social care assessment. This will help them to decide what support they need to improve their day-to-day life.  This information will not help them decide what they need, it will help them know what is available.
101	Healthwatch Norfolk	Statement 2	In Norfolk, through our network sources we know that 20% of older people in Norwich aren’t online and don’t use a computer at all and older people say they would like to access information and advice at their local library, GP surgery or Citizen’s Advice Bureau. Verbal, face to face communication is still highly favoured. Written (paper-based) materials remain important and older people value leaflets and factsheets. In Great Yarmouth, a survey conducted recently revealed that 56% of older people don’t use the internet and don’t have access to the internet; also, 78% would never think of going to the county council website to look for health and social care related information. It shouldn’t be taken for granted that every older people has a computer or tablet, has access to the internet or is confident with using a computer or tablet. This is not always the case and connectivity in rural areas may be patchy at best. Healthwatch Norfolk’s insight combined with AgeUK information and signposting services show that the sorts of information that older people are most frequently seeking are: Aids, equipment, adaptations and assistive technologies Home care (domiciliary care) Care assessments Community/personal alarms Dementia services Mental health services Paying for residential or nursing care Which services can accessed for free, and which need to be paid for privately

ID	Stakeholder	Statement number	Comments <sup>1</sup>
			<p>End of life care planning (advanced care planning)                      Finding a care home; the quality of care homes                      Local support groups and opportunities for social activities and friendship                      Disability support groups                      Day care availability and accessibility                      These topics are likely to be amongst those most frequently requested by older people with long-term conditions health and social care needs (and their families and carers).</p>
102	OPAAL UK	Statement 2	<p>OPAAL is pleased to see advocacy services mentioned in the list of information to be provided. We feel that it's important that this does not simply take the form of a leaflet handed to an older person. Rather, an explanation of the potential benefits of advocacy should be provided face to face by at the very least an information provider who is trained to understand what advocacy is and can do. There seems to be little scope for this in the standard.</p>
103	National Community Hearing Association	Statement 2	<p>In addition to this, supporting access to hearing care and information, as per the Accessible Information Standard, is likely to positively contribute to the listed desired outcomes in this quality standard (p.3). This is because unsupported adult hearing loss increases the risk of</p> <p>depression[iv]                      social isolation[v]                      loneliness[vi]                      cognitive decline[vii]                      early retirement[viii], and                      reduced quality of life[ix].</p> <p>[iv] Acar, B. et al. 2011. Effects of hearing aids on cognitive functions and depressive signs in elderly people. Archives of Gerontology and Geriatrics, 52(3), pp. 250-252.                      [v] Hidalgo, J. L. et al. 2009. Functional status of elderly people with hearing loss. Archives of Gerontology and Geriatrics, 49(1), pp. 88-92                      [vi] Cacioppo JT, Hawkley LC, Norman GJ, Berntson GG. Social isolation. Ann N Y Acad Sci. 2011;1231:17-22                      [vii] Lin, F. R. et al. 2011. Hearing Loss and Incident Dementia. Archives of Neurology, 68(2), pp. 214-22; [viii] Lin, F. R. et al. 2011 Hearing loss and cognition in the Baltimore Longitudinal Study of Aging. Neuropsychology. 2011; 25(6):763-770.                      [ix] Helvik, A. 2012. Hearing loss and risk of early retirement. The Hunt study. European Journal of Public Health, 23(4), pp. 617-622                      [ix] Appollonio, I. et al. 1996. Effects of Sensory Aids on the Quality of Life and Mortality of Elderly People: A Multivariate Analysis. Age and Aging, 25(2), pp. 89-96.</p>

ID	Stakeholder	Statement number	Comments <sup>1</sup>
104	MHA (Methodist Homes)	Statement 2	<p>The statement regarding the support of older people ‘in the most appropriate setting’ (Table 1) often concerns us, as we find that generally the aim is to keep people in their own homes because that is what a person says they want. This decision can be an uninformed one and the older individual may not realise that this can mean social isolation and a sense of being forgotten, with difficulty accessing the level of support that they really need. It is important that information not only covers the fact about their options, but also raises considerations that not be immediately obvious, such as risk factors around isolation and loneliness.</p> <p>Information is not always in a format that is understandable and is dependent on the cognitive function of individuals. A high level of support is often needed to ensure that people know and understand and are able to act on what support is available to them.</p> <p>Given the complexity of navigating the care system, the need for customer-focussed information is essential - regard should be given to ensuring is truly accessible i.e. its clear who an older person have a conversation to discuss ALL their choices and not just a large print leaflet.</p>
105	Carers UK	Statement 2	This should also include information about housing (e.g. housing options, residential care)
106	Carers UK	Statement 2	Older people, who are in couples, are often co-carers and there needs to be details advice on caring also provided. It is important that housing information is also provided because it is only with all the information that older people can make an informed choice about their future financial and housing situation.
107	United Kingdom Homecare Association	Statement 2	It may be useful to cross reference to the work being undertaken by the Social Policy Research Unit at University of York B Block Alcuin Heslington, York YO10 5DD on their ‘SlgN Project’ concerning information to service-users
108	Housing LIN (Learning and Improvement Network)	Statement 2	<p>This section lists the types of information that can help older people with social care needs and multiple long-term conditions. Included in this are telecare services but absolutely no mention of housing-related services, for example specialist housing, home improvement agencies for repairs and adaptations, housing-related support and a range of local initiatives and services offered by housing organisations.. Housing and related services should be added to the list.</p> <p>The Housing LIN is in the process of publishing a dementia and housing self-assessment tool supported by Public Health England, the Alzheimer’s Society and others targeted at local authority and health professionals. Its aim is to enable local commissioners to assess their progress in including housing-related options in their commissioning decisions to maximise integrated working and make best use of all available resources. It will be available on the Housing LIN website very soon. <a href="http://www.housinglin.org.uk">www.housinglin.org.uk</a></p>
109	NHS England	Statement 2	The statement focus is on being ‘given information’ that can help them but outcome uses measure ‘perception of ease of finding information and advice’. This doesn’t make sense giving and finding information are two different things.
110	NHS England	Statement 2	Outcome needs to be developed which measures the suitability of the information given to meet individuals identified

CONFIDENTIAL

ID	Stakeholder	Statement number	Comments <sup>1</sup>
			needs.
111	Royal College of Speech and Language Therapists	Statement 2	Information must be provided in an accessible format and in a format suitable for an individual's needs.  Additional time should be spent with people with communication problems to explain their plan to ensure that they understand the content of this. It cannot be assumed that merely giving someone their plan equates to understanding.
112	Age UK	Statement 2	This statement (statement 2) should be similarly reworded in order to state that the carer should receive an assessment.
5	LondonADASS	Statement 2	We strongly support this statement. We strongly support this measure.
6	LondonADASS	Statement 2	The resources that would be required include: <ul style="list-style-type: none"> <li>• There needs to be accurate recording of social care assessments and what information is provided and whether the information was condition specific, this is especially relevant for people with dementia. This could be held on a local authority database.</li> <li>• More investment in training and role development for Support Planners.</li> </ul> Potential cost savings or opportunities for disinvestment by implementing this statement include: <ul style="list-style-type: none"> <li>• Service users will be better informed and could therefore express higher levels of satisfaction.</li> </ul>
7	College of Occupational Therapists	Statement 2	As above occupational therapists should be named in the list of social care practitioners
115	British Dental Association	Statement 2 - Question 5	Advice on diet and oral hygiene should be required to try to ensure that there is no serious decline in oral health, which would impact negatively on nutrition and self-esteem and could cause unnecessary pain.
116	Alzheimer's Society	Statement 2 - Question 5	Peer support and social interaction is important to people with dementia to help them maintain a good quality of life. A survey of people with dementia in 2014 (Alzheimer's Society, 2014) found that 40% of people with the condition had felt lonely recently. As research shows, loneliness can lead to an early mortality. People living with dementia should be provided with information about dementia advisers and dementia cafes if they are available in the local area. It would also be beneficial to share with them information about social groups and activities in the local area which would encourage them to socialise and stay active.
117	National Pensioners Convention	Statement 2 - Question 5	It is important to recognise that not every individual will be able to rely on a friend or family member to support them in the care system. Even for those with families, it would be wrong to make the assumption that they will be able to offer the necessary and appropriate support. The provision of advocacy services for all who need it is therefore vital for ensuring that individuals are aware of their entitlements, able to exercise any choices they may be given and can put forward their wishes in an appropriate way.
118	RCGP	Statement 2 - Question 5	For a large number of older people with mild to moderate frailty, the interventions needed will be social – i.e. improving participation and resilience through exercise and activity. It is not feasible for information about opportunities for these interventions to be delivered solely through health and social services encounters. We have to

ID	Stakeholder	Statement number	Comments <sup>1</sup>
			find a way of delivering this information in a personalised, location specific way through web based resource – for example using the Council. (DP)
119	OPAAL UK	Statement 2 - Question 5	It's vital that "information" is not simply the provision of leaflets. It is OPAAL's view that there also needs to be a check on the understanding of the information by the older person and a check on their ability to do something with that information once understood. Independent advocacy can support the voice, choice and control of older people with multiple long term conditions and could be much better utilised.
120	Carers UK	Statement 2 - Question 5	It is important that housing information is included for older people as this aims to keep older people independent for longer – access to advice about home adaptations is vital in this. It needs to be tied into the advice and information on finances as a home is often the biggest asset an older person and their carer have. It also needs to provide information about various housing options because it might be that moving into sheltered accommodation will keep an older person and their carer more independent than waiting until the older person has to move into residential care.
121	NHS England	Statement 2 - Question 5	<p>People with multiple LTCs develop cumulative health deficits and their increasing propensity to do so can be described using index frailty as referred to above. There are few evidence based interventions to prevent progression of frailty and maintain independence although there is emerging and increasingly robust evidence that exercise based interventions will delay progression and improve outcomes for targeted populations:  <a href="http://www.sciencedirect.com/science/article/pii/S0003999313012136">http://www.sciencedirect.com/science/article/pii/S0003999313012136</a></p> <p>By targeting this Quality Standard at the right population of people with social care needs (that is those with defined levels of frailty) and for whom there are evidenced based interventions to offset or manage the impact of their cumulative health deficits in the way described it is suggested that quality statement 2 is more likely to achieve its objective. For people with higher levels of frailty (more advanced levels of deficit as a result of their LTCs) the concept of independence may be lost, and there are few evidence based interventions to reverse their accumulated need:  <a href="http://www.sciencedirect.com/science/article/pii/S0140673612621679">http://www.sciencedirect.com/science/article/pii/S0140673612621679</a></p> <p>It is suggested that this group's needs would be more appropriately targeted around care planning for supportive care rather than trying to achieve independence for which there is no evidential basis of reversibility:  <a href="http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4085093/">http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4085093/</a>.</p>
122	NHS England	Statement 2 - Question 5	<p>Consultation question asks if there are types of information for this group that need improved?  Do we need to be identifying what information gaps are being identified during assessment?</p>
123	British Geriatrics Society	Statement 2 - Question 5	For a large number of older people with mild to moderate frailty, the interventions needed will be social – ie improving participation and resilience through exercise and activity. It is simply not feasible for information about opportunities for these interventions to be delivered through health and social services encounters. We have to find a way of delivering this information in a personalised, location specific way through web based resource. ( IN our SouthWest New Forest Vanguard, we are working on this with Hants County Council).
124	Foundations	Statement 2 -	The quality and breadth of and access to information and advice on housing options for older people with care needs

ID	Stakeholder	Statement number	Comments <sup>1</sup>
		Question 5	<p>and longer term conditions needs to be greatly improved. 90% of older people live in ordinary housing and a significant majority own the home they live in. In order for people to be enabled to make informed decisions about their lives information on health and care options must include housing options. The Care Act and its guidance makes explicit reference to housing as a health related services. Where people live matters and currently older people with care needs and long-term conditions are often forced to make decisions about their home at crisis point.</p> <p>Therefore there is not just a need to improve housing related advice and information for them but also a need to ensure people receive this advice and information at a time and place where they are enabled to exercise choice and control as to where to maintain their independence and quality of life. The current reference to telecare and adaptations in the Quality Standard provides inadequate scope for choice and control on housing with care options.</p>
8	LondonADASS	Statement 2 - Question 5	<p>The following specific types of information could be improved:</p> <ul style="list-style-type: none"> <li>• People living with dementia should be given information about services which are specific to dementia, for instance memory cafes or singing for the brain.</li> <li>• Benefits Entitlement/Financial Advice.</li> </ul>
125	Parkinson's UK	Statement 3	<p>Parkinson's UK supports the draft quality statement's recommendation that older people with multiple long-term conditions should have a named care coordinator. The social care system can be extremely complex and difficult to access, as highlighted above. For this reason, an individual responsible for coordinating care across multiple condition areas, as well as primary, secondary and community care would be of great value, particularly in cases where individuals are experiencing dementia related symptoms, or lack mental capacity altogether. This could also have a cost-saving benefit, if people are able to get the support they need before they reach crisis point.</p> <p>However, we note, that the draft quality standard states that individuals 'should be given the name of a person in the team that supports them who will be their care coordinator' but does not specify whether an individual has any responsibility for recommending or approving their care coordinator. We feel this is a critical element of person-centred care, and it is important that an individual feels confident that the coordinator fully understands and respects their wishes.</p> <p>Recommendation: The quality standards ensure that an individual is involved in the appointment of their care coordinator, where appropriate.</p>
126	Dudley MBC. The Directorate of People Services	Statement 3	<p>While these standards are desirable they are likely to place considerable pressure on work-force capacity and available resources which will greatly undermine Adult Social Care's ability to deliver against them. The prospect of achieving these standards from currently available resources is not tenable. There is not a single approach to care-co-ordination and we feel that it will yield the best results if delivered jointly with health. Furthermore, we feel this also needs to be assessed in the context of empowering and supporting carers and people with long-term conditions to</p>

ID	Stakeholder	Statement number	Comments <sup>1</sup>
			manage their own support as well as outcome-based and person-centred care and support being provided by all practitioners. A co-ordinator has a broader remit than just being delivered by statutory professionals; the voluntary and independent sector will also need to be part of this discussion
127	Age UK	Statement 3	This statement refers to older people with multiple long term conditions and social care needs having a care co-ordinator but does not refer to when this should happen. The need for this role might be seen as being at the point that support options are considered or services arranged following assessment, but if people have fluctuating or increasing support needs the role of the care co-ordinator might not be restricted to a single intervention and might be on-going. It is not clear whether measurement of this indicator is intended to be based on the proportion of all older people with multiple long term conditions and social care needs, or the proportion of those who are at the stage of post assessment support planning. Given that, for many older people the need for a care co-ordinator might be longer term we would prefer the former.
128	Stroke Association	Statement 3	<p>Stroke survivors should have a named co-ordinator as part of a single multi-disciplinary team delivering care at the same intensity as would be provided if they had remained on a specialist stroke unit, and we would like to see the statement's wording amended to reflect this. Older people especially – who may not have the same wide circle of family and friends as younger people – benefit from having a named person who they know is responsible for overseeing their care and who they can go to if they have questions or concerns.</p> <p>The co-ordinator should work closely with the hospital discharge co-ordinator so that relevant information can be shared, and we would like to see the statement's wording reflected to reflect this as well. A smooth, joined-up system, involving both health and social care professionals ensures that when they return home from hospital, stroke survivors receive the support they need. Unfortunately, the current lack of multi-agency working is causing serious problems for stroke survivors. Stroke survivors' accounts of these problems include:</p> <p>"My discharge papers had somehow not been completed so nobody knew I was home".</p> <p>"Transfer took from 9:00am to 2:00pm and was a shambles. I missed meals and medication during this period"</p> <p>"I live on my own so there was no-one to care for me, but they sent me home anyway"</p>
129	evidENT	Statement 3	Patients with age related hearing loss would benefit from improved coordinated care. Most people with age related hearing loss delay seeking help and live with their symptoms for an average of 10 years before appropriate referral. When they do seek help from primary care, there is considerable variation in the subsequent pathway with 11 fold variations in the rate of audiology assessments between hearing centres. This is reflected by 1 in 3 people with hearing loss reporting problems in accessing hearing rehabilitation. Moreover, once care is accessed, there is variation in service quality and provision. Hearing loss and its consequences become harder to manage the longer it

ID	Stakeholder	Statement number	Comments <sup>1</sup>
			is ignored. Timely diagnosis and management may improve social interaction, improve mental health and slow cognitive decline
130	British Thoracic Society	Statement 3	Such patients will also need help in navigating the care system especially if they are younger where there is less provision of services so these patients with thoracic respiratory problems and such multi-morbidity may effectively be a “hard to reach” group. The help of a care co-ordinator to navigate the care is essential (statement 3).
131	Cochrane ENT	Statement 3	Patients with age related hearing loss would benefit from improved coordinated care. Most people with age related hearing loss delay seeking help and live with their symptoms for an average of 10 years before appropriate referral. When they do seek help from primary care, there is considerable variation in the subsequent pathway with 11 fold variations in the rate of audiology assessments between hearing centres. This is reflected by 1 in 3 people with hearing loss reporting problems in accessing hearing rehabilitation. Moreover, once care is accessed, there is variation in service quality and provision. Hearing loss and its consequences become harder to manage the longer it is ignored. Timely diagnosis and management may improve social interaction, improve mental health and slow cognitive decline
132	Alzheimer’s Society	Statement 3	The named care co-ordinator for a person living with dementia could be a dementia adviser provided by Alzheimer’s Society (QS 3) as they will know best how to navigate the health and social care system for a person with dementia. Dementia Advisers are specifically trained in the skills to support people with dementia and can signpost to appropriate services and support which meet the needs of the individual. This means that they can make informed decisions in managing their own support. An evaluation for the Department of Health showed that Dementia Advisers can have a positive impact on the quality of life and wellbeing of a person with dementia, as well as their carer. The evaluation also found that there could be cost-saving implications of Dementia Adviser services.
133	RCGP	Statement 3	Risk of circularity. Denominator of those with social care needs, numerator those with a named care coordinator. The tendency will be to make the definition the other way around. In other words to record ‘having social care needs’ only when the referral to a named care coordinator is made. The RCGP recommends to consider a more objective test of the former and set the target quite a way below 100%. (DJ)
134	RCGP	Statement 3	It would be appropriate to count a GP as care coordinator too. (DJ)
135	RCGP	Statement 3	QS 3 – It would be helpful to include details as to who can be care coordinators – i.e. does not need to be a Social worker – or a new type of Health Care Practitioner - this was mentioned in the original guidance but could be repeated.
136	Healthwatch Norfolk	Statement 3	Having a named Care Coordinator is a sound idea. On Page 20 it is suggested that this individual could be a practitioner working for a voluntary or community sector organisation. Whilst this is in theory possible and for service users probably appropriate and appealing, there are ethical, practical and financial issues which would need to be carefully considered. Care Coordinators sourced from the voluntary and community sector would require appropriate training, background checks, support from health and social care providers, appropriate access to information and care plans, appropriate access to health, mental health and social care practitioners etc. This would surely require a



ID	Stakeholder	Statement number	Comments <sup>1</sup>
			<p>localised programme that includes a scoping of gaps and needs, planning for resources and sufficient levels of resourcing and support in addition to a fairly rapid evaluation of effectiveness and outcomes for service users. Many community and voluntary sector organisations have faced considerable financial challenges in the past few years and this may possibly be viewed as a statutory, social care responsibility that is being passed onto the community and voluntary sector.</p>
137	OPAAL UK	Statement 3	<p>Whilst agreeing that a named care coordinator is a good idea, we are concerned about the practicality of this for already over-stretched practitioners. This concern leads us to fear another potential tick box exercise rather than a real and equal relationship between practitioner and older person.</p>
138	MHA (Methodist Homes)	Statement 3	<p>We think there needs to be more clarity of the care coordinator role. There is nothing in the draft standard that indicates what choice the older person has in who performs that care coordinator role for them.</p> <p>We have also just reviewed the draft 'Quality Standard on transition between inpatient hospital settings and community or care home settings for adult with social care needs', which makes reference to a discharge coordinator. There does not seem to be any linkages between these two roles and we think the older people with social care needs and multiple-long term conditions are likely to need the support of both roles, therefore they need to be joined up.</p>
139	[Carers UK]	Statement 3	<p>Any care coordinator must also liaise with the older person's carer, if they have one, and where appropriate keep them informed and provide the information the carer needs to manage the older person's condition and future plans</p>
140	EPA UK/EU	Statement 3	<p>It is ideal and preferred for an older person and carer to have a named care co-ordinator, someone the person can get to know, feels confident to consult and who walks them through the process of meeting ill-health and social care needs. The older person relies on consistency and reliability. There are some concerns associated with applying the standard in practice, particularly in relation to communication. What, for example, happens when a named care co-ordinator is on leave, or sick or gets a new job? In one example, a social worker having built a good relationship with an older person, gets a new job and leaves without telling them or their family, or informing them of what happens next. This disrespects the client and leads to anxiety. In instances like this, local authorities should consider the likely impact when a named care co-ordinator leaves and have an agreed way of responding to this.</p> <p>Do local authorities have the capacity to meet Quality Statement 3? Many are stretched to the limit. This standard already exists in some local authorities, but not always met. A named care co-ordinator may be assigned at the start of the process but not maintained. Resource levels and sheer volume of cases make it less possible to meet this standard consistently. One local authority assigned a named social worker to an older person. Five years later no one person seems to have that responsibility and each year the person changes. This breaks continuity. A social worker may read case notes, before meeting the older person for the first time, but will not have the benefit of a deeper relationship or understanding of that person, their carer or family.</p>

CONFIDENTIAL

ID	Stakeholder	Statement number	Comments <sup>1</sup>
141	British Geriatrics Society	Statement 3	<p>In QS 3- would be helpful if it said what sort of people could be care coordinators – ie does not need to be a Social worker – or a new type of HCP- this was mentioned in the original guidance in the original guidance but needs repeating.</p> <p>I have concern about skills needed for care planning- essentially health coaching, motivational interviewing etc – what we need to push is for this process of care planning to be embedded in every day practice .</p>
9	LondonADASS	Statement 3	<p>We strongly support this statement.</p> <p>We support this measure but note that IT systems have been unable to overcome this to date.</p>
10	LondonADASS	Statement 3	<p>The resources that would be required include:</p> <ul style="list-style-type: none"> <li>• An allocated person who has the time and resource to undertake the role of care coordinator. It may be that this is somebody from the voluntary sector for instance a dementia support worker.</li> <li>• Better IT Systems that support information sharing.</li> </ul> <p>Cost savings or potential opportunities for disinvestment.</p> <ul style="list-style-type: none"> <li>• It could save duplication and professionals time.</li> </ul>
11	College of Occupational Therapists	Statement 3	<p>There is possibly some confusion for service users who receive support from mental health services as well as social care services. All mental health services will already have a care co-ordinator under the Care Programme Approach (CPA). The difference in roles should be made clear and how these services will work together should be clear for the service user. Otherwise it looks as though there will be 2 people doing the same role.</p>
12	College of Occupational Therapists	Statement 3	<p>Named care co-ordinator, as above the list should include occupational therapists</p>
142	Parkinson's UK	Statement 4	<p>We strongly support this draft quality statement. We are pleased that the statement sets out clear examples of the types of information that should be included in a personal health and social care plan, and the recognition of the importance of 'identify[ing] the help they need to look after their own care and support' in particular.</p> <p>However, we are disappointed that this does not make a specific mention of medicines management.</p> <p>Parkinson's UK believes that self-administration of medication should be included in any health and social care planning document, as this will enable people to receive their medication in a timely manner and could prevent their condition from worsening unnecessarily, regardless of their care setting.</p> <p>Ascertaining the ability of a person with Parkinson's to self-administer their medication in hospitals and care homes is essential to ensure those who are able can maintain their complex medication regime.</p> <p>A person with the condition explains: 'My walking suffered a lot without getting my tablets on time especially as I was</p>

ID	Stakeholder	Statement number	Comments <sup>1</sup>
			<p>rather weak anyway. Nurses started asking "Why can't you walk, what's wrong with your legs?" So having the meds myself saved time'.</p> <p>Recommendation: The examples of the types of information that should be included in a personal health and social care plan should be amended to include medicines management information.</p>
143	Age UK	Statement 4	<p>A health and social care plan should focus on individual priorities and aspirations, but is not restricted to this as it should also set out how the person's assessed needs are to be met. Page 25 of the standard includes a list of issues that the care plan should cover and which the person being assessed should be given the opportunity to consider. This list should include those matters which a social care assessment under the Care Act must consider such as the ability to carry out activities of daily living.</p>
144	Age UK	Statement 4	<p>An issue that the quality statement should address is how the contribution made by a carer is included. The Care Act takes the approach that assessment of need should be 'carer blind' and the contribution that the carer is willing and able to make is recorded in the support plan. In other words the presence of the carer is seen as meeting needs but not as resulting in their being no need to meet. This means that gaps in support that would occur if the carer was ill or otherwise unable to carry out their role are recorded, and if necessary a contingency plan is included. The extent to which the support plan properly records the carers' role should form part of how compliance with this quality statement is monitored.</p>
145	Stroke Association	Statement 4	<p>We welcome this quality standard and we are pleased that it has been identified as an area that needs to be improved. Care plans are absolutely essential. Without them, stroke survivors leave hospital with no idea if they will receive vital rehabilitation, let alone who will administer it and how often. Too many stroke survivors feel like they have 'fallen off a cliff' when they leave hospital because they are not supported with their additional needs resulting from their stroke.</p> <p>While this situation is improving – over the course of 2015, the percentage of applicable patients receiving a joint health and social care plan on discharge from hospital increased from 82.7% to 89.3% - only around 49% were discharged with plans for ongoing rehabilitation from a specialist team. [6]</p> <p>Our survey shows that almost 40% of stroke survivors did not have a care plan in place when they went home from hospital. 30% of stroke survivors did not feel prepared when it was time to return home.</p> <p>There is a need for joined up working between health and social care when preparing for the discharge of a stroke survivor. According to the latest Sentinel Stroke National Audit Programme (SSNAP) data, 11% of stroke survivors do not receive a joint health and social care plan on discharge, and our survey shows an even greater problem in this area than the SSNAP figures suggest.[7] Given that 48% of stroke survivors and their carers report problems caused</p>

ID	Stakeholder	Statement number	Comments <sup>1</sup>
			<p>by either poor or non-existent co-working between health and social care, this is clearly an area where improvements need to be made.[8]</p> <p>There needs to be a recognition of the importance of communication and shared decision-making when developing care plans. We would like to see the wording of this statement amended to cement these two critical aspects of effective care plans.</p> <p>[6] RCP Sentinel Stroke National Audit Programme National Results (March 2016) Available: <a href="https://www.strokeaudit.org/Documents/Results/National/OctDec2015/OctDec2015-PublicReport.aspx">https://www.strokeaudit.org/Documents/Results/National/OctDec2015/OctDec2015-PublicReport.aspx</a></p> <p>[7] Royal College of Physicians, 'SSNAP Clinical Audit October-December 2015 Public Report', March 2016, <a href="https://www.strokeaudit.org/Documents/Results/National/OctDec2015/OctDec2015-PublicReport.aspx">https://www.strokeaudit.org/Documents/Results/National/OctDec2015/OctDec2015-PublicReport.aspx</a></p> <p>[8] Stroke Association, 'State of the Nation', January 2016, <a href="https://www.stroke.org.uk/resources/state-nation-stroke-statistics">https://www.stroke.org.uk/resources/state-nation-stroke-statistics</a></p>
146	Royal College of Speech and Language Therapists	Statement 4	<p>People with communication needs must be able to understand the contents of their health and social care plan. To ensure that people are involved in developing this, time must be taken to support communication needs.</p> <p>Appropriate support with communication will allow people to be involved in decisions about their care provision. Especially for people with complex communication problems, the provision of specialist support is essential.</p>
147	Royal College of Speech and Language Therapists	Statement 4	<p>RCSLT recommends adding dysphagia to the list.</p> <p>Harm and even death that can result when people with dysphagia are given the wrong food, medication or access and consume thickening products incorrectly (Patient Safety Alert NHS/PSA/W/2015/002). This is a key area and should be specified in the Personal health and social care plan.</p>
148	Care and Repair England	Statement 4	<p>We would like to see the Quality Statement talk about a 'jointly agreed health, social care and housing plan and where a social care and health plan is mentioned in this section it is amended to state 'health, social care and housing plan'</p>
149	British Thoracic Society	Statement 4	<p>Younger patients will have personal priorities and included in this are the issues around potential transplantation and all the funding / social aspects associated with this and of course a younger population may well have sexual priorities that need to be addressed (statement 4).</p>
150	British Dental Association	Statement 4	<p>Dentistry should explicitly be part of the co-ordinated care package and reviews.</p>
151	Faculty of Pain Medicine	General	<p>Chronic pain is very common in the elderly, has a far reaching impact on disability, impedes rehabilitation, increases social care and in the PSC view a greater consideration may be crucial to the aims of this work.</p>

ID	Stakeholder	Statement number	Comments <sup>1</sup>
152	Alzheimer's Society	Statement 4	It is vital that people with dementia and their carers are involved in their care plan to ensure the services they receive are appropriate and can meet their needs (QS 4).
153	Association of British Neurologists	Statement 4	P24 They should agree and sign their personal health and social care plan and be given a copy to keep. There needs to be a mechanism for what happens if the person does not agree with their health and social plan. Given the limitations on services, there is a risk people may feel coerced into signing plans that they do not agree with, particularly when the plan is set up to facilitate discharge from an acute hospital bed.
154	RCGP	Statement 4	Numerator given as the number who sign it This may be excessively bureaucratic and formal for the patients. On page 23 says 'This should include ensuring that the health and social care plan is signed by all parties'. The process of signing a form would be regarded by patients as very odd, and might evoke considerable suspicion of what it meant. There is not enough evidence in the document to reflect the effect of making patients sign these kind of documents. (DJ)
155	RCGP	Statement 4	QS4 – Recommendation that care planning process should be embedded in ever day practice – concerns about skills needed for care planning (essentially health coaching, motivational interviewing etc.). Care plans require a considerable time investment of about 3 hours per plan and at present resources in health and social care are unlikely to meet this statement. Similarly resources are not available to review already completed plans. There is also a need to standardise care plans across the country to ensure a standard format which is recognisable by health and social care workers including out of hours. Currently there a range of care plans including carers support plans, admission avoidance care plans, person centred plans, long term condition plans, health action plans, wellness recovery plans, direct payment plans and mental health care plans. The care plans should be in a standard paper and electronic format with similar key format including the patient's identification details. (MH)
156	Healthwatch Norfolk	Statement 4	Regarding a jointly agreed health and social care plan: In theory yes this should be achievable but in practice it may difficult. Whilst there has been much discussion on the topic of integration it can be challenging to find evidence of real integration at a strategic level (i.e. pooling/integration of budgets). An example of the challenges for integrated services in Norfolk is the complexity of negotiations since we have five local Clinical Commissioning Groups and one local authority adult social care directorate. Some aspects of commissioning are very well integrated and others are not. Access to GP appointments and primary care relationships continue to be a pressing issue locally, evidenced through our recent focused work with GP surgeries across the county, listening to practice staff and patients.
157	Compassion in Dying	Statement 4	Compassion in Dying is a national charity working to inform and empower people to exercise their rights and choices around their treatment and care.  We do this by: providing information and support over our freephone Information Line; supplying free Advance Decision to Refuse Treatment (ADRT) forms and publications which inform people how they can plan ahead for the end of their lives;

ID	Stakeholder	Statement number	Comments <sup>1</sup>
			<p>delivering one-to-one support to older people through our outreach service, My Life, My Decision; running information sessions and training for professionals, community groups and volunteers on a range of end-of-life topics, including accredited Continuing Professional Development (CPD) modules; and conducting and reviewing research into end-of-life issues to inform policy makers and promote patient-centred care.</p> <p>We welcome this quality standard, in particular statement 4. However, we feel that in the rationale for statement 4 there needs to be specific reference made to the tools people can use to plan ahead for their treatment and care in a legally binding way.</p> <p>Our research shows there is a knowledge gap in peoples' understanding of advance care planning. For example, in one poll 53% of people wrongly believed they had a legal right to make care and treatment decisions on behalf of their next of kin should they lose capacity (YouGov, 2011) and more recent polling shows that only 7% of people have actually set out their wishes for treatment and care in a legally binding way (ComRes, 2016). This lack of understanding shows a need for health and social care professionals to explore these issues in more depth. While we would hope many would do this as part of fulfilling statement 4, we feel more explicit reference to specific tools that people can use would make this more likely to happen.</p>
158	Compassion in Dying	Statement 4	<p>Relating to the comment above, service providers and commissioners must ensure that health and social care practitioners are sufficiently trained to be able to have discussions about planning ahead.</p> <p>The House of Commons Health Committee report on End-of-Life Care recognised that more needs to be done to train professionals to be able to help patients plan ahead. This was also reflected in the Government's response to a House of Lords Select Committee Report on the Mental Capacity Act, which stressed the urgency to: "promote better understanding among health care staff of Advance Decisions". A recent report by the Care Quality Commission (<a href="http://www.cqc.org.uk/content/different-ending-end-life-care-review">http://www.cqc.org.uk/content/different-ending-end-life-care-review</a>), when discussing end-of-life care provision for older people, recommended that "Commissioners and providers make sure that staff who care for people who are likely to be approaching the end of life in any setting to have appropriate training and support to enable them to care for people approaching the end of life."</p> <p>While we acknowledge that quality standards should be read in the context of existing guidelines on training and competencies, we strongly feel that in order to reflect the strength and urgency of the points above reference to training should be added to this section. This would enhance the likelihood of the quality standard meeting its aim to contribute to improvements in older peoples' involvement in decision making.</p>
159	Carers UK	Statement 4	<p>The jointly agreed health and social care plan must also explicitly include an emergency care plan for what happens if their carer is take ill. Older people who have a carer are often very reliant on their carer and a support plan needs to</p>

CONFIDENTIAL

ID	Stakeholder	Statement number	Comments <sup>1</sup>
			<p>be in place and included alongside their health and social care plan.            Where older people have a carer, if appropriate the carer should be included in agreeing the health and social care plan. In many cases, the carer will be providing large amounts of care and it is important their voice is heard too            Where older people have a carer, a copy of the plan should also be given to the carer.</p>
160	Housing LIN (Learning and Improvement Network)	Statement 4	<p>Again no reference to housing and housing related care and support. Useful tools been published on NHS Choices website eg on delayed transfer of care <a href="http://www.nhs.uk/NHSEngland/keogh-review/Pages/quick-guides.aspx">http://www.nhs.uk/NHSEngland/keogh-review/Pages/quick-guides.aspx</a> There is also no reference the role housing sector staff can play in developing the care and support plan.</p>
161	NHS England	Statement 4	<p>The measurement focus is on care plan being written/agreed etc            Suggest develop measure to determine if care plan is actually being carried out, and/or is being effective (could be audited locally/clinical supervision) Otherwise in theory could be a year before there is any requirement to review.</p>
162	NHS England	Statement 4	<p>Review seems driven by the professional rather than the person, why shouldn't the person hold the original and the copy is with the professional?</p>
163	NHS England	Statement 4	<p>What if carer/advocate is agreeing plan on their behalf? Or carer is a key part of the plan?</p>
164	EPA UK/EU	Statement 4	<p>We support this quality statement that older people have a jointly agreed health and social care plan that identifies how their personal priorities and outcomes are met. A concern would be how to ensure true quality is assured in practice and how genuinely 'person centred' the process is. It is important to ensure the completion of care plans is not a paper filling exercise, but an enabling process that involves the older person, carer and family members. There needs to be close and respectful communication between care co-ordinator and older person. The older person would need guidance on how to inform the social care practitioner of any significant changes. An advocate may have to do this on behalf of the older person as navigating local authority phone systems can be complex. Local authorities should consider devising less complex incoming call systems for older people to use.</p> <p>Older people living alone without close family or friendship networks need to be flagged to receive particular attention and support. For example an older person lives alone at home, loves going out but increasing immobility prevents this. His daughter lives in another town. The care plan would have to reflect and seek ways to support access to the community. Because this level of support had not been written into the care plan, it was left to a paid carer, who on her own initiative, chose to take the older person out with her each week when carrying out weekly shopping tasks.</p> <p>The use of voluntary service provision in such instances should also be fully leveraged.</p> <p>There are excellent examples of a private social care providers producing detailed care plans that accurately reflect the person, their needs and committed to ensure needs are met by well briefed and supervised home carers.</p>
165	Tees Esk and Wear Valleys NHS Foundation	Statement 4	<p>This statement may be difficult to measure where services are not joined up - the older person may have a number of care plans which are relevant to each service being provided e.g. mental health, social care, physical health services</p>

CONFIDENTIAL

ID	Stakeholder	Statement number	Comments <sup>1</sup>
	Trust		rather than one plan.
166	Royal College of Speech and Language Therapists	Statement 4	The RCSLT is pleased that communication needs are specified in the Personal health and social care plan.
167	National Community Hearing Association	Statement 4	Suggested change: Sensory loss should be spelt out as hearing loss and sight loss. This is because hearing loss is often overlooked even though it is the most common sensory impairment in people aged 65 and over.
13	LondonADASS	Statement 4	We strongly support this statement. We note that a cohort of patients need to be agreed/defined between health and social care and regularly reviewed / up dated.
14	LondonADASS	Statement 4	Potential cost savings or opportunities for disinvestment by implementing this statement include: <ul style="list-style-type: none"> <li>• Could integrate the care provided if clients / patients were shared across the system.</li> </ul>
15	College of Occupational Therapists	Statement 4	Health and social care practitioners, as above the list should include occupational therapists.
168	Parkinson's UK	Statement 5	We strongly support the draft quality statement's recommendation around the need for reviews of people with multiple conditions with social care needs to be conducted at least annually. Given that Parkinson's is a degenerative condition, regular reassessments of individuals' needs are essential in ensuring that social care support keeps pace with a person's condition and helps them maintain their independence for as long as possible.
169	Dudley MBC. The Directorate of People Services	Statement 5	In order to fully deliver on quality standard 5 it will require integrated and co-ordinated health and social care systems. The use of best practice and Health and Social Care resourcing could lead to improvements in dealing with discharges and referrals.
170	Age UK	Statement 5	This statement refers to an older person having a review of their care and support plan at least annually. However the Care Act takes a more nuanced approach to review that recognises that where someone has fluctuating or declining health, monitoring may need to be more flexible. The Care Act requires that support plans are kept under review generally and guidance calls for proportionate and reasonable, and in some cases 'light touch' review arrangements. This issue is closely related to the point made above regarding when a care co-ordinator is needed. If a person needs to be kept under review through more frequent proportionate or light touch monitoring rather than through a single annual review then more frequent interventions are likely to be needed from the care-co-ordinator.
171	Stroke Association	Statement 5	We very much welcome this statement as we know that stroke survivors are not receiving the reviews they are entitled to and that are set out in guidelines, so this is a key improvement area. Stroke survivors should be receiving reviews at 72 hours, 6 months and then annually, but we know that this is not happening nearly enough.  Not enough stroke survivors are receiving vital 6 month assessments of their care needs – nationally, only 26% of



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			<p>eligible stroke survivors are receiving a six month assessment.[9] In London, only 16% of patients are receiving six month assessments.[10] Our recent survey of stroke survivors found that almost half (47%) were not contacted at all when they returned home from hospital to check on progress or to identify additional support needs. Without proper reviews, we cannot be sure that stroke survivors are getting access to the important rehabilitation services they need to continue to make progress. This is especially important for older stroke survivors who are more likely to be living with multiple long term conditions, and it is equally important for care home residents as well as those in their own homes.</p> <p>There is still too much geographical and quality variation in relation to six month reviews. According to SSNAP, only a quarter of patients considered applicable actually receive a six month assessment and this is clearly unacceptable given the importance of six month reviews to a stroke survivor’s recovery.[11]</p> <p>We are also concerned that only those registered with a GP can get access to six month reviews and believe this needs to change. In London alone, around 150,000 people presenting at A&amp;E every year are not registered with a GP and many of those will be stroke patients.[12]</p> <p>[9] RCP Sentinel Stroke National Audit Programme National Results (March 2016) Available: <a href="https://www.strokeaudit.org/Documents/Results/National/OctDec2015/OctDec2015-PublicReport.aspx">https://www.strokeaudit.org/Documents/Results/National/OctDec2015/OctDec2015-PublicReport.aspx</a></p> <p>[10] NHS London, ‘Six Month Stroke Reviews: A Commissioning Guide (2015) Available: <a href="http://www.londonscn.nhs.uk/wp-content/uploads/2015/11/stroke-six-mo-review-commissioning-guide-082015.pdf">http://www.londonscn.nhs.uk/wp-content/uploads/2015/11/stroke-six-mo-review-commissioning-guide-082015.pdf</a></p> <p>[11] RCP Sentinel Stroke National Audit Programme National Results (March 2016) Available: <a href="https://www.strokeaudit.org/Documents/Results/National/OctDec2015/OctDec2015-PublicReport.aspx">https://www.strokeaudit.org/Documents/Results/National/OctDec2015/OctDec2015-PublicReport.aspx</a></p> <p>[12] BBC News, 12 November 2015. Available: <a href="http://www.bbc.co.uk/news/uk-england-london-34789785">http://www.bbc.co.uk/news/uk-england-london-34789785</a></p>
172	Royal College of Speech and Language Therapists	Statement 5	The RCSLT is pleased that communication needs will be reviewed in the Personal health and social care plan. As need can change over time, we recommend regular review.
173	Alzheimer’s Society	Statement 5	It is important that a review of a person’s health and social care plan is flexible to their needs which may fluctuate (QS 5). Health and social care practitioners must recognise that a person with dementia may need a review on a more regular basis than annually.
174	RCGP	Statement 5	QS 5 – Automatic annual review is a very big ask. Each care plan takes up to 3 hours to complete, especially for people with cognitive impairment in whom there may be many other stakeholders to consult. It’s the conversation that is important – not the care plan itself . The timing of review should be dependent on the individual and may need to be more frequent for some than others.
175	MHA (Methodist Homes)	Statement 5	We agree that the review needs to be at least an annual review and the review timing needs to be dependent on the

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			changing needs of a person. However we do think the statement needs to be clearer about the timing being dependent on changing needs, as the inclusion of the word 'annual' could be seen as the minimum that needs to take place.
176	[Carers UK]	Statement 5	The draft mentions 'What the quality statement means for service users and carers' but does not address what it does mean for carers. Service users having their personal health and social care plan reviewed annually is important for carers because it is a chance to ensure that their needs are also being met, however this needs to be explicitly mentioned and it must include a review of the carers' needs at the same time.
177	EPA UK/EU	Statement 5	'We support the statement that older people have a review of their personal health and social care plan at least once annually. It is stated that 'the frequency of reviews will depend on the individual circumstances and should be agreed with the person' Frequency of social care reviews is also dependent on resources and capacity of provider, private or public, to have more than one review a year. There needs to be flexibility but consistency in the process. There are examples of private sector social care providers with sound and applied regular review processes. There is also evidence of poor practice. In one private social care provider of live-in home care services, care co-ordinators visit the older person once, to complete the initial assessment. They do not carry out annual reviews or visit the client again, but rely on written reports from live-in carers or wait until there's a complaint from the family. 'In a Welsh local authority, the daughter of an older person age 93 and with dementia is the one to initiate a review as the review date had passed and he had reached an advanced stage of care. A comment made by the social worker she spoke to, assumed that 'no news was good news'. Another asked 'is there a problem with the home?' The general impression was 'why are you ringing us?' A review meeting with a resident in a dementia care home was scheduled at a time no family member could be present. The copy of the handwritten report appeared hurried, was brief and made no recommendations. Both these examples suggest social work teams and social care providers are under immense pressure, having to prioritise which clients to see, and follow up. They are just about coping. With rising numbers of older people in the social care system can the social care system as it exists meet NICE guidelines to have an annual or earlier review? And if not, what happens then?
178	EPA UK/EU	Statement 5	How does the statement on an annual review process relate to people living in residential care homes? Where does responsibility lie in initiating annual reviews or change in circumstances? Whose responsibility is it - the care home or local authority? There is an impression that older people receiving domiciliary care are prioritised over those in residential care. The assumption being that if in residential care, needs are more likely to be met. This is not necessarily the case. Resourcing constraints sometimes mean that basic needs, like being taken for a daily walk are not met. Relatives may be busy or becoming aged themselves, the volunteer sector could be utilized much more in this area. Instead, older people in residential care homes are kept in a holding position, sitting in chairs all day, previous interests and occupations forgotten, no longer referred to or supported.
179	British Geriatrics Society	Statement 5	Automatic annual review is a very big ask. – Each care plan takes up to 3 hours to complete- especially for people with cognitive impairment in whom there may be many other stakeholders to consult. It's the conversation that is

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			important – not the care plan itself . The timing of review should be dependent on the individual- and may need to be more frequent for some . NHS England has just funded a project through ICHOM to develop some internationally valid health and social outcome measures for older people – they are due to be published in July – would be nice if these could be referenced.
180	NHS England	Statement 5	Is at least an annual review best practice? Although reviews can be more frequent depending on changes, should we be having a more staged approach to this e.g.: Initial assessment, review by 6 months, at first year then at least yearly.
16	LondonADASS	Statement 5	We strongly support this statement. Would need to agree on what a care plan is and what a joint care plan would look like.
17	LondonADASS	Statement 5	Potential cost savings or opportunities for disinvestment by implementing this statement include: <ul style="list-style-type: none"> <li>• Patients/families may feel more empowered and encouraged towards self-management.</li> </ul>

### ***Registered stakeholders who submitted comments at consultation***

- Age UK
- Alzheimer's Society
- Arthritis Research UK
- Association of British Neurologists
- British Dental Association
- British Geriatrics Society
- British Thoracic Society
- Care and Repair England
- Carers UK
- Cochrane ENT

## CONFIDENTIAL

- College of Occupational Therapists
- Compassion in Dying
- Department of Health
- Dudley MBC. The Directorate of People Services
- evident
- EPA UK/EU
- Faculty of Pain Medicine
- Foundations
- Healthwatch Norfolk
- Housing LIN (Learning and Improvement Network)
- LondonADASS
- MHA (Methodist Homes)
- National Community Hearing Association
- National Pensioners Convention
- NHS England
- Northumbria Healthcare NHS Foundation Trust
- OPAAL UK
- Optical Confederation and Local Optical Committee Support Unit
- Parkinson's UK

CONFIDENTIAL

- RCGP
- Royal College of Nursing
- Royal College of Physicians
- Royal College of Speech and Language Therapists
- Stroke Association
- Tees Esk and Wear Valleys NHS Foundation Trust
- United Kingdom Homecare Association