

Dementia update

Stakeholder engagement – deadline for comments 5pm on 10/10/18

email: QStopicengagement@nice.org.uk

	<p>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.</p> <p>We would like to hear your views on these questions:</p> <ol style="list-style-type: none">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.
Organisation name – Stakeholder or respondent (if you are responding as an individual rather than a registered stakeholder please leave blank):	Care & Repair England
Disclosure Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.	None
Name of person completing form:	Jane Minter
Supporting the quality standard - Would your organisation like to express an interest in formally supporting this quality standard? More information.	No
Type	[for office use only]

<p>Key area for quality improvement</p>	<p>Why is this important?</p>	<p>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?</p>	<p>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.</p>
<p>Separately list each key area for quality improvement that you would want to see covered by this quality standard.</p> <p>EXAMPLE: Pulmonary rehabilitation for chronic obstructive pulmonary disease (COPD)</p>	<p>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.</p> <p>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 MRC dyspnoea grade 3, based on the NICE guideline.</p>	<p>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.</p> <p>Individual programmes differ in the precise exercises used, are of different duration, involve variable amounts of home exercise and have different referral criteria.</p>	<p>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</p>

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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.

<p>Support for people to remain independent as long as possible in a home that meets their needs as dementia progresses</p>	<p>Having a good, decent, warm, accessible home is important in supporting the delivery of good care and support services people with dementia.</p> <p>Housing interventions such as repairs and adaptations to the home to make the home more suitable or a well thought through move to more supported or specialist housing, if appropriate, are essential ingredients in delivering good care and support services for people with dementia</p> <p>Ensuring that a person's home environment is considered when a person is diagnosed with dementia and as the condition progresses makes good sense where the aim is to enable people to live with dignity and independence in the community.</p>	<p>Evidence that areas requires improvement include: -</p> <p>Information and advice Information on the options available and related advice are key to ensuring a positive experience of the provision of care and support services. We consider this should include housing options and solutions more clearly in considerations of a person's social care and support needs. This has not always been the case. A short study undertaken by older people in the NW of England, for example, identified shortcomings in the information and advice available on housing options locally. We know that this is also the case in other parts of the country. Offering bespoke advice and information at the right time and in the right format is crucial to enable people with dementia and their carers to make the best choices for them.</p> <p>http://ageactionalliance.org/search-engine-failure-housing-and-care-advice-in-the-north-west/</p>	<p>Many of the chronic health conditions people face are exacerbated by poor and inappropriate housing and can be alleviated by improving and adapting people's homes.</p> <p>There is an expanding evidence base that considers the impact of housing on health on wellbeing and the value of housing interventions to care and health planning and provision.</p> <p>See NICE evidence at https://www.evidence.nhs.uk/Search?q=housing%20wellbeing (unfiltered) https://www.evidence.nhs.uk/Search?q=housing+impact+on+health+ (unfiltered)</p> <p>Whilst we would not expect social care practitioners to deal with housing issues, per se, we would argue that housing needs (where people live) to be considered in any care and support assessment and links established with the key agencies locally that can support the development of appropriate housing solutions for people with dementia</p> <p>Social care staff need to know about the common housing issues that might affect someone with dementia and who to contact locally to ensure that people's housing circumstances are addressed as far as they impact on a persons' health and wellbeing as they grow older and as dementia progresses.</p>
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		<p>Care assessment</p> <p>Ensuring housing factors are properly considered will mean that people dementia live in the right (warm, safe, secure) environment to provide the foundation for their care and support, and their health and wellbeing as they age.</p> <p>The Care Act 2014 expects that housing factors are part of an integrated assessment. It also calls for housing options to be considered in the provision of information and advice highlighted above. This recognises that a consideration of people's housing needs and circumstances is essential to good social care and support. We would suggest that the variable practice in this area could be improved by adding a consideration of where and how people live – their housing - to this quality standard.</p>	
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		<p>Care planning and provision</p> <p>We would like to see more focus on ensuring that the care plan and thus the provision on offer includes the person's housing circumstances and needs. This means identifying and planning actions that will improve their home circumstances as people with dementia age - for example home adaptations, home repairs or moving options. It also means ensuring that the support needed to undertake these agreed housing changes can be identified, put in place and monitored over time.</p>	
Additional developmental areas of emergent practice			

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.
- 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.

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- 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.

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