

Improving supportive and palliative care (update)

NICE National Institute for
Health and Care Excellence

Consultation on draft scope – deadline for comments 17.00 on 29/01/2016

email: Supportivepalliativecare@nice.org.uk

Please note:		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. Developing NICE guidance: how to get involved has a list of possible areas for comment on the draft scope.	
Stakeholder organisation (if you are responding as an individual rather than a registered stakeholder please state name here):		Marie Curie	
Name of commentator (if you are responding as an individual rather than a registered stakeholder please leave blank):		Natasha Wynne, Policy and Public Affairs Manager	
Comment No.	Page number or ' general ' for comments on the whole document	Line number or ' general ' for comments on the whole document	Comments Insert each comment in a new row. Do not paste other tables into this table, as your comments could get lost – type directly into this table.
1	General	General	<p>Overall Marie Curie supports the underlying notion that supportive and palliative care services go together, that the scope of individuals who receive these services should be widened beyond those with cancer, and that provision of this care should be based on individual needs as determined by comprehensive holistic needs assessment, not the stage of disease or prognosis (lines 331-334).</p> <p>It is our view that the concept of 'end of life care' as a service in and of itself - which may be variably interpreted as applying to the last year or the last days of life – is often unhelpful, and will increasingly become redundant when adequate provision for supportive and palliative care is defined.</p> <p>This is particularly true given our knowledge that prognostication (i.e. estimated length of survival) in most conditions is deeply problematic – not only technically, for the doctor, but emotionally, for the patient and their family. This problem is rooted in the fact that even the most accurate estimates are probabilistic, and based on information about populations rather than that particular individual. It follows that service provision tied firmly to prognosis cannot be accurately targeted.</p> <p>We therefore welcome this approach to service delivery, which should consistently be based on individual needs rather than proximity to death.</p>

2	1	12	We propose to replace 'life-limiting conditions' to 'other conditions in need of this care', or to include a comprehensive definition of life-limiting.
3	1	20	<p>It should be sufficient to say: 'Healthcare professionals in primary and secondary care' to make clear that the guideline is applicable to all healthcare professionals.</p> <p>The concept of a generalist compared to a specialist healthcare professional is peculiar to policy in palliative care and can be unhelpful (for example, it seems odd to refer to a cardiologist as a generalist, but according to this division this is what they would be if they lacked specialist training in palliative medicine). We have concerns that applying the term 'generalist' to a professional on this basis may add to confusions about roles and responsibilities.</p>
4	1	26	We suggest amalgamating these lists (lines 20-29). We are unclear why there is a distinction between 'who this guideline is for' and who 'it may also be relevant for' – surely it should aim to be relevant for all the listed groups?
5	2	38-44	We welcome the special consideration that this guideline will give to groups that face unequal access to services. However, we are concerned that those listed are apparently a random selection from a wider group. Research by the London School of Economics and Political Science [Dixon, J et al. (2015) Equity in the provision of palliative care in the UK: Review of evidence] found that inequalities of access to palliative care services exist for people who: have a condition other than cancer (and rare conditions in particular); are aged 85 years or over; are from a Black, Asian or minority ethnic background; live in deprived areas; are single or live alone. We would welcome special consideration of how services can be equitably delivered to these groups.
6	12-13	260-277	We are very supportive of these sections on supportive care and palliative care and feel they provide a comprehensive description of these services.
7	3	Table – 'Palliative care'	<p>We suggest that the definition of palliative care echoes the WHO definition and the description set out in the Context section of this document (270-277) so that it reflects the holistic nature of this care, and its suitability early in the course of illness alongside investigations and therapies to prolong life. We have some concern that the definitions as set out here suggest an unhelpful division between supportive and palliative care in practice.</p> <p>We oppose the phrase 'care towards the end of life' for the reasons set out in comment 1. There is the potential for serious confusion about professionals' roles and access points into services if this terminology is to be used.</p> <p>Suggest replacing existing definition with: 'Active, holistic care of people with advanced, progressive illness that aims to provide relief from pain and other distressing symptoms, integrate the psychological, social and spiritual aspects of the person's care, and provide a support system that allows people to live as actively as possible until their death.'</p>

Please add extra rows as needed

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8	3	Table – 'Non-specialist palliative care'	<p>Within the context of this guideline and its focus on service delivery, we suggest that an approach which focuses on roles and responsibilities rather than a definition of care would be more helpful. As set out in comment 3, the generalist or non-specialist/specialist divide, when used in this way, is unique to palliative care and may lead to confusion about who is responsible for which aspects of a person's care if not given further explanation.</p> <p>The Association of Palliative Medicine [2008, Palliative Medicine in Supportive, Palliative and End of Life Care: A Strategy for 2008 to 2010; p.18.] sets out a description of the role of the doctor in palliative medicine (based on consensus of the APM membership) as such: 'All doctors, whether general practitioners or specialists in any setting, hold clinical responsibility for the treatment of their patients and have a role in providing medical leadership in their patients' palliative care'.</p> <p>This contrasts to the role of the palliative medicine physician, whose core role includes the medical assessment of distress, symptom management and care for patients with complex clinical needs due to advanced progressive or life threatening disease, and medical leadership within palliative care services. We encourage NICE to consider adopting this sort of approach.</p>
9	3	Table – 'specialist palliative care'	We welcome this definition of specialist palliative care. We would like to emphasise that specialist palliative care should be considered as the safety net available to everyone whose needs for palliative care cannot be met in any other context.
10	5	109	We acknowledge the fact that there is limited conventional evidence on the efficacy of complementary therapy services for people with palliative care needs, and recognise that some complementary therapies may pose risks to patients, as well as benefits. However, for specific therapies (such as acupuncture used for breathlessness) there is a growing evidence base which we suggest may warrant future consideration. We suggest that it should be acknowledged (as it is in the 2004 guideline) that many NHS and voluntary sector organisations offer complementary therapy services and that it is important for patients to be empowered to make their own decisions about complementary therapies and therapists through the provision of high quality information.
11	5	112-115	We strongly oppose the removal of user involvement and information from the new guideline as there are all important aspects of care that those with supportive and/or palliative needs should be able to expect services to deliver. We are not aware of these aspects of care being sufficiently covered elsewhere?
12	5	114	We are also strongly opposed to the removal of social support services, and actively encourage the inclusion of services that seek to integrate the delivery of health and social care. Considering the wider policy environment, promulgating the distinction between the two is likely to make the guideline obsolete in the future.
13	6	123	We are very supportive of the inclusion of economic analyses in the development of the guideline. A lack of valuable economic data has historically hindered progress in service development.

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14	6	134...	In our view, holistic needs assessment for supportive and palliative care should be combined and there is no obvious merit in this division. Combining the two is more coherent with the approach set out in the rest of the guideline, which places individual need before prognostication, and it avoids the potential errors where an individual misses out on appropriate care because the wrong tool is used due to difficulties with prognostication.
15	6	144-148	We emphasise that ultimately, how often supportive and palliative care needs should be reviewed must be based on individual needs, rather than prognosis.
16	8	186	This should include Patient Reported Outcome Measures and qualitative data.
17	8	General	Another important population-level outcome should be coverage, ie. the proportion of people with needs that are eligible for supportive and palliative care (including families and carers) who receive adequate care.
18	4	65	The document does not appear to comment on tools/strategies for the identification of patients who may need to be assessed.
19	General	General	We feel that there is insufficient consideration of the needs of families and carers throughout this document. Supportive and palliative care services should formally be required to support families, carers and those important to the person needing care.
20	General	General	We are pleased to see the inclusion of the 5 Priorities of Care.

Add extra rows if needed

Checklist for submitting comments

- Use this form and submit it as a Word document (not a PDF).
- Include page and line number (not section number) of the text each comment is about.
- 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
- For copyright reasons, do not include attachments such as research articles, letters or leaflets. We return comments forms that have attachments without reading them. The stakeholder may resubmit the form without attachments.

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