NATIONAL INSTITUTE FOR HEALTH AND   
CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1. Quality standard title

Supporting adult carers

Date of quality standards advisory committee post-consultation meeting:   
8th December 2020

1. Introduction

The draft quality standard for supporting adult carers was made available on the NICE website for a 4-week public consultation period between 12th October and 9th November 2020. 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 25 organisations, which included 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 are provided in appendices 1 to 3.

1. 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 data for the proposed quality measures? If not, how feasible would it be to be for these to be put in place?

3. 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 resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

4. Do you have an example from practice of implementing the NICE guideline that underpins this quality standard? If so, please provide details on the comments form.

1. General comments

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

* Support for the quality standard but recognition that it needs to be strengthened in some areas.
* Concern that some of the statements do not reflect current laws for social care and therefore fall short of carers’ existing rights.
* Concern that the limited focus of the statements is not compatible with the good practice work included in the [NHSE&I GP Quality Markers](https://www.england.nhs.uk/publication/supporting-carers-in-general-practice-a-framework-of-quality-markers/).
* Lacks robust outcome measures and will be easy to ignore, particularly without legislation making it a duty for the NHS to identify and support carers.
* Important to emphasise that carers are not obliged to provide care.
* More emphasis on ‘circles of care’ where several carers are involved and how this should be managed.

### Consultation comments on data collection

* Concerns that the systems and structures are not in place to collect the data required. Data collection and monitoring is limited in social care but even more limited across healthcare.
* Sharing information across IT systems can be problematic. Resources will be required to bring data together from a range of sources across organisations.
* Include the GP Patient survey as an important data source.
* Helpful to add indicators for carers to the QOF.
* Concern about a potential over-reliance on surveys.

### Consultation comments on resource impact

* Concern that it will be difficult to achieve the quality standards within current resources as there are already capacity issues, particularly during the pandemic.
* Important for health and care organisations to work with local third sector organisations that support carers. However, many carer support services have no capacity to support additional work.
* Could be potential for local authorities to develop invest to save models in adult social care with specialist teams working with carers to relieve pressures on first point of contact and operational services.

### Consultation comments on equality and diversity considerations

* Reflect wider issues like poverty and the lack of societal acceptance of disability.
* Ensure that carers communication, cognitive or literacy difficulties are recognised and supported to ensure better engagement and shared decision making.

1. Summary of consultation feedback by draft statement
   1. Draft statement 1

Carers are identified by health and social care practitioners at appointments for people with long-term conditions.

### Consultation comments

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

* General
  + Although there was some support for this statement there were concerns that it is too limited and does not work well across both health and social care.
  + This falls short of the Care Act 2014 requirements for social care which indicates that local authorities have a wide-ranging duty to identify carers (including children), not just at appointments for people with long-term conditions.
  + It is unhelpful because it differs from [NHS England’s framework of quality markers for general practice](https://www.england.nhs.uk/publication/supporting-carers-in-general-practice-a-framework-of-quality-markers/) in relation to identification and registration.
  + Should recognise that people with long-term conditions may be providing as well as receiving care from someone else.
* Statement
  + Recognise that local authorities do not have appointments with people specifically because they have a long-term condition, but focus on assessing, planning and reviewing care and support for a person in need.
  + There should be a broader focus to capture wider opportunities to identify carers including hospital discharge, people receiving end of life care and support, elective surgery, A&E, housing, DWP, optician or hearing appointments, chiropody, and at the carers own appointments.
  + Include a focus on identifying ‘hidden carers’, for example, through data analysis and comparisons with demographic data and outreach work.
* Rationale
  + Make it clearer that long term conditions include mental health conditions and addiction.
  + Clarify that recording and sharing information about carers should be with their consent.
* Measures
  + Include a measure to capture conversations with carers about how they see their role and how they want to be defined.
  + Using more inclusive terminology such as ‘family’, ‘significant others’ or ‘support network’ rather than ‘carer’ in data collection systems would be a better match with how ‘carers’ view themselves.
  + Highlight the potential to share information between health and care organisations and the voluntary and community sector. Change ‘system’ to ‘process’ in structure b) to help ensure details about carers are shared.
  + Highlight Carers Passports to ensure carers are identified as they move between services.
  + Outcome a):
    - The QOF for dementia could be included as a data source
    - Important to avoid double-counting.
  + Outcome b) could be collected by carer support services when carers register with the service.
* Audience descriptors
  + Commissioners should actively consult and involve carers in the co-production of commissioning processes and decisions.
  + Health and social care practitioners ‘should’ rather than ‘may’ offer carers the opportunity to have a confidential conversation.
  + Include mental health practitioners, community pharmacists and social prescribers.
  + Recognise that carers may not attend appointments with the person with a long-term condition, but information and advice could still be shared with them.
* Definitions
  + A definition of ‘care’ should be added to clarify that it is not limited to personal care and includes instrumental activities of daily living such as shopping, preparing meals, or providing respite to a primary carer.
* Equality and diversity considerations
  + Practitioners should recognise that it may be more difficult for some carers to seek support, including those whose first language is not English and LGBT+ carers. Cultural awareness can also help with identifying carers who may require an approach outside a formal appointment.
  + Recognise that people with severe learning disabilities may not be able to say if someone is giving them help and support.
  + Highlight that young adult carers should not be ignored
  + The NHS Long Term Plan identifies the need for early identification of carers in vulnerable communities including BAME, LGBT, very elderly, young adults and others.

### Issues for consideration

* Should we progress this statement to the final quality standard?
* Can we include health and social care in the same statement given the different contexts?
* How can we focus the statement to ensure it is manageable and measurable in practice?
* Would an organisation-focussed statement work better?
* Some of the initiatives highlighted in the ‘identification and registration’ section of the NHSE&I GP quality markers e.g. carers register, reviewing registers, are not included in the NICE guideline.
* Carer passports are a research recommendation in the NICE guideline.
  1. Draft statement 2

Carers are kept up to date and contribute to decision making and care planning for the person they care for, with the person’s consent.

### Consultation comments

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

* General
  + There was support for this statement and recognition that it reflects good practice.
  + Information on the Mental Capacity Act should be added. Recognise that not everyone has capacity to give consent and that some carers may have Lasting Power of Attorney for someone that does not have capacity. It should also be clear what should happen if the person does not have capacity.
  + Recognise the need for staff training in how to involve carers as partners and the value that this can bring.
  + Emphasise the role of a carers champion and a carers passport in promoting the involvement of carers.
* Statement
  + Strengthen the wording to ensure carers are ‘treated as partners’ or ‘actively engaged’ in decision making and care planning.
  + Recognise that even if the person does not give consent it is still important to share generic information e.g. about the condition and medicines with the carer and to give them advice on where to get help and support.
* Rationale
  + More emphasis on how involving carers can improve the care for the person they care for, by helping to ensure that the care plan is implemented and successful resulting in reduced hospital admissions.
  + Important to ensure that the wishes of the person receiving care are central and if they have capacity, the carer would not ‘own’ the plan.
  + Suggestion to change ‘kept up to date’ to ‘properly informed with timely information that is useful to them as a carer’.
* Measures
  + Add a measure to ensure carers are given a written copy of a care plan.
  + Structure b) should include evidence of the carer contribution and discharge plans.
  + Concern about the resource implications of carrying out a local survey.
  + Additional outcomes suggested:
    - proportion of carers who feel supported in their caring role
    - proportion of carers who feel recognised and valued by professionals.
* Audience descriptors
  + Helpful to provide more detail on how to involve carers meaningfully. This could include adding a link to [NHS England’s Ask, Listen, Do principles](https://www.england.nhs.uk/learning-disabilities/about/ask-listen-do/).
  + Include pharmacists and care homes.

### Issues for consideration

* Should we progress this statement to the final quality standard?
* Do we need to include consent in the statement? Should we add a link to the NICE guideline on decision-making and mental capacity (NG108)?
* Does the statement wording capture the role of the carer?
* What do we mean by ‘kept up to date’?
* A carer champion is a ‘consider’ recommendation – will it be helpful to include?
* What information about carers do we expect to be included in care plans?
  1. Draft statement 3

Carers having a carer’s assessment are asked about what matters most to them, including consideration of their health, wellbeing and social care needs, and work, education, or training.

### Consultation comments

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

* General
  + There was some support for this quality statement although it was suggested that it may be too limited.
  + Concern that the shift towards a ‘what matters most to you’ approach is truncating carers assessments and overlooking key areas that should be included under the Care Act 2014.
  + The focus of the statement is already covered in the Care Act 2014.
* Statement
  + Suggestions to broaden the scope of the statement to include other markers of quality such as:
    - ensuring carers are offered a separate assessment from the person they care for
    - asking whether the carer is willing to continue in their caring role
    - include carers breaks as they are essential to health and wellbeing and should be included in all carers assessments as per the Care Act
    - the need to plan for the future in order to support carers at different stages of the caring journey
    - what comes after an assessment and the duty to meet assessed need as identified in the Care Act
    - ensuring the information, training and support provided to carers is helpful.
  + ‘Consideration’ should be strengthened.
  + Include carers’ assessments and reviews.
* Rationale
  + Emphasise that the carers assessment should be high quality.
* Measures
  + Structure b)
    - Does it include carers who are in work?
    - Is it the number of carer assessments completed or the number completed with a support plan?
  + Outcome b) could measure the impact of the assessment and support as before and after.
  + Outcome c) should focus on carers who want to work.
  + Additional outcome measure for ‘proportion of carers who say they are in good health’ suggested.
* Audience descriptors
  + The requirement for providers to have ‘knowledge and understanding of potential opportunities for returning to, or remaining in, work, education or training’ needs clarification.
  + More detail on the staff training required.
* Equality and diversity
  + Strengthen requirements to ensure that people can have an assessment that is accessible and takes account of their needs.

### Issues for consideration

* Should we progress this statement to the final quality standard?
* Is the statement covered by the Care Act?
* Is the focus on a ‘what matters most’ approach appropriate?
* Could we include additional components of a ‘high quality’ assessment?
* Should ‘reviews’ be added?
* Can we be more specific about the training and knowledge that staff require?
* Is it confusing to have a separate but overlapping statement on breaks?
  1. Draft statement 4

Carers discuss, during their routine assessments and reviews, the value of having a break from caring and the options available to them.

### Consultation comments

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

* General
  + There was some support for this statement and recognition of the importance of breaks in helping carers to maintain their physical and mental health.
  + Concerns that there is not a consistent stream of funding for carers’ breaks and funding for replacement care has been subject to cuts. Options can be limited, particularly for people with specific needs e.g. positive behavioural support.
  + Access to breaks during the pandemic has been even more limited and it has been challenging to provide alternative options which has put carers at risk.
* Statement
  + The wording seems to put the onus on the carer.
  + Concern that routine assessments, reviews and health checks are not happening in practice and therefore it is not appropriate to focus on them.
  + Concern that practitioners carrying out some routine assessments and reviews may not be well placed to discuss breaks and options available for carers.
  + Carers assessments and reviews are not carried out routinely.
  + It needs to be clearer that discussing breaks is an essential rather than an optional quality component for carers assessments and reviews.
  + Focus should include access to breaks. It should be clear that there is a duty to meet assessed need which goes beyond discussion and providing information for breaks.
* Measures
  + Outcome a):
    - is a timescale needed?
    - local data on breaks provided may be recorded separately depending on the funding stream.
  + Outcome b) could measure the impact as before and after.
* Audience descriptors
  + Helpful to collect data on unmet needs for breaks by type of support to inform commissioners who have a market shaping duty under the Care Act.
  + Commissioners should co-produce services and support options with carers.
  + Add social prescribers and mental health practitioners.
* Definitions
  + The term respite care should be replaced with replacement care.
  + Helpful to highlight that breaks can take different forms including the option for the person with care needs and the carer to be able to take a break together.
  + A definition of a ‘break from caring’ is needed for measurement. However, having a break is very subjective, which could make measurement difficult.
* Equality and diversity
  + Services that provide replacement care and support for carers to have a break should be accessible, culturally diverse and make reasonable adjustments.

### Issues for consideration

* Should we progress this statement to the final quality standard?
* Should carers assessments be included?
* Is the focus on routine assessments and reviews helpful?
* Does it need to be clearer that the discussion is with health and social care practitioners?
* Respite care or replacement care?
* How is a break defined for measurement purposes?
  1. Draft statement 5

Carers work in organisations that offer supportive working arrangements.

### Consultation comments

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

* General
  + There was support for the quality statement.
  + Is it within the remit of the NICE quality standard and local health and social care organisations to influence all employers to take action?
  + Some carers have benefited from more flexibility by working from home during the pandemic. Employers should be aware of this as they move towards returning people to the workplace.
* Statement
  + It needs to be clearer which employers are included e.g. those that employ carers, large organisations.
  + Suggestion to restrict the statement to health and social care organisations and third party commissioned services.
  + The statement is very broad – could it be more specific?
* Rationale
  + Working carers are often hidden. Raising the profile of support for carers among employers will help to reduce stigma.
  + Needs to be clearer how carers are protected by the Equality Act.
  + Could help to address the gender pay gap as more women are carers.
  + Could attract a more diverse workforce.
* Measures
  + Data on the number of employers accredited as carer friendly or participating in relevant initiatives would be helpful.
  + Outcome a) - concern about the accuracy of the data as some carers will choose not to work and only a proportion of carers are in contact with the local authority. By the time carers are in contact with the local authority they are less likely to be in work.
  + An additional outcome measure on the proportion of carers reducing or stopping work in order to care should be included.
* Audience descriptors
  + Employers should involve carers in developing policies and plans to support carers.
  + It would be helpful to refer to the [Carers UK Employers for Carers](https://www.employersforcarers.org/) website.
* Definitions
  + Supportive working arrangements could also include:
    - Carer passports
    - Agile working
    - Using technology to support flexible working
    - Transport such as accessible car parking
    - Training for managers on supporting carers

### Issues for consideration

* Should we progress this statement to the final quality standard?
* Should we focus on all employers or just those in health and social care?
* Is the focus on supportive working arrangements helpful?
* Are there any accreditation schemes that we could include?

1. Suggestions for additional statements

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

* **Providing information to carers about support that is available and the right to have a carer’s assessment. Ensuring carers are offered or referred for a carer’s assessment.**
  + NG150 recommendations 1.1.1 to 1.1.3 cover the right to information and support for carers. Recommendation 1.2.1 covers providing information about a carer’s assessment. This area was discussed at the prioritisation QSAC meeting but not progressed.
* **Psychological and emotional support for carers including psychoeducation, and trauma informed support and interventions.**
  + NG150 recommendations 1.7.1, 1.7.3 and 1.7.6 cover psychological and emotional support for carers. This area was included in the briefing paper but the committee agreed not to discuss it in detail at the prioritisation QSAC meeting because the recommendations are ‘consider’.
* **Skills training**
  + NG150 recommendations 1.6.1, 1.6.5, 1.6.6 and 1.6.11 cover carer training programmes. This area was discussed at the prioritisation QSAC meeting but not progressed.
* **Supporting carers towards the end of their caring role and when it has ended.**
  + NG150 recommendations 1.8.2 and 1.8.3 cover the provision of emotional and practical support to carers when their role changes, including when it comes to an end. Support during changes to the caring role was included in the briefing paper but the committee agreed not to discuss it in detail at the prioritisation QSAC meeting because there is an existing statement on involving carers in discharge planning in the transition between inpatient hospital settings and community or care home settings for adults with social care needs quality standard QS136.
* **Safeguarding – risk thresholds when the cared for person or carer poses a risk**
  + This area is beyond the scope of the NICE guideline on supporting adult carers (NG150). There are no other NICE accredited guidelines that cover this area. This area has not previously been discussed by the committee.

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

| **ID** | **Stakeholder** | **Statement number** | **Comments[[1]](#footnote-1)** |
| --- | --- | --- | --- |
| 1 | Alzheimer’s Society | General | Alzheimer’s Society would like to take this opportunity to welcome this quality standard on supporting adult carers. Of course, this standard is designed to be a valuable tool in any situation – however, it is worth taking account of the impact of the current Covid-19 on carers and the landscape of support.  The Coronavirus Act introduced in March 2020 allowed councils to adopt easements to their duties under the Care Act 2014. The purpose of this was to temporarily relax certain responsibilities in order to prioritise care during this period of significant pressure. These easements included reducing obligations to carry out assessments of people’s needs, to undertake financial assessments for care needs, to prepare or review care and support plans, or to undertake assessments of the needs of informal carers. This raised concerns that people with dementia may experience reduced support with potential for irreversible deterioration to their condition if their needs were not met. Alzheimer’s Society published recommendations for how to adopt Care Act easements appropriately if they are required in exceptional circumstances.  Link: <https://www.alzheimers.org.uk/sites/default/files/2020-05/Dementia%20and%20Care%20Act%20Easements%20-%20briefing%20for%20Local%20Authorities.pdf>  Since coronavirus (COVID-19) lockdown on 23 March, an Alzheimer’s Society investigation has discovered family and friends have spent an extra 92 million hours caring for loved ones with dementia.   * 95% of family carers we surveyed said extra caring hours had negatively impacted their physical or mental health, with 69% of over 1,000 people the charity spoke to reporting feeling constantly exhausted, 64% feeling anxious, 49% feeling depressed, and 50% developing problems sleeping. * 14% had no time to see a GP about a health problem, and more than one in ten (13%) said they’d had an injury from caring. * The percentage of people spending 100 hours or more a week looking after or helping the person they care for increased from 40% before 23rd March to 50% after 23rd March. * 73% of carers reported that their caring responsibilities have increased during lockdown. * 76% reported their caring responsibilities had increased because of worsening dementia symptoms of the person they care for.   Source: <https://www.alzheimers.org.uk/news/2020-10-05/exhausted-family-and-friends-spent-92-million-extra-hours-caring-loved-ones>  An Alzheimer’s Society survey of 1,800 carers and people living with dementia showed that 41% of people who received a care and support package had had this reduced or stopped since lockdown began. Most respondents (57%) stated they did not receive these services in the first place, although the survey did not indicate whether those respondents needed such services and we know many struggle with access to basic care. Combined with distancing and shielding guidelines, this means that many people affected by dementia have been struggling to cope in isolation, with even less support than usual to deal with the sometimes severe and complex care needs that dementia can bring.  Source: <https://www.alzheimers.org.uk/news/2020-07-30/lockdown-isolation-causes-shocking-levels-decline-people-dementia-who-are-rapidly>  The ONS Vivaldi study carried out between 26 May and 20 June estimated that 97% of care homes had been closed to visitors.  Source: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/impactofcoronavirusincarehomesinenglandvivaldi/26mayto19june2020>  We know the impact that this lack of social contact is having on people affected by dementia. This is why we’ve been calling for allowing for at least one informal carer per care home resident to be designated a key worker, with access to training, COVID-19 testing/ vaccinations and PPE to enable them to visit, provide care, and connect with their loved ones safely.  Source: <https://www.alzheimers.org.uk/sites/default/files/2020-06/Social-Contact-Briefing_June-2020.pdf>  In this response we will additionally provide content from three recent reports from Alzheimer’s Society. Links are provided here for ease and will not be provided for each instance. All can be cited as “Alzheimer’s Society (2020)”  Worst Hit: Dementia During Coronavirus: <https://www.alzheimers.org.uk/news/2020-10-05/exhausted-family-and-friends-spent-92-million-extra-hours-caring-loved-ones>  The Fog of Support: An inquiry into the provision of respite care and carers assessments for people affected by dementia <https://www.alzheimers.org.uk/sites/default/files/2020-09/as_new_the-fog-of-support_carers-report_final-compressed.pdf>  From diagnosis to end of life: The lived experiences of dementia care and support <https://www.alzheimers.org.uk/about-us/policy-and-influencing/from-diagnosis-to-end-of-life> |
| 2 | Alzheimer’s Society | General | “Other quality standards that should be considered when commissioning support for adult carers include:” could also include NICE standard NG97: [www.nice.org.uk/guidance/ng97/chapter/Recommendations#supporting-carers](http://www.nice.org.uk/guidance/ng97/chapter/Recommendations#supporting-carers)  This covers psychoeducation and skills training intervention, support packages and assessments. This is consistent with including other condition-specific NICE standards in this section. It is important to include dementia here given our recent analysis of the Survey of Adult Carers in England (SACE) for our report with CEBR “The economic cost of dementia to English businesses – 2019 update” found that 35% of carers who provide care to adults in England are providing care to someone with dementia. This totals 1.8 million people who provide some level of care and support to another adult (which may not mean they are someone’s primary carer).  Source: <https://www.alzheimers.org.uk/blog/yvonnes-story-career-on-hold> |
| 3 | British Association of Social Workers | General | BASW welcomes the quality standard but feel that they could be improved by highlighting some of the complex issues which social workers (and other professionals) need to address in some cases as outlined in relation to each of the statements above.    We would ask for consideration of adding safeguarding as a statement 6 to this Quality standard- see rationale in relation to statement 2 above. |
| 4 | Carers Trust | General | Carers Trust would also urge NICE to take on the points made in Independent Age’s response to this consultation and review the data and evidence in Independent Age’s In Focus: Experiences of older age in England report and Experiences of being an older carer data briefing.  <https://independent-age-assets.s3.eu-west-1.amazonaws.com/s3fs-public/2020-03/Report_vF_0.pdf?uvSO_QlHsZnM7SBuCIZ7lqenyLm7PQ6o=>  <https://independent-age-assets.s3.eu-west-1.amazonaws.com/s3fs-public/factsheets/2020-03/IA-PI-377_Carers_snapshot_v4.pdf?Q_zkx1vVmCSRlKBUCoGe99aswpIOEeWS=> |
| 5 | Carers Trust | General | Carers Support Centre Brigg and Grimsby are a Network Partners of Carers Trust. As the registered stakeholder which most closely represent their interest, the Carers Support Centre contacted Carers Trust. The Carers Support Centre Brigg and Grimsby worked closely with their local commissioners, North East Lincolnshire CCG, and the below is their joint response. |
| 6 | Carers Trust | General | Caring Together are a Network Partners of Carers Trust. Carers Trust contacted all Network Partners in England about this consultation and sought their feedback and comments. Below is Caring Together’s response. |
| 7 | Carers Trust | General | What about when the caring role comes to an end? |
| 8 | Carers UK | General | Summary of our overall response  We are concerned that some of the quality statements, as currently written, fall short of current laws on social care. Whilst we recognise that some of the standards might help to increase support across the NHS, the standards in their current form are not fully compatible in their breadth with good practice work such as the NHSE GP Quality Markers.  NICE standards and statements are developed for use by a whole range of different stakeholders. Given that we feel these statements fall short of carers’ existing rights, we would suggest that this is providing inaccurate information to those stakeholders, due to the limited nature of the statements.  We would strongly suggest that the standards are rewritten to reflect social care law and the NHSE/I GP Quality Markers good practice work. |
| 9 | Carers UK | General | Broader issues needing to be tackled by Government  NHS legislation and carers: What this work highlights are the differences between the legislation across health and social care. Whereas in social care legislation, carers have parity of esteem, within health legislation they are legally less visible. We believe that the Government needs to level-up the legislation with social care and ensure that future NHS legislation recognises carers clearly.  Data collection and monitoring: A second issue highlighted by this work are the different ways in which data collection and monitoring are limited across social care, but almost non-existent particularly across health care. The most valuable data source in healthcare is the GP Patient Survey which we feel could be utilised better. |
| 10 | Motor Neurone Disease Association | General | About this quality standard (improving outcomes)  We think there is something missing in terms of improving carer skills and competencies in undertaking agreed care. This could be important when the caring role will be enduring and as the need for more complex care provision increases. |
| 11 | NHS England and NHS Improvement | General | Emergency provision of care if the carer is taken ill is vital (PC) |
| 12 | NHS England and NHS Improvement | General | We recommend the guidance places emphasis on the need to be aware of carers’ traumatic experience and to be able to deliver trauma informed support and interventions when required, and also emphasises the effect of wider issues like poverty and lack of societal acceptance of disability. (RD) |
| 13 | NHS England and NHS Improvement | General | As family carers are within families, we recommend the guidance refers to the need to be aware of the potential impact of caring on the wider family, for example on siblings. (RD) |
| 14 | NHS England and NHS Improvement | General | We recommend this guidance includes a section on forward life planning. Family carers are often concerned about the long term prospects for themselves and for the person for whom they provide care to- “What happens after I am gone”. There should be active support to think about the future and make provisional/robust plans(RD) |
| 15 | NHS England and NHS Improvement | General | We recommend the guidance includes a section on transition planning. Organisations cannot assume that parent carers want to or can continue caring. (RD) |
| 16 | Royal College of Physicians (RCP) | General | Care homes should be included in the list of Service providers.  PCN member said ‘The Care home where Jean lived kept myself and her daughters fully in the picture and encouraged us to help in her care and were very supportive to me.’ The role of care homes needs to be recognised in the QS; as it does not come across clearly. |
| 17 | Royal Pharmaceutical Society | General | Many care receivers are supported by several unpaid care givers. (Carers UK often reference ‘circles of care’). This is mentioned briefly in the guidance but could do with more emphasis. For example would multiple carers support decision making for the care receiver or would there be a primary carer bearing in mind that care needs and who cares often change too.  Now that virtual consultations are more common there is value in pharmacists supporting carers and care receivers with their medicines and questions and having conversations with both the carer and the care receiver at the same time rather than just including two people in the discussion. |
| 18 | The Challenging Behaviour Foundation | General | Family carers should have access to appropriate and timely psychological and emotional support.  There needs to be recognition that families experience trauma too (as well as children, young people and adults with learning disabilities and autism) and the impact on them needs to be acknowledged and addressed.  (Children with intellectual disabilities experience a greater number and range of adverse life events- Hatton & Emerson, 2004 (<http://www.research.lancs.ac.uk/portal/en/publications/the-relationship-between-life-events-and-psychopathology-amongst-children-with-intellectual-disabilities(a39b0426-5d1c-4ab7-b51c-f1f7808d7d62)/export.html>)  It is important to recognise that carers (often traumatised themselves) are sometimes also providing trauma support to their family member, due to lack of available trauma support for people with severe learning disabilities. Recent NHSE work (Respond, CBF and the Tizard Centre) soon to be published has looked at this issue in a report entitle ‘Predictable and Preventable’, and the CBF has a report entitled “Broken”. |
| 19 | University Hospitals Birmingham (UHB) NHS Foundation Trust | General | Staff training could/should be included in the sections focusing on ‘What the quality statement means for different audiences’ as well as the ‘outcomes’ and ‘measurements’ sections. In large organisations such as UHB staff training in Carer Awareness which covers how to identify, recognise and support carers is a vital component of delivering against the standards. It is also easy to measure through audit and link to improvements |
| 20 | Alzheimer’s Society | Question 1 | “Does this draft quality standard accurately reflect the key areas for quality improvement?”  We would suggest that this standard should also incorporate standards for access to carer interventions e.g. psychoeducation and skills training. This would be consistent with existing NICE guidance, including for dementia. |
| 21 | Carers Trust | Question 1 | Question 1 Does this draft quality standard accurately reflect the key areas for quality improvement?  To a degree. The areas are right, but some standards need to go further in recognising the contribution of Carers and the important role Carers play. More direction is needed on statements 3 and 4 regarding assessment outcomes and duties. |
| 22 | Carers Trust | Question 1 | Missing focus on early identification and also ensuring carers can plan ahead (including for emergencies and when their caring role is likely to come to an end) |
| 23 | Carers Trust | Question 1 | Concerning that young carers/parent carers aren’t being included, unless there is separate work going on to include them |
| 24 | RCSLT | Question 1 | Question: Does this draft quality standard accurately reflect the key areas for quality improvement?  No. We would like to see a much greater focus on health literacy underpinning all care planning and the carer’s assessment.  Based on the experiences of our members, they report that engagement with services generally can be challenging for people if they have poor health literacy or poor literacy, let alone to carers with specific communication difficulties.  This consideration goes beyond an equality issue for carers with additional needs and should underpin all conversations that take place to enable shared decision making between all carers, the person they care for and the health or care practitioner. At present the importance of health literacy is missing from the quality standard. |
| 25 | Royal College of Physicians (RCP) | Question 1 | Does the Quality Standard (QS) accurately reflect key areas for improvement?  The QS clearly focuses on a Carer's needs, how to find out if there is a carer; how to ensure they can contribute to the overall care process; and ways in which their own needs can be ascertained and met, etc.  There are a few great ideas in the QS, and also careful consideration of many aspects of adult care.  The QS lacks robust outcome measures and will be very easy to ignore  In some cases, it falls short of Care Act legislation and current social care law  Without legislation making it a duty for the NHS to identify and support carers, very little will change  The draft states that employers should be flexible in order to support the carer to carry out their caring responsibilities. Is there a way for health care workers to influence employers?  The QS is a very worthy statement, the content of which is hard to dispute and there is a huge amount of content.  The question which jumps out is; out of all this worthy material and great aspiration what is going to be of most use to Adult Carers, what would carers feel is most important to be delivered to support them especially given resource limitations.  It is a matter of identifying priorities with carers and focusing on them with laser like intensity.  Patient and Carer Network (PCN) member said – “I have long wished for this kind of help to be around.” |
| 26 | University Hospitals Birmingham (UHB) NHS Foundation Trust | Question 1 | NEW statement (6)  It is felt that there needs to be a Quality Statement 6 which focuses specifically on ‘supporting carers towards the end of their caring role and when their caring role has ended.’  When the person they care for has died, ensuring that carers don’t slip through the gap and are supported to access ongoing care and support whilst dealing with their personal grief is vital. Carers are often left with a void when the caring role ends so information, support and signposting at this point is closing the loop in terms of holistic support throughout their caring journey. This statement would also need to cover other scenarios for example if the caring role ends for reasons other than bereavement, for example due to increased independence through recovery, the person they care for moving into residential or nursing care establishments, or the care being taken over by others due to the failing health of the care. Feelings of loss, guilt, loneliness all need to be addressed and the carer supported to work through this. |
| 27 | Alzheimer’s Society | Question 2 | “Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be for these to be put in place?”  Our research Fog of Support suggests that local authorities do not have access to data at a more detailed level than the publicly reported datasets, even at a Director/commissioner level. Furthermore, the current reporting framework significantly inhibits an assessment of local spending and provision which would enable appropriate assessment of whether local authorities are meeting their responsibilities. Much data that does exist is not condition specific which limits capacity to develop holistic interventions.  We would recommend that some standards could be added to existing QOF standards. |
| 28 | British Association of Social Workers | Question 2 | 1. Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be for these to be put in place?   Sharing information can be problematic when using different IT systems to capture and store data, reliant on professionals or other involved to share information as systems do not talk to each other. |
| 29 | Carers Trust | Question 2 | Question 2 Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be for these to be put in place?  Largely yes. Work will need to be done on bringing data together from a range of relevant sources, including departments within organisations and third party commissioned services which will take time. Resources will be needed to put processes in place. |
| 30 | Motor Neurone Disease Association | Question 2 | Question 2: It is unclear whether the necessary localised data collection systems are in place locally to collect the data that measuring these statements would require. In particular, we are concerned by a potential over-reliance on surveys. |
| 31 | Royal College of Physicians (RCP) | Question 2 | Are there local systems and structures in place to collect data for the proposed QS and if not how feasible would it be to put such systems in place?  PCN members experience suggests they are not in place; it would only be feasible to put them in place if there were enough resources embedded in the care system. Given the pressures on the NHS this is unlikely. However, some method of monitoring a carer's needs must be found.  Our PCN suggest a quick call every few months from Social Services or charity like Age UK/ Alzheimers just to check how the carer is. Or possibly a volunteer 'buddy system', making use of the huge numbers of volunteers who came forward to help the NHS earlier this year.  Routine assessments, reviews and health checks are not happening in practice so our PCN believes it disingenuous to include them. |
| 32 | Alzheimer’s Society | Question 3 | “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 resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.”  We recommend proper training in dementia for all staff involved in supporting people affected by dementia. This may come with a resource requirement.  With regards to statement 3 and the delivery of carers assessments, The Fog of Support report highlighted positive experiences were reported from alternative assessments or contact (such as from charities and occupational therapists). Improvements in standards could be made by properly involving experts in the process at the appropriate juncture. |
| 33 | British Association of Social Workers | Question 3 | 1. 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 resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.   Not in terms of data collection see above comments |
| 34 | Carers First | Question 3 | It would be extremely difficult to achieve all of these standards nationally within current resourcing, as many commissioned or inhouse carer support services have no capacity to support additional work around employers or Primary Care. There may be potential for Invest to Save models within ASC in Local Authorities through developing specialist teams working with carers to relieve pressure on First Point of Contact and/or Ops services. |
| 35 | Carers Trust | Question 3 | Question 3 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 resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment  Yes. Health and care practitioners should recognise the work of third sector organisations in the support of Carers/the community, and include their work when collecting data. Quality cannot be achieved without working with or liaising with local providers of Carer services and support. |
| 36 | Carers Trust | Question 3 | The resource requirement is time for practice staff to ensure systems around carer identification and support are in place (e.g. updating carers register, targeting carers for flu vaccination etc) – used to happen when practices were paid/incentivised around this work |
| 37 | Motor Neurone Disease Association | Question 3 | Question 3: Many carers currently feel unsupported which suggests capacity issues in local services currently |
| 38 | RCSLT | Question 3 | Question: 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 resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.  Carers may present with invisible communication, cognitive or literacy difficulties making understanding more challenging. Having the right wrap around multi-disciplinary team to support that carer will be crucial.  We would like to see information clearly recorded on:   * Any specific difficulties with communication * Literacy difficulties * How the person engages with or access health services * Any health literacy needs   This would support better engagement and shared decision making. It would also enable local services to plan their workforce response according to carer need. |
| 39 | Royal College of Physicians (RCP) | Question 3 | 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 resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.  At a time when the pandemic is stretching resources, it is a tall order to add these extra tasks onto the daily workload.  PCN member said, “I fear that as Covid takes more of a hold, carers will be relied on even more, rather than having the well-deserved help suggested in this document.”  The QS is not achievable by local services given the resources needed.  PCN member said “I didn't receive any calls or enquiries from Social services as to how I was doing when I was helping care for Jean. I was quite fortunate in that Jean's daughters organised daily visits from Age UK via the local Social Services in 2014 as Jean's condition progressed. I'm not complaining; I was managing, and I wasn't at work. Many others are not so fortunate.”  The QS suggests Carer Reviews, survey's, data collection etc needs to be properly resourced which is not the case at present. A 'buddy system' staffed by trained and vetted volunteers linked to Social Services would be a good first step.  PCN member said ‘I know of one carer who has stopped having local authority carers in for her husband, in case they bring in Covid 19. I cannot imagine many carers opting for respite care in nursing homes, for instance, while the pandemic is still around.’ |
| 40 | Alzheimer’s Society | Question 4 | “Do you have an example from practice of implementing the NICE guideline that underpins this quality standard? If so, please provide details on the comments form.”  Identifying and assessing carers Nottingham City Council (NCC)  NCC has a contract with Carers Trust, who deliver their Nottinghamshire Carers Hub and the Carer Respite contracts. These arrangements are jointly commissioned between NCC, Nottinghamshire County Council, and the NHS via the local area Better Care Fund. A former commissioning cycle in Nottingham identified the need to support carers at varying levels of need, including people who did not meet certain thresholds for support. Carers Trust is contracted to conduct assessments of individual carers, to make decisions related to carer support needs on a person-by-person basis, and the provision of respite which could be up to 100 hours across a 12-week period. This contract includes a budget for the provision of this respite and the responsibility for allocating it based on individual needs.  The nature of this external contract and related monitoring arrangements has enabled NCC to see a more detailed level of information than is present in some other areas, particularly around the volume and type of carer assessments being conducted and provision of respite care for carers. For instance, the contract provider is responsible for collecting detailed data related to people supported, the reasons they require support, and how resources have been used to support them. As such, NCC is able to generate a clearer picture of local support for carers than might be seen in routine reporting data.  Source: The Fog of Support  Carer Resource Information Support Programme (CRISP) – Bournemouth, Christchurch and Poole (BCP Council)  The CRISP portal and discount card sign-up process has allowed BCP and Dorset to gather greater detail about the local carer population, including those who may not necessarily come into contact with the local authority through traditional means. This enables better and more accurate assessment of the number of local carers, and the types of conditions of the people they are caring for. It also serves as a tool for the council identifying carers to conduct carer assessments, a means to share information and advice to the local carer population, and a way to organise emergency support schemes for carers, and respite care (such as the use of local beach huts and holiday lodges). BCP report being able to use CRISP to access more detailed information about carers of people living with dementia, which in turn guides their approach to providing additional information, advice, and support.  Source: The Fog of Support  Supporting Older Co-Resident Carers of Older People – The Impact of Care Act Implementation in Four Local Authorities in England  This research paper has several relevant sections to consider  “A common theme across all sites was the importance of informality in the conduct of carer assessments. This was considered necessary to put carers at their ease and to guard against giving them the impression it was the quality of their caring that was being assessed. Some interviewees suggested that the concept of assessment might itself be problematic:”  “VSOs embraced the notion of assessment as ‘conversation’ or ‘chat’ as in keeping with the values of their sector and preferable to the bureaucracy they associated with local authority practice. However, this did not always translate as intended. The assessment form in Site 3 had recently expanded from one to fourteen pages, and some assessors were observed sticking rigidly to assessment forms, sometimes to the point of insensitivity.”  “At least two of the carers whose assessments were observed did not understand the purpose of the assessment and were therefore unable to prepare or develop any expectations of it. This was probably true, albeit to a lesser extent, of at least four others. Some assessors failed to give a clear explanation of why the assessment was being carried out and potential outcomes. In most cases carers were not offered a clear account of their rights and which organisation (i.e. the local authority) was responsible for realising them.”  Source: <https://www.cambridge.org/core/journals/social-policy-and-society/article/supporting-older-coresident-carers-of-older-people-the-impact-of-care-act-implementation-in-four-local-authorities-in-england/D133EA07EB9B70DCB1B1B1C6D8A44020>  Camden Memory Service have a dedicated Assistant Psychologist who offers the START intervention. It’s available at any time for any informal carers experiencing increased stress, anxiety or depression associated with caring. The practitioners who review patients on a six-monthly basis can identify carers’ stress. They can provide basic psychological strategies at every review or they can signpost to local services. Patients, carers and GPs can also contact named workers if the patient or carer is struggling, or if they’ve noticed changes before the review is due. This allows for an intervention before a crisis occurs. The psychology team also offer CST and Carers’ CST in cases where English isn’t the patient’s first language, as well as individualised patient and carer psychology interventions when needed.  The Bristol Dementia Wellbeing Service helps carers access support. This includes carrying out Integrated Carers Assessments on behalf of the local authority, enabling them access to vital respite funds or alternative provision that supports them in their caring role. It provides opportunities for carers to access psychoeducational counselling and has commissioned both specialist individual and couples’ counselling.  Bristol There is evidence of local areas seeking to overcome barriers to the identification of carers who may require support, including a service of volunteers based in GP practices across Bristol and South Gloucestershire.  Source; Parveen, S., Fry, G., Oyebode, J., Morrison, V., & Fortinsky, R. (2019). Obligation, Willingness and Preparedness to Care: The Caregiving HOPE Study. <https://www.bradford.ac.uk/dementia/research/caregiving-hope/CG-HOPE-resultssummary-booklet.pdf> |
| 41 | Carers Trust | Question 4 | 1.2 - Identifying carers – 1.2.2 - Outpatients  Case Study Caring Together worked with the outpatients' department at Addenbrookes Hospital to help increase the opportunities for carers to be identified on the back of outpatient appointments.  The outpatients' department identified 8 staff members from across the department (e.g. team leaders, receptionists, deputy matron) as carer champions, who helped to ensure carers are identified and supported whenever they come into contact with the department.  The department incorporated the hospital’s carers’ agreement into the departmental operational plan and have included information for carers within resource folders in every clinic in the department. We also supported them with carer awareness sessions specifically for staff from the department to help improve confidence in identifying and supporting carers.  Information about carers and the Carers Plan is also covered in-clinic team meetings, quality meetings and clinic sister meetings as well as department-wide meetings.  There is also information about carers and carers support on digital screens in the waiting areas of every clinic in the department, as well as leaflets in the main outpatient reception and posters on the back of public and staff toilet doors.  A departmental education plan is in place, which covers the trust’s carers strategy, but also includes department-specific carer scenarios. |
| 42 | Carers Trust | Question 4 | Working with and involving carers  Case Study (Highlighting why this quality standard is needed and young adult carers need to be recognised)  Young Adult Carer (aged 17, nearly 18) - called us explaining that mum had had another collapsing episode. Mum was currently in hospital and had been for the last 2 weeks.  Jason had been informed that the Hospital was planning to discharge mum the next day.  Jason told us that despite numerous requests to speak with the clinical and discharge team in relation to the care and support his mum may require once home, this had not happened, and he did not feel like anyone was listening to him. He had also emailed the PALS team at the hospital (a week earlier) with no response to date. Jason is the primary carer and the only person best placed to understand the needs and support of his mum.  Adding him further distress is that the family home currently did not have a working heating system (Jason had reported this to the housing association but they didn’t arrive at the arranged time to fix the problem – when he tried to rearrange this appointment he was told he could not do this because he was not an adult)  Jason was also concerned for his younger brother, who lived with mum, if mum had another episode.  Jason was further concerned as he had been told that whilst in hospital, mum had been self-harming, and whilst Jason is used to dealing with mums physical condition, he felt unprepared for her current mental health state and wanted to know what support the hospital were put in place via the discharge team.  Jason asked for support from Caring Together to escalate his concerns as he felt despite his numerous efforts, that he was unable to make any progress alone. |
| 43 | Royal College of Physicians (RCP) | Question 4 | Do you have an example from practice of implementing the NICE guideline that underpins this quality standard? If so, please provide details.  The RCP’s Falls and Fragility Fracture Audit Programme through its patient panel will be launching a useful carers information resource at the end of Nov 2020. This could be used as a good example of carers being given valuable information upon hospital admission and the concept transferred to other areas of care. |
| 44 | Alzheimer’s Society | Statement 1 | Quality Measures  While these measures will identify and record carers, it doesn’t necessarily follow that they will follow up with identified carers to ascertain support levels.  We recommend that  Councils should ensure newly identified carers are contacted to recognise them as such within 4 weeks. That communication should include information on how to access a carer’s assessment. If a carer’s assessment is not taken up, the person with caring responsibilities should be reminded of the offer at least annually.  Councils must proactively offer carers assessments to people when they are identified as carers, rather than wait for a request for an assessment.  Data should include time to referral  The Quality and Outcomes Framework for Dementia (QOF) should include identification of main carer  There should be evidence of a regular review of the language used in these policies and processes. Although not a marker for the number of carers identified, a regular review of language used when identifying, should improve the quality of this process. |
| 45 | Alzheimer’s Society | Statement 1 | Structure A Data source  Audit of local policies and processes – we recommend that such audits are centrally compiled and analysed |
| 46 | Alzheimer’s Society | Statement 1 | Structure B Data source  “Evidence that health and social care organisations have systems to record and share details about carers.”  Details shared about carers should include the condition of the person cared for, as it can have different impacts on the carers’ wellbeing |
| 47 | Alzheimer’s Society | Statement 1 | Outcome A Data source  “Local data collection, for example, Carers Register and NHS Digital’s Short and Long Term (SALT) data collection.” could also include QOF for dementia. |
| 48 | Alzheimer’s Society | Statement 1 | Commissioners  Carers should be actively consulted and involved in co-production of commissioning processes and decisions |
| 49 | Alzheimer’s Society | Statement 1 | Definitions  In terms of identifying carers, this should include that there may be a broad definition of “care” that doesn’t just extend to delivering personal care, but can be broader (for example, supporting someone to meet Instrumental activities of daily living – IADLs - such as shopping, preparing meals, or handling medication, or providing respite to primary carer). These people may not consider themselves to be the ‘primary carer’ but are still providing care.  Regarding that “carers may prefer to continue identifying primarily as a husband, wife, partner, sibling, parent, child or friend rather than as a carer”, due to this identity some may see caring as a duty in itself. This may limit their identity as a carer, while increasing their responsibilities as a carer (seeing their role as a natural part of their relationship with the person with dementia).   * Barriers to assessment and support for older, co-resident carers: “At the same time many older, married carers were said to regard looking after their spouse as a non-negotiable aspect of their marriage ‘contract’ and an essential aspect of their identity. Mutual exchange of care between spouses was felt to intensify this mindset. Older carers’ negative perceptions of ‘social services’, including fear that the quality of their caring would be questioned was also felt to be a cause of reluctance.”   Source: <https://www.cambridge.org/core/journals/social-policy-and-society/article/supporting-older-coresident-carers-of-older-people-the-impact-of-care-act-implementation-in-four-local-authorities-in-england/D133EA07EB9B70DCB1B1B1C6D8A44020>  Regarding that “carers often become engulfed by competing demands….and may not seek support” we would recommend including “or have time or opportunity to access support even if they seek it”. |
| 50 | Alzheimer’s Society | Statement 1 | Equality and Diversity Considerations  Carers may have many reasons for not having the time or capacity to proactively seek support (not least of which their caring responsibilities). Those carers who are still working (or studying), or who do not have English as a first-language, may struggle even further with accessing support.  We recommend signposting to [www.alzheimers.org.uk/get-involved/bring-dementia-out](http://www.alzheimers.org.uk/get-involved/bring-dementia-out) for support for the LGBT+ community. |
| 51 | British Association of Social Workers | Statement 1 | Systems need to capture conversations with carers about how they see their role and want to be defined. Suspect lots of conversations about caring role taking place but not being captured |
| 52 | Carers First | Statement 1 | Structure b  Local data protocol would need to be put in place to avoid double counting of carers. Where would this data be held so all service can have access to it? Would any timescales be recommended to set up local systems, protocols, to record and share the data? |
| 53 | Carers First | Statement 1 | Outcome b  It may be difficult to quantify the average time it takes for carers to recognise their caring role. This could be taken from the point that the service identifies they are a carer to the point the carer says yes I am a carer. |
| 54 | Carers Trust | Statement 1 | Carers Trust strongly welcomes the inclusion of this Statement. The importance of identifying carers has been recognised and should remain. Carers Trust are pleased to see the definitions that have been included, as well as the encouragement given to practitioners using every opportunity to identify carers.  The Quality Statement would be strengthened with the inclusion of a) the importance of (informing carers of their rights to an assessment of their needs under the Care Act 2014 and the Children and Families Act 2014 (and to statutory support if the assessment finds this is needed), and also b) referring carers for support.  Identifying carers is the first step in ensuring that carers get the support they need. Health and care providers should also be encouraged to refer carers for support to local specialist support providers.  We suggest that:   * The evidence needed would be that health and social care organisations are referring carers to specialist support * the outcome would be “Number of carers referred to local carer support organisations” or “Number of carers referred for a carers needs assessment” * Data source would be local data collection, for example, an audit of local recording systems such as a Carers Register |
| 55 | Carers Trust | Statement 1 | Structure (b)  Having systems to record and share details doesn’t mean that these details will be shared. Perhaps something more like the (a), which requires a process to be in place – details are more likely to be shared if part of an imbedded process of which that is a natural step |
| 56 | Carers Trust | Statement 1 | Outcome (a)  Carers are likely to overlap between health and care organisations – how would you remove the duplication? And what about the charity sector supported carers? |
| 57 | Carers Trust | Statement 1 | Quality Measure  The measures need to have a more pro-active element to them, that highlight the importance of engaging with local providers of Carer support services – this is vital to Carers accessing support but is too often seen as optional or not a priority. Equal importance needs to be given to statutory services and support (such as assessments) and the preventative, free to access support provided by local charities and organisations who provide both commissioned support and privately funded support. |
| 58 | Carers Trust | Statement 1 | Outcome (Data Source)  NICE should add:  c) Evidence that health and social care providers are engaging with local Carer support services and provide local information when Carers are identified  Data Source: Local data collection, for example, an audit of policies and processes, and engagement statistics from commissioned Carers services. |
| 59 | Carers Trust | Statement 1 | Outcome (Data Source)  Nice should add “including third party commissioned organisations” so it reads:  “Number of carers known to local health and care organisations, including third party commissioned organisations.” |
| 60 | Carers Trust | Statement 1 | Outcome (Data Source)  Some commissioned Carers’ Services collect this information as a matter of course e.g. asking ‘how long before registering with our service have you been a Carer?’ This isn’t scientific but a good indicator. It is easy for commissioned services to start asking this question and collect the data if they don’t already. |
| 61 | Carers Trust | Statement 1 | What the quality statement means for different audiences  Under Health and Care practitioners, the statement should be strengthened from “this may include offering them the opportunity to have a confidential conversation…”  To “this should….” |
| 62 | Carers Trust | Statement 1 | The default should be that Carers are made aware of their right to have an assessment without their cared for person present. |
| 63 | Carers Trust | Statement 1 | What the quality statement means for different audiences  Under the People with long term conditions attending health and social care appointments – the last sentence should read:  “If someone is doing this, a health or social care practitioner will discuss the benefits of identifying them as a carer and provide information on local Carer services and support.” |
| 64 | Carers Trust | Statement 1 | Statutory services should be directed to work/liaise with local support services, to ensure they are aware of the support available and how to refer/signpost to it. |
| 65 | Carers Trust | Statement 1 | Should also include terminal diagnosis/end of life/palliative |
| 66 | Carers Trust | Statement 1 | Rationale  Health and social care team should also be asking if there is anyone likely to provide care/support/be affected – not just those who are already established in the caring role |
| 67 | Carers Trust | Statement 1 | Data source  It will be hard to measure when a carer recognised their caring role – when/how would this be captured? Might need to ask when they first started caring and then also record when they registered as a carer – that is the gap in time that needs to be measured/reduced |
| 68 | Carers Trust | Statement 1 | What the quality statement means for different audiences – Service Providers  Can it be broadened to include potential carers (e.g. those who are likely to become carers)? |
| 69 | Carers Trust | Statement 1 | What the quality statement means for different audiences –Health and Social Care practitioners  Should social prescribers be included within this list? What about mental health practitioners? |
| 70 | Carers Trust | Statement 1 | What the quality statement means for different audiences –Health and Social Care practitioners  “ask people with long-term conditions attending appointments if anyone is providing care or support to them” – Should also ask if they are providing care or support / looking after someone themselves - carers are often patients too |
| 71 | Carers Trust | Statement 1 | People with long-term conditions attending health and social care appointments  They should also be asked if they themselves are giving any of this help and support unpaid to someone else |
| 72 | Carers Trust | Statement 1 | People accompanying someone with long-term conditions attending health and social care appointments  Health/social care practitioners should discuss the benefits with them anyway, as depending how the question is asked, chances are the person will say, “oh no, I’m just their husband/wife/daughter/friend” and not realise that giving them help and support is exactly what they are doing (which is one of the reasons why it takes so long for carers to be identified / self-identify) |
| 73 | Carers Trust | Statement 1 | Definitions – Identifying carers  Also need to take into account that carers may have their own health needs (mutual carers) |
| 74 | Carers Trust | Statement 1 | Definitions  People may not view themselves as a carer because: - They have care needs themselves (mutual carers) - The term “carer” is not common parlance (or is associated with paid care workers/key workers (as seen with the “clap for carers”)  - In some languages, there is no translatable term at all for carer |
| 75 | Carers Trust | Statement 1 | Equality and diversity considerations  Age should be included in this so that young adult carers aren’t ignored (as it is on page 10 for Statement 2) |
| 76 | Carers UK | Statement 1 | We consider this statement to be falling short of the law under the Care Act 2014. Local authorities have a duty under s.4 of the Care Act 2014 to identify carers. This is not limited to appointments for people with long term conditions, but a wide-ranging duty to identify carers broadly. We do not believe this is an appropriate statement of quality for social care. Given the practice of local authorities currently, which is broad and diverse, and the way that they commission local services, this statement falls short.    In terms of health, it falls short of the GP quality markers statements that are produced by NHSE, and which are in the NHS Long Term Plan as a target to fulfil. We do not feel it is useful to have a quality marker that differs from other quality-related work published by NHSE. We have endorsed NHSE’s work and give it our full backing.  The definition also does not promote identification at key points of the system, e.g. hospital discharge. Some conditions may involve intense caring for many months but may not constitute a long-term condition, e.g. late diagnosis terminal cancer, recovery from a major operation, or a road traffic accident.  Furthermore, the legislation for adult social care sets out a requirement to identify any children within the household and this should be incorporated within the statement. Whilst there is a focus on adults, those implementing legislation from adult services must be implementing the Care Act 2014 legislation.  We have redrafted the quality statement to reflect the level of the law and practice along the lines of which we would consider to be acceptable – see below:  Carers, including young carers, are identified through a variety of measures by local authorities. GP practices regularly identify carers through the GP quality markers and carers are identified through community trusts and secondary care. |
| 77 | Central and North West London NHS Foundation Trust | Statement 1 | Data Source b  Electronic medical record systems need to have a clear and consistent place for recording the details of the main carer/s. Carers Passports may be useful in helping make sure that carers are identified as they move between services. |
| 78 | College of Mental Health Pharmacy | Statement 1 | It is confusing to use the abbreviation SALT. People are normally referred for a SALT assessment to a speech and language therapist if they have swallowing difficulties. |
| 79 | Hampshire County Council | Statement 1 | Quality Statement 1: “Carers are identified by health and social care practitioners at appointments for people with long-term conditions.”  Most people being cared for or who have a carer would have a Long Term Condition and appointments are made appropriately. Hampshire County Council (HCC) Adults’ Health and Care (AHC) do not have regular appointments with people specifically because they have a long-term condition. Appointments are made with people primarily for the purposes of assessing social care need, planning the support people need, and reviewing care and support. Current systems record carers where identified. Approximately 10% of the estimated number of carers in the county have contact with AHC; increased numbers of carers being registered would enable better targeting of resources and improve HCC’s recording of data. HCC has a new adult social care IT system planned for launch in 2021 which should make recording and reporting much easier. All stats that are based on the number of carers in the county are difficult to enumerate as numbers are unknown at present. However, a new GP Registration form has been developed by a subgroup of the new Carers Partnership Board as part of the Hampshire Joint Carers Strategy that will be shared across the county (via CCGs, carer provider services etc) to increase the number of carers registered with GP practices which should aid earlier identification of carers. One impact of COVID-19 has been the decrease in the number of face-to-face appointments by AHC which may well impact on the number of carers being identified. Although there has been a decrease in face to face appointments for the safety of carers and service users, there have been alternative meetings arranged to offer the support for carers, eg by Zoom calls, telephone calls etc. HCC has worked hard to find alternative ways of identifying and supporting carers in these unprecedented times. Carers that paused and stopped care in March, April and May have all been contacted recently and offered services. Discussions with carers have included reviewing contingency plans and alternatives where possible. At Senior management meeting all operational staff are asked to proactively review the position for carers in their areas and for those with relatives coming out of hospital to ensure that we are supporting as many people as possible. The COVID crisis has had an impact on those services that have provide some form of respite, eg day services, Take A Break and others. Staff across HCC are encouraged to complete Inclusion & Diversity training which identifies the most common biases, and this will alert staff on the front line to prevent assumptions being made as to what Carer support may be required as within Hampshire we have a rich and diverse population. |
| 80 | Healthwatch Richmond | Statement 1 | We appreciate NICE’s effort in identifying carers “that do not know they are carers” or that do not fully recognise their role. In our practice, and by sharing discussions with other stakeholders, we understand that Covid-19 has led to many people undertaking caring roles, and that these people are harder to reach than ever. Evidence of policies and processes that allow organisations to identify these carers are now key to provide the support needed to existing carers. Nevertheless, these individuals may be providing only short terms caring assistance to people with long term conditions. Consideration should be given to provide evidence of policies and processes to identify carers of people who do not need care permanently.  The list of practitioners indicating those making appointments for people with long-term conditions does not include organisations like ours (Healthwatch Richmond). Although we do not provide long term support to people, we come into contact with individuals sharing personal experiences, which sometimes may lead us to identify people with long-term conditions, and their carers, in need of support. As serendipitous as this may be, we regularly signpost members of the public to services they may need, and therefore we feel that signposting agencies like us have a role in this process.  Finally, we’d like to point out that the draft explores how organisations can support carers but not how carers can be empowered to support themselves and it would be appropriate to identify measures that indicate how this is achieved. Carers should be empowered to understand their rights and benefits, and encouraged to make themselves known to providers. Quality measures should take this into consideration to reach out to as many people as possible. |
| 81 | Humber Teaching NHS Foundation Trust | Statement 1 | Measure  Use of the term ‘Carer’ in data collection systems is problematic for all the reasons stated in the Quality Standard. Language used should fit with how ‘Carers’ view themselves (rather than convincing people that they are Carers). It also fosters a restricted view for professionals when identifying carers. Inclusive language, such as family, significant others, support network would make this easier to implement. |
| 82 | Humber Teaching NHS Foundation Trust | Statement 1 | Measure  Local systems and structures used for collecting data and measuring the standard should enable the recording of all caring/supporting people, and the nature of their caring/supporting role so unique needs can be identified. |
| 83 | Humber Teaching NHS Foundation Trust | Statement 1 | Measure  Gail Bradbury and Steve Greenway wrote an article “Embedding family inclusive practice in a secondary mental health service: An expanded role for family therapists” (October 2018). Humber Teaching NHS Foundation Trust’s family inclusive care co-ordination training is an example of implementing the standard in practice (in particular, supporting the early identification of carers, keeping them up to date/ involving them in decision making and care planning). |
| 84 | Independent age | Statement 1 | Evidence that health and social care organisations have policies and processes to identify carers at appointments for people with long-term conditions  It is difficult for us to ascertain if local systems and structures are in place to collect data for this measure. Appointments for people with long-term conditions is a crucial moment in identifying carers who may need support at that time or in the future as we know from the Carers Trust report No longer able to care published this year that the majority of carers are not currently being supported to plan for a future when they are less able or unable to care.[[2]](#footnote-2)  Please see the Carers Trust response to this statement and associated evidence that we fully support. |
| 85 | Motor Neurone Disease Association | Statement 1 | Audiences  We are pleased to see that this statement takes an approach that does not entirely place the burden of identifying carers on people living with MND themselves, but also on practitioners and commissioners. |
| 86 | Motor Neurone Disease Association | Statement 1 | Health and Social Care Practitioners  Where the statement says, ‘this may include offering them the opportunity to have confidential conversations,’ we feel the gold standard would be to say it should always be offered. It is otherwise hard to actually get to what carers really need, given they may be unwilling to discuss with the person they are caring for present. |
| 87 | Motor Neurone Disease Association | Statement 1 | Definitions  Where is says ‘there may be more than 1 person involved in caring,’ we feel it should say including children. Although the quality standard is not aimed at young carers, it may be an important factor when considering support for adult carers. |
| 88 | Motor Neurone Disease Association | Statement 1 | Definitions  We suggest that the section on encouraging carers to recognise their role and seek support should highlight making carers aware of their rights, e.g. the right to a carers assessment. Knowing there are rights to specifically help carers may be a good way to engage with some carers. Secondly, as part of the list detailing why some people may not view themselves as carers, a point should be added on the impact of internalised stigma and shame i.e. not wanting to ask for help or be seen as needing help. |
| 89 | MSA Trust (Multiple System Atrophy Trust) | Statement 1 | Carers are not identified in a systematic way and there often little co-ordination between health and social care. In a survey we found 36% of former carers of people with MSA rated GP support poor/just adequate so GP’s may not be the best people to identify carers. |
| 90 | MSA Trust (Multiple System Atrophy Trust) | Statement 1 | GPs could promote special treatment for carers in getting appointments and this may be a “hook” to identify carers |
| 91 | MSA Trust (Multiple System Atrophy Trust) | Statement 1 | MSA Trust asks people who register with them who their main carer is yet we have no way of feeding back locally that we have identified them as such– how can LA and the NHS work better with voluntary organisations to support identification? |
| 92 | MSA Trust (Multiple System Atrophy Trust) | Statement 1 | Better understanding by the NHS of carers assessments and support available is needed. |
| 93 | Newcastle City Council and Partners | Statement 1 | Rationale  It is important to acknowledge that for whatever reason, carers of people with long term conditions may not attend appointments with them – if this is the case, the person with that long term condition should be asked if anyone is providing them with care and support and if so, given information to take away that can be shared with their ‘carer’ and where appropriate/possible, encouraged to bring their ‘carer’ with them. A number of the opportunities listed to review with a carer are not their appointments at all. |
| 94 | Newcastle City Council and Partners | Statement 1 | Rationale  Some carers do not want to be formally recorded as such on patient/health and social care records – this needs to be carefully managed, especially if the information is to be shared – must seek formal permission to record details |
| 95 | Newcastle City Council and Partners | Statement 1 | Rationale  Generally the identification needs to be in place before the rest can follow –the use of the term “long term conditions” should explicitly say that this includes mental health conditions and addiction, as otherwise there is a danger this will be interpreted as physical health conditions only |
| 96 | Newcastle City Council and Partners | Statement 1 | What the quality statement means for different audiences (Health and Social Care Practitioners)  These are guidelines, unlike local authorities, the NHS does not have a duty to identify carers; as such, there is inconsistency in approach with some health practitioners only identifying carers/ongoing support if they are incentivised (despite the publication of the GP quality markers) |
| 97 | Newcastle City Council and Partners | Statement 1 | Definition of terms used in this quality statement (Identifying Carers)  Would a proactive approach to seeking support not be better; rather than encouraging the carer to do this, practitioners do this for them with their permission – this ensures timely interventions by carer specific support services and takes the pressure off carers having to do ‘just one more thing’  Newcastle City Council offers carers identified at first point of contact the opportunity to have a routine referral into specifically commissioned (independent) carer support services |
| 98 | NHS England and NHS Improvement | Statement 1 | It is really important to proactively ask patients and their carers if they are a carer as many won’t necessarily realise that they are or may not know/how they can get access to support. (PC) |
| 99 | NHS England and NHS Improvement | Statement 1 | The reference to equality and diversity considerations need to reference all the protected characteristics and have a greater focus on cultural awareness. For example, there may be additional barriers to identifying people, it might need to be outside of formal appointments. (RD) |
| 100 | NHS England and NHS Improvement | Statement 1 | We are concerned there is not enough in the guidance about ‘hidden carers’. For example, if a person with the long-term condition is not going to appointments, their carers will also not be going. We would like there to be a sentence about the need to analyse information gathered about carers to ascertain whether it matches demographic data, so that organisations can see if they are missing groups of carers. (RD) |
| 101 | Royal College of Occupational Therapists | Statement 1 | Does this draft quality standard accurately reflect the key areas for quality improvement?  Yes; it is important to identify carers for people with long-term conditions at the earliest opportunity; carers being identified by health and social care practitioners at appointments for people with long-term conditions would help to initiate support frameworks for the carers if required. |
| 102 | Royal College of Occupational Therapists | Statement 1 | Assessments and records should include details about the person’s carers so that this information can be shared with other practitioners (with the carers’ consent). |
| 103 | Royal Pharmaceutical Society | Statement 1 | We agree with this statement around identifying unpaid carers and that this should be undertaken at the earliest opportunity. Across the UK today 13.6 million people are unpaid carers to someone who is older, disabled or seriously ill. And this has estimated to increase by 4.5 million because of the COVID-19 Pandemic.  Utilising community pharmacists to identify carers, refer them to support services and ensure they are identified as a carer at their GP surgery has proven to work. The evaluation research suggests that the Carer-Friendly Pharmacy Pilot, undertaken in 2014/15,is an effective and pragmatic approach to identifying and supporting carers, with pharmacy staff being an invaluable resource.(<http://psnc.org.uk/wp-content/uploads/2015/02/20224-Evaluation-2015.pdf>)  Research carried out for Carers Week 2015(<https://www.employersforcarers.org/news/item/1012-carers-week-we-re-calling-on-all-communities-to-become-more-carer-friendly>) revealed that carers consider community pharmacies to be the most carer-friendly of all health and care services, with their accessibility, longer opening hours, helpful staff, advice from the pharmacist without an appointment among the reasons carers gave for ranking them top. |
| 104 | Shropshire Council | Statement 1 | Comments from Active carers in Shropshire  There seems to be a very deliberate attempt to limit the number of carers who will be recognised. Little recognition of the great need for specificity in many areas where generic is unhelpful and often damaging. |
| 105 | Shropshire Council | Statement 1 | Note: It is important to gain consent from carers that their details can be shared with other professionals.  Quality Measures - Information governance procedures for sharing information needs to be in place. |
| 106 | Shropshire Council | Statement 1 | Rationale  Comments from Active carers in Shropshire.   * The inclusion of 'long term conditions' is excluding routine carers. Eg. ' Old age' is not a 'condition'. * Mental health issues are not necessarily long term conditions (ie first episode) but family carers should be recognised and still need support, and their knowledge is extremely valuable. * Carers should be identified as people in their own right and not contingent upon the cared-for having an appt * Too much emphasis on long-term conditions. Carers equally care in shorter term situations e.g. following hospital discharge |
| 107 | Shropshire Council | Statement 1 | Appointments for people with long-term conditions GPs in particular should identify carers at carer's appointments not simply at cared-for's appointments. |
| 108 | The Challenging Behaviour Foundation | Statement 1 | What the statement means for different audiences  Families are diverse – their individual circumstances vary, so understanding each family context is essential to offering appropriate support. The family carers of people with severe learning disabilities whose behaviour challenges may be particularly isolated, especially in minority groups. Extra proactive efforts need to be taken to reach these hidden groups in order that they can access appropriate support as carers. This support may have to be adapted to meet their specific needs.  Iriss notes that it is the relative ‘invisibility’ of BME (Black and Ethnic Minority) carers which means they are not made aware by their local authorities of support which exists for them- Iriss, Improving support for BME Carers, May 2011: <https://www.iriss.org.uk/resources/insights/improving-support-black-minority-ethnic-bme-carers>  For service providers and health and social care practitioners there needs to be an emphasis on identifying hard to reach carers e.g. carers of children, young people and adults are often isolated and do not have existing social networks/ links. |
| 109 | The Challenging Behaviour Foundation | Statement 1 | What the statement means for different audiences  Needs to be recognition in the guidance that people with learning disabilities might not be able to tell practitioners this information about their carers, and therefore practitioners will need to speak directly to family members and other professionals working with the individual.  In the case of people with severe learning disabilities, the person accompanying the individual to the appointment should then be asked if there is anyone else supporting the individual as an unpaid carer. |
| 110 | University Hospitals Birmingham (UHB) NHS Foundation Trust | Statement 1 | Quality Statement  This needs to go further to include identification of carers at every opportunity, not all are carers of people with long term conditions, people with long term conditions also attend A&E, come in for elective surgery. Some carers become carers overnight e.g. through trauma, and other opportunities include identification of carers at their own medical appointments, or health checks. It is also important to identify that someone is a carer when they themselves are admitted in a emergency for example via A&E. |
| 111 | University Hospitals Birmingham (UHB) NHS Foundation Trust | Statement 1 | Definition of terms  Important to acknowledge the carer may not be next of kin, need to establish who the person has a significant relationship with to establish if this person(s) are in a caring role |
| 112 | University Hospitals Birmingham (UHB) NHS Foundation Trust | Statement 1 | Outcome b) average time it takes someone to recognise their caring role – not sure how easy it would be to measure this in a healthcare provider setting as it is difficult sometimes to distinguish between supporting someone as a spouse or family member/friend and when it turns into supporting the person as a carer. This may happen before, during or after their hospital journey. |
| 113 | British Association of Social Workers | Statement 1 – Question 1 | 1. Does this draft quality standard accurately reflect the key areas for quality improvement?   [Statement 1](file:///\\basw-fs01\USERS$\liz.howard\My%20Documents\Liz%20Howard\Adult%20PPEG\NICE%20Quality%20standard%20Adult%20Carers\NICE%20Quality%20standard%20carers-%20LH%20comments.30.10.20.docx#_Quality_statement_1:) Carers are identified by health and social care practitioners at appointments for people with long-term conditions.  get to know who is providing the care and what care they are providing  Info. sharing with health- GDPR,  respecting independent decision making    Relationships- treating as human beings, identifying as a carer- Label- stigma "person in need"  Who is the carer? Role of carer for someone who is in hospital or care home care still be provided by family alongside that of care or health and setting    Adults with physical disabilities - higher proportion may have care provided by people with needs themselves  Improved professional who is asking care and support is provided, recognising a number of people are providing care and support  Consent to be gained by other practitioners  Integration of working systems - systems don't talk to each other, possible duplication of capturing information    Offering carers confidential space to talk about their caring role- is this possible within the set up or organisations, working remotely how can this be achieved in covid-19 context, safe spaces need to be identified- carers centres  Quality standard 1 doesn’t adequately cover the need in Equality and Diversity considerations: Carers from vulnerable communities (BAME, LGBT, very elderly or young adult carers and others) identified in NHS Long Term Plan as priority for early identification to avoid later challenges- invisible carers  Information for carers should be readily available, accessible, culturally sensitive, easy to understand and meet the needs of the carer at any point in their caring journey; information should be co-produced with carers and promoted and publicised by all professionals;  Appointments for people with long-term conditions- Housing, DWP, optician or hearing appointments, chiropody, are not identified as opportunities to identify carers |
| 114 | Carers Trust | Statement 1- Question 2 | Theoretically, every GP surgery should have a carers register but isn’t always the case, and not sure how would easily measure how early that identification is |
| 115 | Alzheimer’s Society | Statement 2 | Quality statement  Given the importance, recognised in Statement 1, of treating carers as “partners” in care, this should be recognised in Statement 2 more fully – we recommend changing “contribute to decision making and care planning” to “are treated as partners in decision making and care planning”  Statement 2 should recognise that not everyone has capacity for content, and carers may also have (e.g.) Lasting Power of Attorney over someone without capacity, which can complicate their relationship. |
| 116 | Alzheimer’s Society | Statement 2 | Quality Measures  Carers should be given a written copy of a care plan. We recommend adding a measure for providing copies and recording it. |
| 117 | Alzheimer’s Society | Statement 2 | Data source b  Regarding proportion of carers who agree they can contribute to decision making and care planning, as above this should be more active involvement - contribute implies not being valued as an equal participant in planning |
| 118 | Carers First | Statement 2 | Outcome a and b  This statement will be welcomed by many carers so they feel a valued part of a team providing care for the person they care for. In terms of carers being involved in care planning, there is a lot of anecdotal feedback by carers that this does not happen consistently, even when legal requirements such as LPAs are in place. Much education work needs to be done with professionals to upskill them around legal and appropriate ways to involve carers as partners in care. |
| 119 | Carers Trust | Statement 2 | Carers Trust welcome the inclusion of this quality statement and the recognition of the potentially vital role unpaid carers can play as expert partners in care.  However, the Quality Statement would be strengthened if NICE explicitly recognised and included a line on mental capacity and situations where the person with care and support needs is unable to give consent. |
| 120 | Carers Trust | Statement 2 | Structure (b)  Care plans should include evidence of carer contributions to the file, not just carer details. Otherwise, it’s just proving identification, as in statement 1, rather than involvement |
| 121 | Carers Trust | Statement 2 | Quality Statement  This should be strengthened. Instead of “contribute” it should read “are actively engaged decision making”. The statement would therefore read:  “Carers are kept up to date and are actively engaged in decision making and care planning for the person they care for, with the person’s consent.” |
| 122 | Carers Trust | Statement 2 | Rationale  This should be strengthened.  The second sentence should read (suggested edits in bold and underlined)  Keeping them up to date about the person’s care and enabling them to contribute to care planning will enhance the care plan, help give them a sense of ownership of the plan, help ensure they are prepared and able to manage their caring responsibilities and can facilitate the implementation of the care plan at home (increasing the likelihood of the plan being successful) |
| 123 | Carers Trust | Statement 2 | It should be recognised that Carers often play a vital role in the successful implementation of care plans, but that they need to be included for this to happen. It places more importance on this statement. |
| 124 | Carers Trust | Statement 2 | If consent is not given, practitioners should discuss the care the carer provides the person being cared for and considers this in the care plan.  It is important that even if the person being cared for does not give consent, that Best Interest decisions are made about informing Carers of care needs when it can reasonably be presumed a Carer will be providing care at home that will inevitably contribute to the success of the care plan. |
| 125 | Carers Trust | Statement 2 | How much does the carer consent to taking on the caring role? |
| 126 | Carers Trust | Statement 2 | Quality statement  Carers should know how to access information and should be given generic information about the condition, the sorts of things to expect and where to get help when needed, regardless of whether the person consents |
| 127 | Carers Trust | Statement 2 | Quality statement  Any references to consent (including in other quality statements) should also reference where the person no longer has capacity. |
| 128 | Carers Trust | Statement 2 | Rationale  They also have a unique insight into what’s ‘normal’ for the person they care for and what’s unusual and therefore an indicator that something might be wrong. They are much better positioned to spot early warning signs  They should be seen as another member of the “team” as better equipping them will reduce pressure on resources  Carers can also play a valuable role in the patient’s experience and reduce distress (e.g. for those living with dementia) and they should be equally valued by the team. It’s not just about how it helps the carer, but how helping the carer, in turn, helps the team – equal partners in care |
| 129 | Carers Trust | Statement 2 | Rationale  Will also increase likelihood of more successful outcomes for cared for, and reduced failed discharges/repeat admission |
| 130 | Carers Trust | Statement 2 | Structure  Confidentiality policies should also make reference to carers and recognise that a huge amount of generic information can be shared with the carer to great benefit, without compromising patient confidentiality.  The more prepared a carer can be for what they’re dealing with / what to expect the less stress for all parties |
| 131 | Carers Trust | Statement 2 | Structure – b  Discharge plans also include details of carers and should be developed with carers where possible |
| 132 | Carers Trust | Statement 2 | Outcome – a  Other potential outcomes are the proportion of carers who feel supported in their caring role and proportion of carers who feel recognised and valued |
| 133 | Carers Trust | Statement 2 | What it means for health professionals  If consent is not given, ensure that carer has the opportunity to ask about generic information (e.g. about the condition) that will help them in their caring role |
| 134 | Carers Trust | Statement 2 | What it means for carers  Carers should be informed of what to expect relating to the condition, regardless of consent |
| 135 | Carers UK | Statement 2 | This statement is close to practice. It should be pointed out in the background information that there are several different areas that need to be considered. |
| 136 | Central and North West London NHS Foundation Trust | Statement 2 | Rationale  Training is key to this – staff need to understand the immense value that input from carers can have in both the assessment process and in subsequent care. Co-produced carers awareness training can be impactful, especially training which allows time for: 1) carer/s explaining their experience of caring; 2) staff discussions that focus on how staff, carers and families can work together to improve patient outcomes and 3) helping staff understand ‘common sense confidentiality’ – what can and cannot not be shared with carers and how to manage a situation where the patient does not want information to be shared.  Carers Champions in every service can also help by promoting the value of carer involvement.  Good practice in strengthening communication between carers and clinical staff is to hold regular open sessions where carers can contact senior staff to ask questions or give feedback. Services that encourage carer feedback and communication tend to see fewer complaints from families. |
| 137 | College of Mental Health Pharmacy | Statement 2 | Where you mention consent, could power of attorney for health and social needs be included here as consent is difficult for people with moderate to severe dementia. |
| 138 | College of Mental Health Pharmacy | Statement 2 | Paid practitioners need training to develop the skill of communicating with carers to ensure they are involved in the decision making. The guideline makes reference to a carers champion, this is a very important role for all the organisations and should be a key requirement for all the service providers. |
| 139 | Compassion in Dying | Statement 2 | In 2019/2020, over 380,000 Lasting Powers of Attorney for Health and Welfare were registered with the Office of the Public Guardian. As such, we strongly recommend that there is recognition in these quality standards that many carers of people who lack capacity may have the legal authority to make decisions as a result of being appointed as an attorney.  The current lack of clarity that exists around Lasting Powers of Attorney means that the Compassion in Dying Information Line receives daily calls from people seeking support to be heard:  “I have Lasting Power of Attorney for Health and Welfare for my father, why are the doctors not listening to me?”  “Caller has LPA for health and welfare for his friend John who is in a care home with Parkinson's and Alzheimer's, and fluctuating capacity. They're having problems because the care home won't involve them in decisions and they don’t know how to ensure his wishes are respected.”  “Caller’s husband had a horrible death. She was his LPA but they didn't listen and he had 'lots of horrible things done to him that he wouldn't have wanted'. She wants to make sure the same doesn't happen to her.” |
| 140 | Compassion in Dying | Statement 2 | Rationale  Please include the following sentence: Some carers may have been appointed as attorneys for health and welfare and their role in decision-making must be recognised in line with the Mental Capacity Act 2005. |
| 141 | Compassion in Dying | Statement 2 | Quality measure – pg 8 (a)  Policies and process must include recognition that carers who are attorneys must be involved in best interest decision-making and not simply “kept up to date” |
| 142 | Compassion in Dying | Statement 2 | Different audiences  We recommend that each section includes the following phrase – “…ensure that carers are involved in decision making as required by the Mental Capacity Act and kept up to date…” |
| 143 | Hampshire County Council | Statement 2 | Quality Statement 2: “Carers are kept up to date and contribute to decision making and care planning for the person they care for, with the person’s consent.”  The newly formed Hampshire Carers Partnership Board was set up early in 2020 under the Hampshire Joint Carers Strategy and this is an essential meeting that evidences the high priority that working with carers is given in Hampshire (the Board is made up of 50% carers) This meeting gives the opportunity to Carers leads and the County to hear, understand issues and influence change in a much more consistent manner. During the COVID lockdown, a Bronze Carers Workstream was set up and this meeting continues to ensure that carers’ concerns that are raised can be escalated quickly and appropriately within the command structure. An example was the preparation and distribution of a signed letter that identified individuals as carers when out shopping if they needed to take the cared-for person with them. Feedback from these two groups has been essential in keeping carers up to date as well as identifying areas of specific concern. Access to information and advice is provided via the Connect to Support Hampshire website which can signpost people effectively to appropriate services: the website language can be changed via a Google Translate when needed. Funding has been made available to carer provider agencies by HCC’s AHC Director as the needs of carers were identified as a priority group for us to address, this money can be given quickly and flexible as need arises. |
| 144 | Healthwatch Richmond | Statement 2 | Some family members may be undertaking caring roles regularly, but not on a daily basis. This may be due to living far away or working schedules that lead them to not view themselves as carers. Practitioners working with people with long term conditions may not always keep them in mind and keep them updated, as the care provided is hidden.  For instance, we came across a lady who could support her grandmother only fortnightly, but who called her on a daily basis to check she was well. She was not notified by social services when their grandmother was hospitalised three times in a month, because she was not registered as a carer, nor as a next of kin. Although this person had great knowledge of her grandmother’s needs and willingness to contribute in supporting her, she was not included in the care plan. After speaking to social services the niece was registered as next of kin and an assessment as carer was considered. There may be a gap in the process of working with carers if only local data and care plans are considered. Next of kin, family members and other people in the client’s life may also have a role and should be considered to ensure their life satisfaction. |
| 145 | Independent age | Statement 2 | Evidence that health and social care organisations have policies and processes to keep carers up to date and ensure that they can contribute to decision making and care planning.  We welcome NICE recognising the valuable information and insight that carers can provide when making decisions and care planning for individuals with care and support needs.  However, we believe it is important to expand this statement to include a line on mental capacity. In circumstances where the cared-for person lacks the mental capacity and therefore cannot consent to make individual decisions relating to their care and support it is also vital that their carer is involved during these situations. They may be best placed, along with others that the cared-for person knows well, to inform health and social care professionals what the cared-for person’s wishes and preferences would have been and be part of the conversations about what decisions would be in their best interests. We feel that the area of mental capacity should also be included within policies and processes to ensure that carers are being included as part of ongoing conversations about care planning should the person concerned lack capacity. |
| 146 | Motor Neurone Disease Association | Statement 2 | We anticipate that in some cases, gaining consent may be a difficulty. This may occur due to cognitive change being experienced by the person living with MND or in some instances because the person living with MND is in denial and unwilling to engage in support. This issue is not addressed as part of the quality standard. |
| 147 | Motor Neurone Disease Association | Statement 2 | Rationale  Where the statement says carers should be recognised and respected as core members of the team, we think this should go further in recognising that carers may often actually provide important learning and instruction for care agencies providing care. This should be more clearly recognised as part of the quality standard. For example, some agencies may not have come across MND before nor used certain pieces of equipment. Therefore, the knowledge and skills carers may have needs to be appropriately recognised because it can ensure good care is provided and also ensures the carer feels a respected member of the team of the person they care for. If they don’t it can feel very demoralising or disempowering. |
| 148 | Motor Neurone Disease Association | Statement 2 | Rationale  Where the statement says carers should be enabled to contribute to care planning, we feel the standard should also include that their contribution to managing the care of the person they care for should be regularly reviewed. |
| 149 | Motor Neurone Disease Association | Statement 2 | Rationale  In relation to helping carers feel prepared and able to manage their caring responsibilities, we believe this standard should also provide an important opportunity for carers to think about and identify their own needs as a care plan is put together for someone living with MND. Importantly, their own needs and the ability to meet caring requirements may change over time as the person with MND they care for experiences disease progression. Where disability increases, there will be more complex care needs to manage such as non-invasive ventilation (NIV), suction, cough-assist, PEG etc. |
| 150 | Motor Neurone Disease Association | Statement 2 | Quality measures, structure, data source  Where the statement refers to evidence that care plans include details of carers, we think it should also specify their agreement to specific details about their role in providing care. |
| 151 | Motor Neurone Disease Association | Statement 2 | Data source  In isolation, we are not sure a local survey would be enough. |
| 152 | Motor Neurone Disease Association | Statement 2 | Audiences, service providers  Where the statement says service providers ensure that care plans include details of any carers, we think it should also include their role and agreement in providing care. |
| 153 | Motor Neurone Disease Association | Statement 2 | Audiences, health and social care practitioners  What would happen if consent is not given by someone living with MND, but a carer is still being relied upon nonetheless? |
| 154 | MSA Trust (Multiple System Atrophy Trust) | Statement 2 | Carers usually have to do far more than just contribute to decision making and care planning – without a qualified, long term ‘keyworker’ for the person they are caring for they are too often left to make decisions alone. |
| 155 | MSA Trust (Multiple System Atrophy Trust) | Statement 2 | Carers need to be given up to date knowledge – for example, they are often not aware of CHC funding. |
| 156 | MSA Trust (Multiple System Atrophy Trust) | Statement 2 | Continuity of care professionals removes stress on carers of having to request new referrals and prevents a crisis for carer and person being cared for |
| 157 | MSA Trust (Multiple System Atrophy Trust) | Statement 2 | LAs should provide info for carers – eg generic resource for voluntary agencies to send to carers. |
| 158 | MSA Trust (Multiple System Atrophy Trust) | Statement 2 | MSA Trust are developing expert resources for carer training – would be helpful if voluntary agencies could have funding where there is specialist info/rare conditions. E.g. in respect of MSA a suite of videos could be compiled on saliva control, blood pressure control etc |
| 159 | Newcastle City Council and Partners | Statement 2 | Quality Statement  There is no reference to the Mental Capacity Act in this document – this impacts on decision making and the involvement of a carer is crucial, even if there is a disagreement about what is in the person’s best interests. |
| 160 | NHS England and NHS Improvement | Statement 2 | Quality measures/carers survey: there are workload implications for health and social care staff.  Who do you foresee undertaking the carer surveys and how often to be repeated? Who would be responsible and accountable? Would CCGs be expected to commission this e.g. from Healthwatch? This has funding implications. Could this be through the local authority? How frequently should the survey be repeated? Workload/resource implications for those undertaking this survey. (PC) |
| 161 | NHS England and NHS Improvement | Statement 2 | We recommend adding a section on the legal rights of parents and carers. (RD) |
| 162 | NHS England and NHS Improvement | Statement 2 | We recommend adding a reference to the Mental Capacity act and the law on parental responsibility so that it can be clear when a carer has the right to be involved. (RD) |
| 163 | NHS England and NHS Improvement | Statement 2 | We recommend adding a sentence on consent in this section to make it clear that whilst there is a recognition of the value of working with family carers there might be some instances where it is not appropriate or possible to involve them - for example; if an adult with mental capacity chooses not to have their family involved/ if there are safeguarding concerns . Need to carefully check out the persons wishes, including how to check if, for example, the person does not communicate verbally: e.g. use of independent advocate, involvement of person who knows them well. (RD) |
| 164 | NHS England and NHS Improvement | Statement 2 | As above a recognition of the need to ensure that person’s wishes are central… carer would not ‘own’ the plan if they are caring for an adult with capacity. (RD) |
| 165 | NHS England and NHS Improvement | Statement 2 | We recommend including some more detail on how to involve carers meaningfully in times and ways that suit them; highlighting that it is not about the carer always having to fit in to the timescales of professionals. (RD) |
| 166 | NHS England and NHS Improvement | Statement 2 | We recommend adding in a section about providing feedback/confirmation that the carer has been listened to. (Ask, Listen, Do principles: <https://www.england.nhs.uk/learning-disabilities/about/ask-listen-do/>). (RD) |
| 167 | NHS England and NHS Improvement | Statement 2 | We recommend highlighting the importance of recognising the contribution of carers and the importance of not ignoring/devaluing/undermining that role by only focusing on the value of ‘services’. Would It be possible to add a metric ‘carers feel that their caring role has been recognised by professionals?’. (RD) |
| 168 | NHS England and NHS Improvement | Statement 2 | There can be a risk that professionals think they have told carers what they need to know rather than telling them the things that they would find useful. We recommend changing the phrase ‘kept up to date’ with ‘properly informed with timely information that is useful to them as a carer’(RD) |
| 169 | Royal College of Nursing | Statement 2 | This states that ‘Carers are kept up to date and contribute to decision making and care planning for the person they care for, with the person’s consent.’ This should include all people who hold lasting power of attorney or court of protection guardianship where individuals are unable to consent. |
| 170 | Royal College of Occupational Therapists | Statement 2 | Asking people with long-term conditions attending appointments, if anyone is providing care or support to them is extremely important. If someone who may be a carer is identified, health and social care practitioners should encourage them to recognise their role. This may include offering them the opportunity to have confidential conversations about their own needs separately from the person they are supporting.  Health and social care practitioners should record details of carers in local systems and share this information with other practitioners involved in providing care and support, with the carer’s consent.  Carers should be kept up to date and contribute to decision making and care planning for the person they care for, with the person’s consent. |
| 171 | Royal College of Occupational Therapists | Statement 2 | It is important for Health and Social Care Practitioners to be made aware that some people may not view themselves as a carer. |
| 172 | Royal Pharmaceutical Society | Statement 2 | We agree that carers should be included in the decision making and care planning for the person they care for, with the person’s consent.  There should be an expectation that carers are well informed about the medicines the person they are caring for is taking, they should have the opportunity to voice an opinion about the medicines and be supported so that they can play a part in helping the patient to take their medicines. This can be supported by pharmacists working in all care settings and may require access to specialist pharmacists, such as those specialising in mental health.  There are a range of carer organisations and many other different organisations providing care and support in a variety of ways. Most of these organisations have little or no proper access to good advice about medicines. They need help and support in order to be well informed around medicines and their use and this guidance could provide the opportunity to make that the norm.  One issue that is encountered when involving carers in the care of their patients is the issue of confidentiality and sharing patient information with a person who is not the patient. This guidance should provide some clarity on this matter so healthcare professionals are able to share information, particularly around medicines, with carers as carers are often the ones ensuring that the patient takes their medicines. |
| 173 | Shropshire Council | Statement 2 | Quality Measures – It is important to have evidence that care plans include details of carers as policies alone do not evidence they have complied with it.  It is important for practitioners to be open and honest on the cared for person health condition while at the same time offering the means for support for the carer as the news may be overwhelming. Highlights the importance of all practitioners having up to date information on support available or who to signpost to. Also an awareness from practitioners that overloading with too much information at the start can be hard for carers to take in. |
| 174 | Shropshire Council | Statement 2 | Comments from Active carers in Shropshire   * Carers report not always invited to meetings around their loved-one, how can they contribute? * Carers also need to be informed around discharge planning * There is a great deal of general information that should be given to carers that does not require consent * Carers should be recognised as the ‘expert’ in the person’s presentation * Where does the responsibility sit for record-keeping? This does not just apply to basic data like addresses but also if there are changes in confidentiality clauses |
| 175 | Shropshire Council | Statement 2 | Outcome a) Proportion of carers who are satisfied that they are kept up to date by health and social care services provided to the person they care for.  Comments from Active carers in Shropshire  Denominator – the number of carers.  There has to be a comparison between the number of people who are in the Health or Social Care setting and the number of carers identified by that system, otherwise the fraction is meaningless.  If the one carer they know about is satisfied with the service, this outcome will yield 100% and completely miss the carers who have not been identified |
| 176 | The Challenging Behaviour Foundation | Statement 2 | Quality statement and Rationale  In addition to families being kept up to date and contributing to care planning, families should be provided with targeted and practical information and support which meets their individual needs. Good, early support can prevent future crises. Where training is offered to professionals, families should also be included to ensure consistent support for the individual being cared for. |
| 177 | University Hospitals Birmingham (UHB) NHS Foundation Trust | Statement 2 | Statement and rest of section  This addresses the need to work with carers really well where consent can be gained, it doesn’t mention or address the scenario (common in hospital) where the person being cared for does not have the capacity (either temporarily or on a more permanent basis) to give consent due to lack of capacity. |
| 178 | University Hospitals Birmingham (UHB) NHS Foundation Trust | Statement 2 | What the quality statement means for different audiences  As above – it sets out clearly what is expected ‘if consent is given’ but not where consent isn’t, or can’t be given |
| 179 | University Hospitals Birmingham (UHB) NHS Foundation Trust | Statement 2 | Quality measures  At UHB there are ‘Partner in Care’ leaflets which accompany a conversation held with the carer around what support they wish to offer during the hospital admission of the person they care for – it acknowledges the carer may want a break from caring, or may want to participate (appropriately) in care. This can then be audited to measure compliance, and inform the need for staff training. |
| 180 | British Association of Social Workers | Statement 2- Question 1 | [Statement 2](file:///\\basw-fs01\USERS$\liz.howard\My%20Documents\Liz%20Howard\Adult%20PPEG\NICE%20Quality%20standard%20Adult%20Carers\NICE%20Quality%20standard%20carers-%20LH%20comments.30.10.20.docx#_Quality_statement_2:_1) Carers are kept up to date and contribute to decision making and care planning for the person they care for, with the person’s consent.  Statement 2 - replication of information shared accordingly, transparency of information sharing.  MCA- clarify capacity and consent issues  Safeguarding- thresholds constitute risk- cared for or carer posing risk  Separate quality statement for safeguarding  Consider adding safeguarding as a statement 6 to this Quality standard    Advanced care planning, advanced statements  Consideration of options- views and wishes of others  Role of advice and information - prevent, reduce, delay  Communication with other agencies and organisations  Nothing here about contingency planning- what do if you have problem  Carers emergency card- Health passport- in the gudinace but not fed through to the statements?    Diverse range of carers and situations - what works best for the person led by the individual carer    If consent from cared for person is required is this recorded with risks to carers identified? |
| 181 | Alzheimer’s Society | Statement 3 | Quality Statement  The experience of carer assessments reported by carers is mixed; however our research Fog of Support confirms findings in the wider literature that only a minority of carers have received an assessment of their needs. Furthermore, these assessments were not always experienced positively, with negative experiences being linked to assessments that were conducted over the telephone and/or did not seem personalised to the individual circumstances of the carer  In our research Fog of Support, for the 53% surveyed who had not had an assessment (Figure 6), this was due to not having been offered one (47%), other reasons (22%), such as not knowing / complications with the process or not being the main carer. Sixteen percent reported not being aware of carer assessments, while 4% reported having been told they were not eligible for one. Some of those people who indicated that they had not had an assessment highlighted the length of time waiting for an assessment (n = 7) and the high thresholds required to receive support (n = 8). Evidence also suggests that local authority support for carers may be reducing in real terms. A recent analysis of NHS Digital data by the King’s Fund (including from the Adult Social Care Financial Return) highlighted reductions in gross expenditure on support for carers and the number of carers assessed and/or supported; although provision of ‘information and advice’ may be increasing.  As part of carers’ assessments, one of the challenges carers found in seeking to access support was that there was an expectation of prior knowledge; they found they were often asked what support they wanted without being given any indication of the kind of support that might be available. Participants in our focus groups noted that where commissioned as part of memory clinics, occupational therapists can be invaluable to carers and those they care for, providing practical care management advice, sharing knowledge and providing warm introductions to other forms of support.  “I was asked ‘what do you want?’ And I thought ‘I don’t know what I want, I’m waiting for you to tell me what’s available’.”  There was a sense from some who had that the assessment was not particularly useful, with the process feeling prescriptive and consisting of form filling; attendees generally felt that little came from the assessments, and there were few reports of subsequent signposting. In addition, carers’ wellbeing was not always fully explored, with many attendees not being asked about their employment or educational aspirations. As such, we welcome that this standard incorporates work and training. We know that over 112,000 people have left their jobs to care for people with dementia.  Source: <https://www.alzheimers.org.uk/blog/yvonnes-story-career-on-hold>  Recommendations  councils should ensure that carers’ assessments take a strengths-based approach, focussing on the positive aspects of carers’ practice, while also acknowledging the areas in which they might need extra support or advice. These assessments should recognise the specific needs of those caring for people living with dementia.  councils should ensure that those undertaking carers’ assessments are skilled in active listening techniques  Assessments should consider the carers capacity (Care Act 10 (5)) and willingness to provide care now and in the future. Assessments should consider what carers want from support. |
| 182 | Alzheimer’s Society | Statement 3 | Quality measures - Structure  We know that many people with dementia do not receive regular carers assessments and reviews. According to Healthwatch once people have a care plan, only 45% are reviewed annually. One third of people with dementia, using long-term care services did not receive any review, whether planned or unplanned.  Source: <https://www.healthwatch.co.uk/news/2019-07-01/why-its-important-review-care-people-dementia>  Recognising the progressive nature of dementia, and therefore the progressive nature of caring responsibilities, councils should ensure that carers’ assessments of carers of people living with dementia are provided at least annually, with the opportunity for more regular reviews if appropriate to circumstances. These assessments should also consider emergency planning if the carer were to unexpectedly no longer provide care (for example, through illness).  Our Fog of Support conducted a survey of directors of social services, where most respondents reported having local outcome targets related to carer assessments (67%) and carer wellbeing (58%); however only a third reported having targets related to the provision of respite care (33%). Most areas were not able to provide clear data related to the number of people living with dementia and carers in their area. Furthermore, this data was limited for many in terms of the carer population and in-care population more widely, with some citing census data and area population data. For those able to provide a number for people living with dementia, (n = 6), most were citing SALT / ASC-FR figures and referencing the ‘memory and cognition’ or ‘health condition’ figures rather than local dementia specific figures. Where figures were given, two people noted that the figures they provided were for those receiving ‘support with memory and cognition’, which could include support needs besides dementia. One respondent noted that dementia is recorded as a health condition on their assessments/reviews. While most respondents were able to provide a figure for the total number of carer assessments conducted (n = 9), fewer had access to figures for the number of assessments where dementia is the primary condition. There was a large variance in the number of assessments reported, which did not appear related to local authority size (mean = 1778.2, range = 5072 – 224, sd = 1759.8).  We recommend  Data metric collecting the number of carers assessments offered and number taken up, with the reason for their caring responsibility (e.g. the condition(s) of the person they care for) also recorded.  A metric for ensuring annual review of care assessments  Local targets for provision of carers assessment, carer wellbeing, and respite care  Data should be broken down by condition |
| 183 | Alzheimer’s Society | Statement 3 | C  Regarding the numerator on proportion in paid work, we are concerned that this does not necessarily reflect that many carers may be in paid work but their work may have been impacted by care responsibilities - whether they are struggling more because of this or through reducing their hours. Our report with CEBR “The economic cost of dementia to English businesses – 2019 update” found   * Approximately 20% of people caring for someone with dementia are in some form of paid work, including working part-time, full-time or being self-employed, totalling over 355,000 people * Over 147,000 workers working age carers supporting a person with dementia, have had to reduce their work commitments, or are having difficulty balancing work and caring. They spend, on average, seven hours per week fulfilling their caring responsibilities, more than 51 million hours. * A total of 112,540 are no longer in paid employment due to their caring responsibilities * With appropriate adaptations, many workers with dementia will be able to work for some time after diagnosis. However, for employees who are unable to continue working, there is a subsequent cost to businesses. We estimate that there are approximately 47,000 people living with dementia in the workforce in 2019. * We estimate that dementia caring commitments cost English businesses £3.2 billion in 2019. It should be noted that a greater share of the total cost arises from carers leaving the workforce altogether, rather than reducing their working hours. On a per employee basis, the cost of workers reducing their working hours amounts to £4,447 per year. On the other hand, the costs for carers leaving the workforce amounts to £23,032 per employee, per year. This is reflective of the higher amount of output businesses lose when an employee leaves the workforce completely. Efforts from businesses to offer flexibility in light of the pressure carers face, will help keep their skills and experience in the workforce, avoiding the greater cost of them leaving altogether.   Source: <https://www.alzheimers.org.uk/blog/yvonnes-story-career-on-hold> |
| 184 | British Association of Social Workers | Statement 3 | Also, data collection for waiting times for carers assessment and support to be in place |
| 185 | Carers First | Statement 3 | Outcome b  This statement is line with the areas covered on the carers star. The carers star has a allows the carers to score themselves at the beginning of the assessment and the again after the assessment and support plan is in place. It can show journey travel and may give an indication to improved quality of life. Other examples of how to measure improve quality of life would be helpful and how often services should measure this. |
| 186 | Carers First | Statement 3 | Process b  Is this the number of carers assessments completed or number of carers assessments completed with a support plan?  Organisations would need to start recording as part of the assessment that the carers has been asked about what matters most to them and consideration has been given to the care’s health and social care needs, and work, education, or training. This information would also need to be recorded outside of the assessment to enable it to be reported on which would be more work for those carrying out carer’s assessments. Assessment and support plans completed by Carers First in Lincolnshire on behalf of Lincolnshire County Council are a good example of an assessment and support which would meet this statement. |
| 187 | Carers Trust | Statement 3 | In the associated briefing paper, NICE discuss support for carers at different stages of caring. The current draft Quality Standards however does not reflect this area of improvement. The Quality Standards would be improved if this aspect of supporting carer at different stages of their caring journey was given more emphasis.  This could be included in statement 3 on carers’ assessments so those commissioning and carrying our carers’ assessments are encouraged to include support for carers focussed on planning for the future and then put support plans in place for that future.  Carers Trust (alongside partners in the Health and Wellbeing Alliance, and commissioned by the DHSC) have recently completed a project focussing on support for carers as they reach a stage of their life when they are less able or unable to care.  No Longer Able to Care: Supporting older carers and ageing parent carers to plan for a future when they are less able or unable to care - highlights how older parent carers and ageing carers who face additional barriers to accessing services should be supported to prepare for a time when they are less able or unable to provide care. The report is accompanied by resources for carers, commissioners, providers and front line staff to use in the development of support for carers to plan for a future when they are less able or unable to care.  The report looked at current practice, and what more can be done to support carers to plan for a future when they are less able or unable to care.  Our main findings:   * The majority of carers are not currently being supported to plan for a future when they are less able or unable to care. * There is a wider lack of confidence in the social care system as a whole, meaning carers do not seek support. * Carers also face the problem of the lack of available social care – both for themselves and the person they care for. This leads to many carers picking up more caring responsibilities, to the detriment of their health and wellbeing. * Carers often feel too busy dealing with the day-to-day to think about planning for the future. Broader support for carers in the day-to-day challenges they face will enable services and individuals to better plan for the/their future. * Some carers are given support to prepare for a crisis where they are unable to care in the short term and for a limited time period. While this is a positive step, much more needs to be done to plan for the long-term future where the carer is unable to care * Carers need support to plan for a future when they are less able or unable to care. * Carers need to be identified early and support put in place to enable them to plan for the future. * Carers who are from communities who face additional barriers to accessing services need services that are open and actively welcoming to them as well as the option of accessing specialist support if they need it. * National government, local authorities, the voluntary sector and service providers must all work together to ensure services are there to support carers to plan for a future when they are less able or unable to care.   We would like to see providers talk to carers about a future when the carer is less able or unable to care. As part of this conversation, a plan should be developed to plan for that future.  We would like to see commissioners ensure that the services they commission for carer support specifically include the need for providers to work with carers to plan for a future when they are less able or unable to care.  For more detailed findings and recommendations for commissioners and providers, please see No Longer Able to Care: Supporting older carers and ageing parent carers to plan for a future when they are less able or unable to care <https://carers.org/resources/all-resources/105-no-longer-able-to-care> |
| 188 | Carers Trust | Statement 3 | Carers Trust welcome the inclusion of this quality statement and the recognition that carers’ assessments should focus on what matters most to carers, including their own health and wellbeing (including their mental health), their own social care needs and any support they need to find or remain in, employment and/or education. |
| 189 | Carers Trust | Statement 3 | Outcome (b)  Does this indicate current position vs original position? Quality of life may be as improved as is possible through an assessment and intervention and still be very low. |
| 190 | Carers Trust | Statement 3 | Outcome (c)  The proportion of carers having assessments who are in paid work doesn’t act to ensure the quality of carers assessments – a low percentage might indicate nothing more than that the group of carers doesn’t value work as “that important” to them. Without comparing this indicator to those wanting to work, the context is lost |
| 191 | Carers Trust | Statement 3 | Quality Statement  Having a break should also be included in this statement, as the next statement says breaks are discussed in ‘routine’ assessments, but Carer breaks (as they are essential to health and wellbeing) should be included in all Carer assessments. |
| 192 | Carers Trust | Statement 3 | Outcome (Proportion of carers in paid work)  It is hard to see how this statistic can give an accurate/true reflection of the actual picture  Is this the proportion that want to be in work that is, as some choose not to work?. Is it based on the number of assessments of Carers who are in work/not in work regardless of whether they want to or not?. Is it based on national statistics? Many Carers don’t identify as a Carers. |
| 193 | Carers Trust | Statement 3 | What the quality statement means for different audiences  In the section for health and social care practitioners suggested edit (edit in bold and underlined)  Practitioners ask carers what might help them and suggest options that may be available so that they can be better supported in their caring role. |
| 194 | Carers Trust | Statement 3 | Carers often don’t know what will help as they often don’t know the full extent of what support is available. It is important that Carers are not guided, but made aware of the options available to them while being clear that some options are outcome-based dependent on the result of the assessment. |
| 195 | Carers Trust | Statement 3 | Statements 3 and 4 don’t make any attempt to suggest what practitioners must do as a result of the outcome of an assessment. There will be variations across the country in terms of provision, but it must be clear that there is a duty to meet assessed need. Regarding breaks, this duty goes beyond discussion and providing information. Carers must be enabled. This is in the Care Act and Children and Families Act which this standard is to be read alongside, but for ease and clarity, it should be clear that duties apply. A quality standard should state what constitutes a quality assessment, which should include what comes after or as a result of the assessment. |
| 196 | Carers Trust | Statement 3 | Should also include whether they are willing to continue in the caring role and what their options are |
| 197 | Carers Trust | Statement 3 | Rationale  It is a high-quality carers assessment that provides that |
| 198 | Carers Trust | Statement 3 | Rationale  There should be some reference to review of assessments to take account of changes |
| 199 | Carers Trust | Statement 3 | Outcome – c – Proportion of carers in paid work  This would be skewed by the number of older carers (e.g. over retirement age) – is there any way to separate out? |
| 200 | Carers Trust | Statement 3 | What the quality standards mean  It’s missing about assessments being reviewed |
| 201 | Carers Trust | Statement 3 | Equality and diversity statements  These are very weak requirements if all that it is requiring is that they “can have an assessment” – says nothing about an assessment which is accessible or takes account of their needs, or it being of good quality |
| 202 | Carers UK | Statement 3 | Practice is tending towards a “what matters most to you” question, to focus on carers’ needs, but it is essential to ensure that any carer’s assessment appropriately explores the full range of areas that need to be considered under the Care Act 2014 provisions for carer’s assessments.  This What Matters Most approach is already adopted in Wales and we have some concerns that this is starting to truncate the carer’s assessment process in a way that then overlooks key areas that are important to carers and a core part of the Care Act 2014. We would urge you to look at the experience of Wales in Carers Wales Track the Act publication here: <https://www.carersuk.org/wales/news-campaigns/track-the-act/track-the-act-survey-briefings> |
| 203 | Central and North West London NHS Foundation Trust | Statement 3 | Data Source  Where NHS providers are not the ones providing the carers’ assessment, NHS staff should be clear about where to signpost people to for a carers’ assessment. Too many carers are not aware they are entitled to an assessment and some clinical staff are unaware of this too. Medical records system should allow for it to be noted that a person has received (or at least been signposted to) a carers’ assessment. |
| 204 | Hampshire County Council | Statement 3 | Quality Statement 3: “Carers having a carer’s assessment are asked about what matters most to them, including consideration of their health, wellbeing and social care needs, and work, education, or training.”  Carers assessments cover the measures included in the NICE documentation and are offered at the first point of contact with the department. Regular auditing takes place, eg for planned respite for carers, although COVID has had a huge impact on this. Work paused has now restarted although the second wave has impacted on this. All operational teams have been asked to ensure there is a discussion with carers around a contingency plan to be placed on a carer’s details, so if the carer becomes unwell or is unable to care, we have a record. There is a Sensory team in the department who undertake carers assessments where there is a particular sensory need as well as a commissioned independent advocacy service that can be used. |
| 205 | Healthwatch Richmond | Statement 3 | We agree that carer’s wellbeing is key. However, the draft should specify that people must be reminded what to expect and what to do in case they wish to contest the assessment, or if their circumstances change. In fact, more or less sudden changes in carers’ circumstances can impact on their ability to care, their wellbeing and satisfaction. On our outreach program we have reached out to local carers who evidently put their needs after those of the person they cared for (as Quality statement 4 also mentions). From our experience it seems to occur that carers often don’t know of their opportunity to be reassessed, or that they do, but do not seek to undertake this process. Quality measures of carer’s assessment should include evidence that carers have been made aware of their opportunity to be reassessed, and that they can request it at any time. Evidence of existing online assessment and self-assessment options may also improve the quality of this measure.  Additionally, quality measures should evidence time-frames within which carers assessments take place. Although it is important that carers’ assessment take into consideration carers’ needs, they should also take place within reasonable time.  Finally, the point made in section 1 about encouraging carers to be empowered in achieving wellbeing still stands for section 3. |
| 206 | Independent age | Statement 3 | Structure (a): Evidence of local processes to ensure that carers having a carer’s assessment are asked about what matters most to them, including consideration of their health, wellbeing and social care needs, and work, education, or training.  In addition to the carers assessment focussing only on the needs of the carer rather than the person they care for, at the point of arranging the assessment, the carer should be offered a separate carers assessment as an alternative option to a joint assessment with the person they care for. This is to ensure that the carer feels they have the autonomy to decide what would be best for them in terms of the support they need and to accurately gauge their wellbeing needs. This is also important to ascertain if they are willing and able to carry on their caring role without the possibility of feeling under pressure and even minimising their needs for the benefit of the person they care for. We know that carer and cared-for person relationship can often be complex.  We are also hearing on our national helpline that when providing older carers with information and advice at the start of their carer journey, it is apparent that awareness of the right to a carer’s assessment is low. We feel that this area needs to be included within the measures for this statement to encourage awareness raising around assessments to ensure people’s rights are not ignored and that they are not having to experience excessive waiting times for carers assessment in the context of potentially high-level carer needs.  Please see the Carers Trust response to this statement and associated evidence that we fully support. |
| 207 | Motor Neurone Disease Association | Statement 3 | Where this statement specifies areas that might be most important to carers, we feel that important questions about finances and financial resilience are missing. |
| 208 | Motor Neurone Disease Association | Statement 3 | We think the scope of statement 3 should include familial circumstances and also finances. |
| 209 | Motor Neurone Disease Association | Statement 3 | Rationale  We think the rationale should also include reference to the carer’s ability to cope as a measure as it will also determine their needs. Some carers will be able to cope with many responsibilities, while others will become stressed with a much lesser requirement to provide care. The Carers Alert Thermometer, piloted with MND, by Edge Hill University is a good tool to test where a carer is on a coping/stress scale and could have real value in assessing carers needs. |
| 210 | Motor Neurone Disease Association | Statement 3 | Rationale  Should it also make explicit reference that it is a right under the Care Act? |
| 211 | Motor Neurone Disease Association | Statement 3 | Audiences  We think the paragraph on service providers should also include being able to sign-post carers to the welfare system if they are no longer able to work and/or to find out more about carers allowance. |
| 212 | MSA Trust (Multiple System Atrophy Trust) | Statement 3 | MSA Trust found in a recent members survey that only 66% of former carers had ever had a carers assessment despite caring for a person with a terminal condition for 5 + years. |
| 213 | MSA Trust (Multiple System Atrophy Trust) | Statement 3 | Carers assessments need to be more than a tick box exercise – funding to provide support for carers is essential. |
| 214 | MSA Trust (Multiple System Atrophy Trust) | Statement 3 | This statement is too woolly – it needs to be more than just ‘consider’ carers needs and ‘regularly’ needs to be quantified. |
| 215 | Newcastle City Council and Partners | Statement 3 | Quality Statement  Statutory Care Assessment (Care Act 2014) takes this into consideration |
| 216 | Newcastle City Council and Partners | Statement 3 | Quality Measures (Structure)  Need to take into consideration their own personal circumstances e.g. parent, caring for others etc |
| 217 | Newcastle City Council and Partners | Statement 3 | What the quality statement means for different audiences (Service Providers)  Care Act/Statutory carer assessments consider this as one of the NMET criteria in relation to eligibility for statutory support; social care staff (and others, if the statutory assessment is outsourced to a Carers Centre for example) will discuss this but clarification is sought to understand what is meant by ‘having a knowledge and understanding of potential opportunities for returning to, or remaining in work education or training’ |
| 218 | NHS England and NHS Improvement | Statement 3 | As we know it is such a big issue that carers neglect their own health because they are caring, we recommend adding a metric about carer health (E.g. ‘proportion of carers who say they are in good health?’ (RD) |
| 219 | Royal College of Occupational Therapists | Statement 3 | Carers having a carer’s assessment should be asked about what matters most to them, including consideration of their health, wellbeing and social care needs, and work, education, or training. |
| 220 | Shropshire Council | Statement 3 | What statement means for different audiences  A question may be what training practitioners receive to provide person centred assessments that have meaning for the carer? |
| 221 | Shropshire Council | Statement 3 | Rationale  Comments from Active carers in Shropshire   * 'Carers having' should be changed to 'Carers should have' * It is no good asking the Carer what they need and then not supplying anything * Carers need to be listened to and what they need recorded, not what practitioner thinks or assumes is needed * Perhaps needs a step back overall to ensure carers are offered assessments at all or at annual intervals. Should not always be up to carer to seek this out. |
| 222 | Shropshire Council | Statement 3 | Outcome  Comments from Active carers in Shropshire  Denominator – the number of carers’ assessments. As above  Denominator – the number of carers’ assessments for carers who want to work. As above |
| 223 | University Hospitals Birmingham (UHB) NHS Foundation Trust | Statement 3 | Quality measures  This doesn’t address the outcome of the carer’s assessment and how helpful it was in terms of them accessing the information, training and support they have identified as being important. For example; carers often struggle to navigate the health and social carer pathways and need information about how to do this and what support ids available along the way – this is a key indicator that is missing from this measurement. |
| 224 | University Hospitals Birmingham (UHB) NHS Foundation Trust | Statement 3 | Quality measures  This statement may be hard to measure because…Carers Assessments are not completed on site during the hospital journey; carers are referred by healthcare staff to the external organisation identified by the local authority who carry out the carers assessments on their behalf. Some measures would be achievable i.e. ‘how many carers were referred and received assessments’ |
| 225 | British Association of Social Workers | Statement 3- Question 1 | [Statement 3](file:///\\basw-fs01\USERS$\liz.howard\My%20Documents\Liz%20Howard\Adult%20PPEG\NICE%20Quality%20standard%20Adult%20Carers\NICE%20Quality%20standard%20carers-%20LH%20comments.30.10.20.docx#_Quality_statement_3:) Carers having a carer’s assessment are asked about what matters most to them, including consideration of their health, wellbeing and social care needs, and work, education, or training.  Don't have to have an assessment  Need to ask people if willing/able to carry on what the caring role - risks and impact  Can't assume what is important to the carer now  Recognising person in their context and what matters to them    What is the best way to carry out the assessment with the carer- based on the way they want it to happen not judgemental about what they do    Being clear about what the assessment can lead to  Money and advocacy are intrinsically linked  Economic well-being an contribution to society  Ability to work or not work income affected  Holistic approach- eligible for PIP and Attendance Allowance  Means testing and permitted work, gateway benefits  Making things easier  The need to provide carers with training programmes and support with health and safety techniques including manual handling, administering medication and safeguarding in general. This is included in some detail in the guidelines but not I believe highlighted in the standards. |
| 226 | Alzheimer’s Society | Statement 4 | Quality statement  We welcome the use of “breaks” not “respite” in this quality statement. We believe this is more positive language. We recommend that councils and providers, including the NHS, should regularly review their use of language in policy and practice. The choice of language can have powerful implications for carers, particularly in relation to feelings of guilt they might have. For example, rather than talking about ‘if’ you need a short break from your caring responsibilities, instead talk about ‘when’; or rather than talking about “carers’ assessments” refer to them as “check ins”. |
| 227 | Alzheimer’s Society | Statement 4 | Rationale  We know many carers struggle to maintain their own wellbeing. When surveyed for Fog of Support, overall, the majority of people (60%) felt ‘mostly positive’ about having breaks from their caring responsibilities, however 12% felt mostly or entirely negative. Where answers were explained (n = 17), respondents raised concerns around the quality of care (n = 4), feelings of guilt / not wanting to leave the person they care for (n = 4) for example |
| 228 | Alzheimer’s Society | Statement 4 | Quality Measures  Councils should provide a straightforward method of booking overnight care in advance, to allow carers to be able to manage when they can have a break from their caring responsibilities.  Regarding recognising the “value of having a break from caring”, this should recognise that it is something positive, “when” not “if” in order to reduce the stigma and anxiety people feel |
| 229 | Alzheimer’s Society | Statement 4 | Outcome  The “proportion of carers who had a break from caring” should also include the ‘type’ of beak it was. Parallel codes should be used for financial spend and the volume of support provided to enable comparisons of unit prices for support |
| 230 | Alzheimer’s Society | Statement 4 | Definitions  Under “carers’ breaks should” with two bullets, we would recommend including that “carers’ breaks should be simple and seamless to arrange” |
| 231 | British Association of Social Workers | Statement 4 | Any delay in accessing breaks or lack of provision of the type of support carers feel would be beneficial is captured in data collection- unmet need |
| 232 | Carers Trust | Statement 4 | Carers Trust welcome the inclusion of this quality statement and the recognition of the importance of carers having a break. However, currently, the Quality Statement states: “Carers discuss, during their routine assessments and reviews, the value of having a break from caring and the options available to them.”  This needs to be strengthened to ensure carers access breaks they need.  To strengthen the statement, Carers Trust would recommend going beyond statements around “discussion of breaks” to the importance of putting processes and procedures in place to ensure that carers do have a break from caring.  This needs to be strengthened to ensure that carers are enabled to get a break. NICE already recognise that not enough carers are accessing breaks (see associated NICE Briefing Paper) and the impact this has.  Alongside the current Quality Measure, NICE would need to add:   * Evidence that there are processes, procedures and services to ensure carers can access breaks. * Evidence that the commissioner is fulfilling their Market Shaping Duty under the Care Act * Data source would be an audit of local processes and provisions of carer breaks * And the outcomes would be the number or proportion of carers accessing breaks |
| 233 | Carers Trust | Statement 4 | Outcome (b)  Does this indicate current position vs original position? Quality of life may be as improved as is possible through an assessment and intervention and still be very low. |
| 234 | Carers Trust | Statement 4 | The way statement 3 and 4 are written suggest that a Carer Break will not be discussed in a Carers first assessment, but will be in subsequent reviews. Breaks should be discussed in any discussion about the support needs of Carers. |
| 235 | Carers Trust | Statement 4 | Quality Statement  Why is the onus on the carer here? How will they know what their options are unless someone has that conversation with them? |
| 236 | Carers Trust | Statement 4 | Outcome – (a)  The challenge is defining the parameters of a “break from caring” |
| 237 | Carers Trust | Statement 4 | What it means for health and social care practitioners  Social prescribers and mental health practitioners missing from this list |
| 238 | Carers Trust | Statement 4 | Equality and diversity statements  Much stronger than the requirement in statement 3 (see comment 31) |
| 239 | Carers UK | Statement 4 | This statement may be appropriate in some instances for health services but would be considered necessary for any Care Act assessment or review. The background evidence does not really explore the definition of routine. Are routine assessments “routine” for the organisation, or for the individual? Carers do not have carer’s assessments routinely. Many do not even receive an annual review. Other some of the routine health assessments would be highly appropriate to identify carers and discuss breaks. Health checks, for examples should collect identification of carers as a standard. Other routine assessments might need further discussion, e.g. medication reviews, which may take place with doctors or with pharmacists. The latter are very well placed to identify carers and signpost to support, but less well placed to discuss breaks and options open to carers. It should also be noted that in all carer’s assessments, breaks should be a core part of the assessment, according to policy guidance and not an optional statement relating to quality. |
| 240 | College of Mental Health Pharmacy | Statement 4 | This statement is a difficult one to implement and measure because of the differing needs of the various health and social care needs of individuals. Areas may have support for physical health needs but not learning difficulties or dementia. |
| 241 | Hampshire County Council | Statement 4 | Quality Statement 4: “Carers discuss, during their routine assessments and reviews, the value of having a break from caring and the options available to them.”  Currently, there is a project dedicated to examining the current provision of breaks for carers that are planned in advance (not emergency respite) with the outcome being to seek information from existing carers for a specific cohort of older adults over the age of 65. Carers will discuss the need and value of having a break with operational staff via various communication points, eg telephone, Zoom calls, Teams calls, etc. Throughout COVID the usual respite services have not been as available: discussions have taken place and alternatives found where possible following discussions with carers. Alternative provisions and services have included some respite, other forms of support, ie live in care, increased use of technology enabled care. In our discussions with carers, we have had to be flexible on the options available. Recommendations and ideas on how to improve the options and provisions are discussed at the Partnership Board and the Bronze Carers meetings and there has to be a flexible and adaptable approach. Again, access to information and advice is available now through the Connect to Support Hampshire website and this has included the development of an online Marketplace where services can be purchased by carers without any assessment/provision being put in place. HCC are currently prioritising individuals and their carers who had paused/stopped their care during the COVID period and offering a review. Carers are able to request an assessment of their own needs. |
| 242 | Healthwatch Richmond | Statement 4 | Respite care is greatly valued by the carers we spoke to. It is known that carers could not access respite breaks during the pandemic or if services providing those breaks are unavailable. The presence of alternative options to traditional carers’ breaks would indicate better quality support to carers. |
| 243 | Independent age | Statement 4 | Outcome (a): a) Proportion of carers who had a break from caring.  Although we know that taking a break will improve the carer’s wellbeing and help them to continue in their caring role. This may be difficult to measure during the COVID-19 pandemic as we are hearing on our helpline that day centres and carer respite are not coming back to pre-Covid levels, putting carers at risk of psychological trauma. We are also hearing about the extended closure of day centres and other social groups such as lunch clubs due to Coronavirus is increasing pressure on carers and reducing their life choices and wellbeing.  Please see the Carers Trust response to this statement and associated evidence that we fully support. |
| 245 | Motor Neurone Disease Association | Statement 4 | Quality statement  We think it should mention specifically somewhere as part of this standard that statement 4 should include the person with care needs and the carer being able to take a break together, as well as replacement care in their own home. |
| 246 | Motor Neurone Disease Association | Statement 4 | Definitions  We suggest that ‘respite care’ be replaced by ‘replacement care’ as it is a less emotionally loaded term and therefore more helpful. |
| 247 | Motor Neurone Disease Association | Statement 4 | Definitions  In relation to ensuring carers breaks are arranged in a way that provides reliable and consistent support to the carer, we think it would be good if care providers were measured against this (perhaps by CQC or others) and other key elements of care delivery, rather than a simple overall agency rating |
| 248 | MSA Trust (Multiple System Atrophy Trust) | Statement 4 | Voluntary agencies should be funded to help provide specialist training to carers, especially in respect of rare conditions |
| 249 | MSA Trust (Multiple System Atrophy Trust) | Statement 4 | Carers do usually know the value of a break – funding is essential to support this and carers and those being cared for need to have confidence in the options offered, including specialist respite. |
| 250 | MSA Trust (Multiple System Atrophy Trust) | Statement 4 | Care co-ordination support is vital to carers – along with anticipatory care and plans for when a carer can no longer cope. |
| 251 | Newcastle City Council and Partners | Statement 4 | Rationale  Each local authority is different when it comes to the offer/provision of carer breaks, some are provided by the local authority and others via a direct payment to the carer to arrange themselves  Breaks provided to carers will only be formally recorded if they are provided by the local authority following a statutory carers assessment – some breaks, as in Newcastle can be accessed separately through a different funding stream. |
| 252 | Newcastle City Council and Partners | Statement 4 | Rationale  Staff will have knowledge of local resources for replacement care, but what about when there isn’t a resource, for example, respite care – options are often quite limited, particularly for people who require positive behavioural support |
| 253 | NHS England and NHS Improvement | Statement 4 | Carers’ breaks: Schemes for carers’ breaks are intermittently funded/available and do not cover all carers. Is there a consistent stream of funding for this scheme? (PC) |
| 254 | NHS England and NHS Improvement | Statement 4 | Does there need to be a time period on the metric for example in the last week/month? (RD) |
| 255 | Royal College of Occupational Therapists | Statement 4 | Carers having the ability to discuss, during their routine assessments and reviews, the value of having a break from caring and the options available to them is vital to help improve/maintain their physical and mental health. |
| 256 | Royal College of Psychiatrists | Statement 4 | Carers should also be informed of what financial support may be available to them and how to access this |
| 257 | Shropshire Council | Statement 4 | Rationale  Comments from Active carers in Shropshire   * Where is the consideration that Carers may become unwilling or unable to continue to care. There is an assumption here that Carers will just keep going. * There needs to be greater clarity around there not being any expectation of on-going care and that carers have every right to step back or disengage * Are there actually any options to support exhausted carers? |
| 258 | The Challenging Behaviour Foundation | Statement 4 | What the quality statement means for different audiences  We support this statement and fully agree that taking a break is very important for family carers. However, in a climate of cuts family carers have noticed that respite is one of the first forms of support to disappear. (Confronting a Looming Crisis, Rachel Forrester Jones, University of Bath and Mencap New Forest, 2019 (<https://www.bath.ac.uk/publications/report-confronting-a-looming-crisis/attachments/Final_FullDocument.pdf>))  This existing problem has been exacerbated by restrictions in place due to Covid 19.  It is essential that replacement care tailored to the needs of children, young people and adults with severe learning disabilities whose behaviour challenges is being commissioned and prioritised as the pandemic continues. This will often mean individualised packages of short breaks. |
| 259 | University Hospitals Birmingham (UHB) NHS Foundation Trust | Statement 4 | Statement and rest of section  This quality statement and section is clear, and relatively easy to measure, other than what constitutes a break from caring is very subjective, for some it is a cup of tea away from the bedside and for others it is full respite for a specific episode of care. Not sure how easy it would be to compare data, or for the data to be meaningful unless it measures like for like. |
| 260 | British Association of Social Workers | Statement 4- Question 1 | [Statement](file:///\\basw-fs01\USERS$\liz.howard\My%20Documents\Liz%20Howard\Adult%20PPEG\NICE%20Quality%20standard%20Adult%20Carers\NICE%20Quality%20standard%20carers-%20LH%20comments.30.10.20.docx#_Quality_statement_4:) 4 Carers discuss, during their routine assessments and reviews, the value of having a break from caring and the options available to them.  Carers breaks  Stakeholder engagement, co-production, consultation opportunities  Direct payment up to carer to negotiate, supportive approach, families with good intent not being given proper information about how direct payments work and what they can/can't do with the payment.  Role of commissioners designing and developing services and support for carers- short breaks or longer term opportunities for carers to go out.  Individual solutions    Commissioners- need to ensure services commissioned are accessible, culturally diverse and make reasonable adjustments  Commissioners: service and support options to be co-produced with carers so that support is designed and developed to reflect carers needs and circumstances and what will work for them- thinking about loneliness, isolation, emotional support |
| 261 | Alzheimer’s Society | Statement 5 | Quality Measures  It is unclear whether this focuses on employers in the LA area, or employers of carers in the LA area? Is it different for SMEs to large corporations?  As above, these measures don’t take account of the impact of care on people who have reduced their hours of work but are still working, or are in work but are unable to cope or are struggling. |
| 262 | Alzheimer’s Society | Statement 5 | Quality Measures Structure  Regarding “Evidence that workplaces have policies and plans in place to support carers” this local data collection review should also find out whether carers in the workplace have been actively consulted in the development of these policies and plans as well. This be led by the LA with attendees from local employers (or even employer representative groups) if there are insufficient carers in one employer. |
| 263 | Carers First | Statement 5 | Measure  As well as encouraging organisations to have carer procedures and policies in place as good practice, when tenders for contracts with health and social care come up as a matter of course the bidder should be asked to provide there carers policy and produces for their employees. |
| 264 | Carers First | Statement 5 | Measure  If carers work for employers in the private sector or SMEs, they have no compulsion to disclose any policies or procedures and it would also be good to see a reference to Carers UK Employers for Carers offer in the NICE guidelines. |
| 265 | Carers Trust | Statement 5 | Statement 5 needs to be restricted to health and care settings and third party commissioned services. |
| 266 | Carers Trust | Statement 5 | Carers Trust welcome the inclusion of this quality statement and the recognition of the importance of enabling carers to stay in paid employment.  Carers Trust recommend including Carer Passports as an example of supportive working arrangements. Carers Trust worked with Carers UK on a Carer Passport scheme funded by the Department of Health and Social Care <https://carerspassports.uk/employment> |
| 267 | Carers Trust | Statement 5 | Quality Measures (structure)  a) Evidence that workplaces have policies and plans in place to support carers.  This measure should be applied to all statutory health and care settings and third party commissioned services, but should not create a burden of evidencing this is being done by all employers. |
| 268 | Carers Trust | Statement 5 | Outcome (a)  a) Proportion of carers in paid work  This is unclear: Compared to what? As in statement 3 – Some carers choose not to work, and some Carers in work do not identify as Carers. How will the data collected for this outcome give an accurate picture. |
| 269 | Carers Trust | Statement 5 | Outcome (a) (Data source)  What percentage of Carers are actually in contact with local authorities? If not all Carers are in contact, this again will not give an accurate picture. |
| 270 | Carers Trust | Statement 5 | Outcome (b)  b) Proportion of carers in paid work who feel supported by their employer.  This information could be collected if limited to statutory providers and commissioned third party providers. A wider scope would make collecting accurately reflective data unfeasible |
| 271 | Carers Trust | Statement 5 | Structure – data source – (b)  Number of employers participating in carer-friendly initiatives/accreditation could be an additional data source |
| 272 | Carers Trust | Statement 5 | Outcome  One of the measures should be around the reduction in the number of carers having to reduce their work (partially or completely) because of caring |
| 273 | Carers UK | Statement 5 | This statement is acceptable as it incorporates the law and goes beyond that to broader measures to support carers.  Unfortunately, the data set would be limited, since it will only record those carers who are in touch with local authorities. It would not cover carers whose relatives are in residential care, self-funders, those in touch with voluntary organisations, those with CHC funding, those only who have contact with health bodies as they have a complex health condition, and those who manage without help.  It is also widely evidenced that, by the time a carer is known to a local authority and requests a carer’s assessment, they are less likely to be in work. Whilst we recognise that data collection is limited, we would encourage broader sources of data collection to be added to this to provide a more rounded view. |
| 274 | Central and North West London NHS Foundation Trust | Statement 5 | Rationale  In referring to the Equality Act 2010 in this sentence “It can also demonstrate that they are meeting the requirement of the Equality Act 2010 to actively promote a positive culture towards people with caring responsibilities” – the document should say what part of the Equality Act it is referring to. This will enable laypeople to understand how carers are protected by the Act. |
| 275 | Central and North West London NHS Foundation Trust | Statement 5 | What the quality statement means for different audiences  A reference to agile working could be included, as well as a reference to using technology to support and improve flexible working. |
| 276 | Central and North West London NHS Foundation Trust | Statement 5 | What the quality statement means for different audiences  Carers passports can also be useful for staff who are carers. |
| 277 | College of Mental Health Pharmacy | Statement 5 | It is important to include access to relevant transport arrangements as well for those who are working in places such as hospitals. E.g. the availability of accessible car parking could go such a long way to supporting individuals with caring responsibilities and free up considerable amounts of time for them. |
| 278 | Hampshire County Council | Statement 5 | Quality Statement 5: “Carers work in organisations that offer supportive working arrangements.”  HCC have HR processes that offer flexible working and other benefits to support staff who have additional caring responsibilities. A formal staff network for carers/working parents has now been established. The network hopes to develop a specific Staff Carer Policy that will complement existing HR policies such as flexible working. Carers leave for staff will be discussed in line with the recent consultation by the government. A good work/life balance particularly for this group of staff and with the added pressure of COVID is essential. Hampshire have extended the use of technology to enable the majority of staff to work from home. The NICE standards submitted will support a robust policy and will encourage effective recording of staff that are also carers. We are willing to share the process of setting up a network with other organisations as a positive step. Future developments include publicising the strategy more widely. |
| 279 | Healthwatch Richmond | Statement 5 | Recently, a carer told us about their difficulties in grieving for the father they cared for, after he died. This person explained that the bereavement process does not only relate to losing a parent, but also losing their caring role. This person explained that whilst caring for their father, they had completely lost a sense of self, aggravated by the fact they quit their job to fulfil caring duties. Once their father died they also struggled financially as they couldn’t get back into work straight away. It is therefore laudable that NICE supports carers to remain into work, and that organisations are supportive in making arrangements for the carer to continue with their home/work duties. However, it is not clear from the draft how carers who work in an environment that is not supportive of their caring duties will be helped to maintain work. This also includes carers on zero-hours contracts, as these may offer flexibility, but would not allow carers to take paid leave. People may give up working hours to care for a family member, then encounter financial/emotional/social issues as a result. |
| 280 | Motor Neurone Disease Association | Statement 5 | Statement  Although we think it is incredibly important for working arrangements to be included as part of the standards, we are unsure how this can be effectively implemented as employers do not need to follow NICE guidance. |
| 281 | Motor Neurone Disease Association | Statement 5 | Rationale  Although in some instances employers can enable carers to remain in work by offering flexible working arrangements, as a severe and progressive condition this might not always be a viable option when people are caring for someone with MND. |
| 282 | Motor Neurone Disease Association | Statement 5 | Data source  We are unsure of who would be best placed to collect this information and whether they would be able to effectively. |
| 283 | Motor Neurone Disease Association | Statement 5 | Supportive working arrangements  As far as we are aware, carer’s leave has not become law yet and was being consulted on this year by BEIS. |
| 284 | MSA Trust (Multiple System Atrophy Trust) | Statement 5 | Not sure how this can be achieved. |
| 285 | Newcastle City Council and Partners | Statement 5 | Quality Statement  Working carers are often hidden, not identifying as such in the workplace because of fear (of job loss) or stigma associated with caring. The profile of carers needs to be raised with employers so that they recognise the benefits of supporting them to stay in work e.g. skill set, knowledge, experience, cost benefits and encourage employers to be carer friendly (e.g..g Employers for Carers  The restrictions in place as a result of COVID 19 has enabled many more employees to work from home, balance their caring responsibilities better with their work life and be as, if not more productive. This needs to be considered by all employers as people are asked to return to the workplaces (flexible approach) |
| 286 | Royal Pharmaceutical Society | Statement 5 | Using community pharmacists to ensure carers receive a flu vaccination, thereby enabling them to continue in work, education or training, as well as continue to undertake their caring duties, has worked in practice and needs to be encouraged.  As the carers flu vaccination campaign has shown, when a carer visits a pharmacy (for example to collect a prescription), pharmacy teams have a window of opportunity to offer services that could help the carer maintain their health and well-being. This is highlighted in a paper exploring who uses pharmacy for flu vaccinations <https://pubmed.ncbi.nlm.nih.gov/26821372/>  Community pharmacists have a huge role in reassuring carers, helping to reduce their anxiety, acting as convenient and accessible points for information/ signposting and general advice on medicines and lifestyle issues. Carers often neglect their own health and wellbeing needs and community pharmacists have the opportunity to recognise this and support the carers. Some examples of services that community pharmacists could provide to carers include:  1.Identify carers and tag their medical records  2.Notify the carer’s GP  3.Provide them with general health advice  4.Provide them with an NHS health check  5.Offer them a flu vaccination  6.Offer them a pneumococcal vaccination  7.Help them access electronic prescription service  8.Provide a home delivery service  9.Screen carers for hypertension, COPD and diabetes risk factors  10.Offer them services such as smoking cessation, weight management etc.  11.Offer them an MUR or NMS for themselves.  12.Give advice on how to use, store and administer medicines safely1  3.Advise them on disability aids and equipment  14.Refer carers to their local carers’ service for information, advice and support  15. Support the mental health and wellbeing of carers |
| 287 | Shropshire Council | Statement 5 | Quality measures – could accreditation as a carer friendly organisation from a respected body be included as a measure? |
| 288 | University Hospitals Birmingham (UHB) NHS Foundation Trust | Statement 5 | Quality Statement  Not sure the quality statement is addressing all of the issues that impact carers. Gaining improved support through flexible working arrangements would indeed be a big step forward in employment. But it is not just about managers needing to provide working arrangements that are supportive (which is essentially about support that allows you to be away from the workplace), but also creating an environment in which the individual feels supported while in the workplace. For example some carers feel that when they come to work they are expected to switch off the ‘carer’ identity – that is hard to do, particularly when the individual they are caring for has high levels of dependency and is at end of life. |
| 289 | University Hospitals Birmingham (UHB) NHS Foundation Trust | Statement 5 | Quality Statement  There also needs to be a quality standard within this statement which is about managers understanding the impact of caring. That is more than flexing hours etc but about responding to the psychological impact – it requires sometimes thinking about flexing the nature of the work that an individual will do when they are at work; if a carer is having a particularly difficult time, it may not be helpful if they are dealing with difficult issues or people in difficulty, or if they are emotionally drained or fatigued by a significant event then they should be supported to adjust their work duties to enable them to recover. |
| 290 | University Hospitals Birmingham (UHB) NHS Foundation Trust | Statement 5 | Quality Statement  Overall, the Quality Statement is very broad so some additional information included here could strengthen it e.g. to add in something like’ Carers work in organisations that recognise and value their caring role, offer support with the impact of caring, and enable carers to access supportive working arrangements flexible enough to suit their ever changing needs’ |
| 291 | University Hospitals Birmingham (UHB) NHS Foundation Trust | Statement 5 | Rationale  Could enhance the rationale by adding in ‘addresses the gender pay gap as more women take on the carer role and it can also help to attract a more diverse workforce if there are supportive carer or family friendly policies in place. |
| 292 | British Association of Social Workers | Statement 5- Question 1 | [Statement](file:///\\basw-fs01\USERS$\liz.howard\My%20Documents\Liz%20Howard\Adult%20PPEG\NICE%20Quality%20standard%20Adult%20Carers\NICE%20Quality%20standard%20carers-%20LH%20comments.30.10.20.docx#_Quality_statement_5:) 5 Carers work in organisations that offer supportive working arrangements.    Employers offering opportunities for reviewing regularly with the carer how the options for flexible working are supporting them- identifying impact |
| 293 | Motor Neurone Disease Association | Statement 5- Question 3 | Question 3: Whilst incredibly important, we are unsure that statement 5 on employment would be achievable by local services and may lie beyond their remit. |

## Registered stakeholders who submitted comments at consultation

* Alzheimer’s Society
* British Association of Social Workers
* Carers First
* Carers Trust
* Carers UK
* Central and North West London NHS Foundation Trust
* College of Mental Health Pharmacy
* Compassion in Dying
* Hampshire County Council
* Healthwatch Richmond
* Humber Teaching NHS Foundation Trust
* Independent Age
* Motor Neurone Disease Association
* Multiple System Atrophy Trust
* Newcastle City Council
* NHS England and NHS Improvement
* Royal College of Nursing
* Royal College of Occupational Therapists
* Royal College of Physicians
* Royal College of Psychiatrists
* Royal College of Speech and Language Therapists
* Royal Pharmaceutical Society
* Shropshire Council
* The Challenging Behaviour Foundation
* University Hospitals Birmingham NHS Foundation Trust

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1. 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. [↑](#footnote-ref-1)
2. No longer able to care: supporting older carers and ageing parent carers to plan for a future when they are less able to unable to care, Carers Trust, 2020 [↑](#footnote-ref-2)