People's experience using adult social care services

NICE National Institute for Health and Care Excellence

email: QStopicengagement@nice.org.uk

	Please read the checklist for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly or arrive after the deadline. We would like to hear your views on these questions: 1. What are the **key areas for quality improvement** that you would want to see covered by this quality standard? Please **prioritise up to 5 areas** which you consider as having the greatest potential to improve the quality of care. Please state the specific aspects of care or service delivery that should be addressed, including the actions that you feel would most improve quality. 2. You may also wish to highlight any areas of practice that might be considered as emergent, are only currently being done by a minority of providers but which have the potential to be widely adopted and drive improvements in the longer term. Please note, these areas should be underpinned by NICE or NICE-accredited guidance 3. [Insert any specific questions you would like considered during consultation, or delete if not needed]
Organisation name – Stakeholder or respondent (if you are responding as an individual rather than a registered stakeholder please leave blank):	**Age UK**
Disclosure Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.	**None**
Name of person completing form:	Joel Lewis
Supporting the quality standard - Would your organisation like to express an interest in formally supporting this quality standard? More information.	**Yes**

Type		[for office use only]	
Key area for quality improvement	**Why is this important?**	**Why is this a key area for quality improvement?** Evidence or information that care in the suggested key areas for quality improvement is poor or variable and requires improvement?	**Supporting information** If available, any national data sources that collect data relating to your suggested key areas for quality improvement? Do not paste other tables into this table, as your comments could get lost – type directly into this table.
Separately list each key area for quality improvement that you would want to see covered by this quality standard. **EXAMPLE:** **Pulmonary rehabilitation for chronic obstructive pulmonary disease (COPD)**	EXAMPLE: There is good evidence that appropriate and effective pulmonary rehabilitation can drive significant improvements in the quality of life and health status of people with COPD. Pulmonary rehabilitation is recommended within NICE guidance. Rehabilitation should be considered at all stages of disease progression when symptoms and disability are present. The threshold for referral would usually be breathlessness equivalent to	EXAMPLE: The National Audit for COPD found that the number of areas offering pulmonary rehabilitation has increased in the last three years and although many people are offered referral, the quality of pulmonary rehabilitation and its availability is still limited in the UK. Individual programmes differ in the precise exercises used, are of different duration, involve variable amounts of home exercise and have different referral criteria.	EXAMPLE: Please see the Royal College of Physicians national COPD audit which highlights findings of data collection for quality indicators relating to pulmonary rehabilitation. http://www.rcplondon.ac.uk/resources/chronic-obstructive-pulmonary-disease-audit

Please return to: **QStopicengagement@nice.org.uk**

NICE reserves the right to summarise and edit comments received during consultations, or not to publish them at all, where in the reasonable opinion of NICE, the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.

Comments received from registered stakeholders and respondents during our stakeholder engagements are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the comments we received, and are not endorsed by NICE, its officers or advisory Committees.

	MRC dyspnoea grade 3, based on the NICE guideline.		
Access to information, advice, advocacy and support	Lack of access to information and advocacy will negatively impact on the experience of social care recipients. Poor public understanding of what is social care, who it is provided by and how much it costs may lead to delays in knowing what is available and in receiving needs-appropriate support.	In recent polling by Ipsos Mori on behalf of Deloitte, nearly two-thirds (63%) of respondents falsely believed that the NHS provides social care services for older people. The same survey also found that 47% of people believe social care services are free at the point of need. These findings are supported by recent listening events undertaken by Age UK. Participants told us that there is little or no information available to people who want to arrange care for older relatives and they were frustrated about the lack of engagement from social care providers and commissioners. Qualitative feedback from councils' suggests access to advocacy is becoming increasingly challenging. "Now only statutory advocacy can be	Please see Deloitte's *The State of the State 2017-18* report who commissioned Ipsos Mori to survey the public's understanding on who provides social care and its cost implications. https://www2.deloitte.com/content/dam/Deloitte/uk/Documents/public-sector/deloitte-uk-the-state-of-the-state-report-2017.pdf Please see the Local Government Association's *Stocktake 6 on the Implementation of the Care Act* which reports on increases in the number of carers requesting advice and support and qualitative feedback about availability and capacity of advocacy services. https://www.local.gov.uk/sites/default/files/documents/stocktake-6-report-pdf-43-675.pdf Please see Age UK's *Health and Care of Older People in England 2017* which provides evidence of the rising demand for older adult social care services. https://www.ageuk.org.uk/Documents/EN-GB/For professionals/Research/The_Health_and_Care_of_Older_People_in_England_2016.pdf?dtrk=true Please see the Institute for Public Policy Research's report *The Generation Strain - Collective Solutions to Care in an Ageing Society* which provides

Please return to: **QStopicengagement@nice.org.uk**

NICE reserves the right to summarise and edit comments received during consultations, or not to publish them at all, where in the reasonable opinion of NICE, the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.

Comments received from registered stakeholders and respondents during our stakeholder engagements are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the comments we received, and are not endorsed by NICE, its officers or advisory Committees.

		delivered and we are working with our provider to ensure this can continue in the face of rising demand and diminishing resources" (LGA, 2016). For service users navigating a complex system, often at a time of crisis, support provided by independent advocates can be invaluable. Advocacy will play an increasingly important role in improving the experience of older people without family support as well as those experiencing cognitive decline or lacking capacity. By 2030, the IPPR estimate 230,000 older people with significant care needs will be without family support. The Quality Standard should consider how the provision of information will support a positive experience of the adult social care system. Age UK's analysis of rising levels of demand for services is	projections on the number of older people without family support https://www.ippr.org/files/publications/pdf/generation-strain_Apr2014.pdf Findings from the Age UK social care listening events are yet to be published

Please return to: **QStopicengagement@nice.org.uk**

NICE reserves the right to summarise and edit comments received during consultations, or not to publish them at all, where in the reasonable opinion of NICE, the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.

Comments received from registered stakeholders and respondents during our stakeholder engagements are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the comments we received, and are not endorsed by NICE, its officers or advisory Committees.

		matched by the LGA's reporting of rising levels of requests for information and advice. The standards should consider the type of information and advice that will be sought by care recipients and carers and how this information is accessed. Information should be clear, concise and support the public to make informed decisions about services they are eligible for and which are appropriate for their needs. Information and advice should be person-centred and support self-care. It should also provide clarity about the cost implications of current and future social care to enable future planning to meet these needs.	
Variations in quality	Social care service users are subject to significant variation in the quality, provision and capacity of care services. The public	Participants at Age UKs listening events told us that quality and location are the most important factors when choosing care services. The	Please see The Care Quality Commission's *The State of Health Care and Adult Social Care in England 2016/17* which analyses variations in capacity and quality across the adult social care sector.

Please return to: **QStopicengagement@nice.org.uk**

NICE reserves the right to summarise and edit comments received during consultations, or not to publish them at all, where in the reasonable opinion of NICE, the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.

Comments received from registered stakeholders and respondents during our stakeholder engagements are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the comments we received, and are not endorsed by NICE, its officers or advisory Committees.

	have a right to choose high quality care and quality improvement must address the factors that create inequalities and inconsistencies across different care environments.	Care Quality Commission reported on the falling capacity in the nursing home sector, 4000 fewer beds in two years, with wide regional variation in the distribution of these beds. This will impact on the experience of those for which residential nursing care is essential; forced to use services which are sub-standard or far away from their home and support network. The report also noted 'substantial variations in the quality of care that people are receiving – within and between services in the same sector, between different sectors, and geographically'. The effect of this is particularly felt in the transitions between systems, leading people to have poor experiences when they are discharged from, for example, supportive hospital care into poor quality domiciliary care and a lack of	http://www.cqc.org.uk/sites/default/files/20171123_stateofcare1617_report.pdf Findings from the Age UK social care listening events are yet to be published

Please return to: **QStopicengagement@nice.org.uk**

		integration between the two systems jeopardising their chance of receiving care that is person centred and recovery focused. The report also noted wide variation in the settings where people receive social care, with service users often having little or no choice about where they receive support. Nearly a third of nursing home beds were rated as inadequate or requires improvement, whereas just 17% of domiciliary care services are. Safety is arguably the most important measure the commission assesses services by, yet nearly a quarter (24%) of adult social care services were rated as 'inadequate' or 'requires improvement' for their standard of safety. The safeguarding of social care service users is paramount with providers responsible for ensuring that their clients	

Please return to: **QStopicengagement@nice.org.uk**

NICE reserves the right to summarise and edit comments received during consultations, or not to publish them at all, where in the reasonable opinion of NICE, the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.

Comments received from registered stakeholders and respondents during our stakeholder engagements are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the comments we received, and are not endorsed by NICE, its officers or advisory Committees.

		receive care and treatment and which prevents avoidable risk or harm.	
Funding	Lack of funding will often determine the quality and quantity of care that people receive. Reductions in funding from central and local government come in spite of rising demand, complexity and cost in care provision.	Creating long-term sustainable health and social care systems is of ever greater importance with demand for both services continuing to rise. Increased longevity means more people are living for longer with complex, long-term conditions. Analysis by the Alzheimer's Society indicates that dementia diagnoses are expected to reach 1 million by 2027 and 1.75 million by 2050. The ONS calculate that the numbers of people over the age of 85, who are most likely to have significant care needs, are expected to double over the next 20 years. Funding has not kept pace with increases in demand. Local authority spending on social care fell by 7% in real	Please see the Alzheimer's Society report *Dementia UK Update* which provides projections of future dementia diagnoses https://www.alzheimers.org.uk/download/downloads/id/2323/dementia_uk_update.pdf Please see the Office for National Statistics *National Population Projections: 2016-based Statistical Bulletin* which provides projections of the number of people aged 85 and over https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/datasets/tablea24principalprojectionenglandpopulationinagegroups Please see The King's Fund, Nuffield Trust and Health Foundation's *Autumn Budget – Joint Statement on Health and Social Care* which provides evidence of reductions in social care funding and tightened eligibility criteria https://www.kingsfund.org.uk/sites/default/files/2017-11/The%20Autumn%20Budget%20-%20joint%20statement%20on%20health%20and%20social%20care%2C%20Nov%202017.pdf

Please return to: **QStopicengagement@nice.org.uk**

NICE reserves the right to summarise and edit comments received during consultations, or not to publish them at all, where in the reasonable opinion of NICE, the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.

Comments received from registered stakeholders and respondents during our stakeholder engagements are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the comments we received, and are not endorsed by NICE, its officers or advisory Committees.

		terms between 2009/10 and 2016/17. As a result, councils have significantly reduced the amount of support available. Tightened eligibility criteria have led to an estimated 25% reduction – more than 400,000 – in the number of older people accessing publicly funded care over that period. At the same time service users report being offered smaller packages of care and are being asked to contribute more in charges – including a growing number of people paying 'top-ups'. The Quality Standard needs to provide clarity about the costs involved in delivering high-quality care and transparency for self-funders of care. Carers at the Age UK listening events told us that they feel unsupported and abandoned by the system. Reports of respite centres	Please see NHS Digital's Adult Social Care Activity and Finance Report – 2016-17 and Personal Social Services. Expenditure and Unity Cost from 2013-14 to 2015-16 which provides evidence of rising social care client contributions. http://content.digital.nhs.uk/socialcare/collections Please see Age UK's *Health and Care of Older People 2015* which provides evidence of increasing amount of client 'top-ups' for social care services https://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/Briefing-The_Health_and_Care_of_Older_People_in_England-2015-UPDATED_JAN2016.pdf?dtrk=true Please see Age UK's *Health and Care of Older People 2017* which provides an analysis of how rising provision of informal care to cope with reduced care funding has not been enough to address increasing levels of unmet need. The same report also references Laing and Buisson's 2015 *Care of Older People Market Report* which provides data on increasing use of 'top-ups' to pay for social care services. https://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/The_Health_and_Care_of_Older_People_in_England_2016.pdf?dtrk=true

Please return to: **QStopicengagement@nice.org.uk**

NICE reserves the right to summarise and edit comments received during consultations, or not to publish them at all, where in the reasonable opinion of NICE, the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.

Comments received from registered stakeholders and respondents during our stakeholder engagements are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the comments we received, and are not endorsed by NICE, its officers or advisory Committees.

		closing down and a reliance on family members rather than paid care workers which left many relatives feeling so overworked and overwhelmed that their own health suffered as a result. Age UK believe that with rapidly rising levels of unmet need, this strongly suggests that the provision of informal care has not been able to expand significantly to fill the gap left by declining provision of formal care services.	Findings from the Age UK social care listening events are yet to be published
Quality of Care Workforce	The social care workforce needs to be sufficiently upskilled and trained to allow it to cope with the demands of caring and provide high quality care to service users, particularly for those with complex, long-term physical and mental health conditions. The variable experience	Participants at the Age UK listening events told us that they greatly value the contribution from care staff that supports them and their families. However, the groups reported a lack of consistency of care and shared a belief that they lacked sufficient training for their roles. Skills for Care report that more than half	Please see Skills for Care's *The State of the Adult Social Care Sector and Workforce in England* which provides an analysis of the training and qualifications within the care sector http://www.skillsforcare.org.uk/Documents/NMDS-SC-and-intelligence/NMDS-SC/Analysis-pages/State-of-17/State-of-the-adult-social-care-sector-and-workforce-2017.pdf Please see the CQC's *Not Just a Number* report on the importance of continuity of care

Please return to: **QStopicengagement@nice.org.uk**

	of social care service users is a reflection of staff with a fragmented set of skills, values and experience. The Quality Standards should reinforce recommendations for care staff to be engaged in role-appropriate training to improve experience of service users. The standards should also promote continuity of care as a principle that will improve patient experience.	(54%) of the care workforce do not hold a relevant adult social care qualification. Participants in the focus group also reported a lack of awareness from care staff about how to communicate with people who have dementia. This is reflected by Skills for Care's analysis that only 39% of care staff are trained in dementia care. Continuity of care is a highly valued by people receiving care and especially for those with dementia or reduced mental capacity. Research by the CQC highlighted the importance of continuity of care in domiciliary care services and it is a key recommendation in NICE's home care guidance.	http://www.cqc.org.uk/sites/default/files/documents/9331-cqc-home_care_report-web_0.pdf Please see NICE's *Home Care Guideline* which provides recommendations on the importance of continuity of care https://www.nice.org.uk/news/feature/home-care-guideline-key-recommendations-for-providers Findings from the Age UK social care listening events are yet to be published
Access	The public should be able to access social care services relevant to their needs in a timely, co-ordinated and	Participants in the listening events groups reported that delays in getting social care needs assessments are putting people in danger. The	Please see Royal London's Freedom of Information request on variation in negotiating care packages with local authorities https://www.royallondon.com/about/media/news/2017/december/foi-replies-reveal-vulnerable-pensioners-

Please return to: **QStopicengagement@nice.org.uk**

NICE reserves the right to summarise and edit comments received during consultations, or not to publish them at all, where in the reasonable opinion of NICE, the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.

Comments received from registered stakeholders and respondents during our stakeholder engagements are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the comments we received, and are not endorsed by NICE, its officers or advisory Committees.

	effective manner. Routes of assessment and engagement access should be streamlined and less bureaucratic to support those requesting services at a time of crisis. There should be access to services regardless of background, means or ability to have others advocate on your behalf.	quality standard should support and consider how to make the process of assessment and engagement more timely and co-ordinated to improve the experience for service users. Participants at the focus groups also spoke of the need for all people to have access to high quality care. Research by Royal London found that local authorities will often negotiate packages of support on a case by case basis, with the effect that those with family and carer advocates able negotiate on their behalf are likely to receive more comprehensive provision than those that do not. The Quality Standard should provide guidance on reducing this inconsistency in accessing care support.	at-risk-of-poor-outcome-under-care-home-funding-lottery-royal-london/ Findings from the Age UK social care listening events are yet to be published

Checklist for submitting comments

- Use this form and submit it as a Word document (not a PDF).
- Complete the disclosure about links with, or funding from, the tobacco industry.

Please return to: **QStopicengagement@nice.org.uk**

NICE reserves the right to summarise and edit comments received during consultations, or not to publish them at all, where in the reasonable opinion of NICE, the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.

Comments received from registered stakeholders and respondents during our stakeholder engagements are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the comments we received, and are not endorsed by NICE, its officers or advisory Committees.

- Combine all comments from your organisation into 1 response. We cannot accept more than 1 response from each organisation.
- Do not paste other tables into this table – type directly into the table.
- Underline and highlight any confidential information or other material that you do not wish to be made public.
- Do not include medical information about yourself or another person from which you or the person could be identified.
- Spell out any abbreviations you use
- Please provide concise supporting information for each key area. Provide reference to examples from the published or grey literature such as national, regional or local reports of variation in care, audits, surveys, confidential enquiries, uptake reports and evaluations such as impact of NICE guidance recommendations
- For copyright reasons, do not include attachments of **published** material such as research articles, letters or leaflets. However, if you give us the full citation, we will obtain our own copy
- Attachments of unpublished reports, local reports / documents are permissible. If you wish to provide academic in confidence material i.e. written but not yet published, or commercial in confidence i.e. internal documentation, highlight this using the highlighter function in Word.

Please return to: **QStopicengagement@nice.org.uk**

NICE reserves the right to summarise and edit comments received during consultations, or not to publish them at all, where in the reasonable opinion of NICE, the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.

Comments received from registered stakeholders and respondents during our stakeholder engagements are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the comments we received, and are not endorsed by NICE, its officers or advisory Committees.