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# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## NICE guidelines

### Equality impact assessment

## END OF LIFE CARE: DELIVERY OF SERVICES FOR ADULTS IN THE LAST YEAR OF LIFE

The impact on equality has been assessed during guidance development according to the principles of the NICE equality policy.

### **1.0 Scope: before consultation (To be completed by the developer and submitted with the draft scope for consultation)**

1.1 Have any potential equality issues been identified during the development of the draft scope, before consultation, and, if so, what are they?

During the development of the draft scope, it was recognised that the groups listed below require special consideration to ensure equal opportunity to access services.

- People with dementia
- People with cognitive impairment
- People with learning disabilities
- People with other long-term life-limiting conditions
- Homeless people

The Committee will need to be cognisant of these groups a when reviewing evidence and formulating recommendations.

It is further recognised that there may be ethnic and cultural issues related to choices and priorities for supportive and palliative care.

The Committee will need to be cognisant of these when reviewing evidence and formulating recommendations particularly in relation to Black and minority ethnic groups and faith groups.

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It is noted that consideration may also need to be given to people accessing supportive and palliative care services who are from traveller communities or those in lesbian, gay, bisexual and transgender relationships when drafting any recommendations from the proposed review areas. This may have particular relevance to the delivery of psychological and spiritual support.

The spiritual needs of those accessing palliative and supportive care are important to consider and whilst faith and belief are protected characteristics in terms of the act, we are aware that spiritual needs may be met by appropriate faith and belief support, other non-religion based needs should also be considered important. We plan to consider spiritual needs in the broadest multi-faith sense within the context of each of our review questions.

1.2 What is the preliminary view on the extent to which these potential equality issues need addressing by the Committee? For example, if population groups, treatments or settings are excluded from the scope, are these exclusions justified – that is, are the reasons legitimate and the exclusion proportionate?

- This is an update of the 2004 guideline: Improving Supportive and Palliative Care for adults with cancer. The remit has been broadened to identify and address these needs in other groups likely to require these services and, as such this update, will broaden guidance provided for the care of people with long term, life-limiting conditions, not just cancer.
- Children - this is an adult only remit and the needs of children accessing palliative and supportive care are specific. NICE has already commissioned a separate guideline for the care of children at end of life, which includes some service delivery considerations.

Completed by Developer \_\_\_ Susan Latchem

Date \_\_\_\_\_ 16/12/15 \_\_\_\_\_

Approved by NICE quality assurance lead \_Christine Carson \_\_\_\_\_

Date \_\_\_ 18/12/15 \_\_\_\_\_

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### 2.0 Scope: after consultation (To be completed by the developer and submitted with the final scope)

2.1 Have any potential equality issues been identified during consultation, and, if so, what are they?

Stakeholders have identified that there are other populations whose access to services should be considered. These included:

- People with advancing heart and lung disease
- Elderly people slowly dying of frailty.
- People with mental health and palliative care needs
- People in prisons
- Socio economic inequalities (people from lower income brackets)
- People with hearing loss
- Young adults at the end of life
- Younger or older carers of people at the end of life

2.2 Have any changes to the scope been made as a result of consultation to highlight potential equality issues?

Stakeholders identified the following populations where there were felt to be equality issues. The scoping group agreed that the needs of these groups are

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important but did not feel that these were automatically linked to an equality issue and therefore no further changes were made to the scope in this regard:

- People with advancing heart and lung disease
- Elderly people slowly dying of frailty

The scoping group noted the stakeholder concerns related to:

- people in prison in the last year of life.

The group felt that care at end of life would be provided by NHS staff accessing prison services and that no changes to the scope would be required in this respect.

The issue linked to:

- socio-economic inequality

related in the main to an individual's ability to purchase additional therapies (such as complementary therapies) creating an increased burden on those from reduced economic circumstances. It was noted that there may also be challenges for people from this disadvantaged group in accessing hospice services. The scope has now been re-focussed to address service delivery in the last year of life and a question added to the scope that will assist the committee in understanding any barriers or facilitators to accessing services (such as hospice care) for people in low socio-economic groups or other groups protected under the act.

The scoping group noted that certain groups for example, the frail elderly, people with learning disabilities, and young people might need extra support when required to provide care or support to people at the end of life. The scope has been amended to highlight this as a potential equality issue.

The particular needs of young people in the last year of life in terms of access to and coordination, integration and delivery of services may require separate recommendations and the scope has been amended to address this to ensure that, where available, evidence is considered.

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2.3 Is the primary focus of the guideline a population with a specific disability-related communication need?

If so, is an alternative version of the 'Information for the Public' document recommended?

If so, which alternative version is recommended?

The alternative versions available are:

- large font or audio versions for a population with sight loss;
- British Sign Language videos for a population who are deaf from birth;
- 'Easy read' versions for people with learning disabilities or cognitive impairment.

N/A

Updated by Developer: S. M Latchem Operations Director

Date: 20.4.16

Approved by NICE quality assurance lead \_\_Christine Carson\_\_

Date \_\_18.5.16\_\_

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3.0 Guideline development: before consultation (to be completed by the Developer before consultation on the draft guideline)

3.1 Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how?

The scoping group noted that certain groups for example, the frail elderly, people with learning disabilities, and young people might need extra support when required to provide care or support to people at the end of life. This potential equality issue was highlighted in the revised scope and was addressed in the following reports:

- Frail elderly:
  - Review of Service Provision
  - Identification of additional services
  - Out of hours
  - Additional Services
  - Inappropriate admissions
  - Facilitating discharge
- People with learning disabilities
  - Identifying people in the last year of life
  - Information sharing
- Young Carers
  - Involving carers
  - Carer support

Ensuring access to end of life care services is an overarching theme throughout the guideline and evidence summarised in the 'Access to end of life care services' report is what underpins the committee's recommendations on this topic and this is particularly applicable to all groups noted for equalities considerations.

The particular needs of young adults in the last year of life in terms of access to and coordination, integration and delivery of services may require separate recommendations and the scope has been amended to address this to ensure that, where available, evidence is considered. The committee believes all areas of the guideline address the review, delivery and provision of services to this group, but the areas listed below address particular challenges around transition from one service to the next and the committee was aware that age was an identified barrier to accessing end of life care services and so considered this factor when drafting recommendations.

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3.2 Have any **other** potential equality issues (in addition to those identified during the scoping process) been identified, and, if so, how has the Committee addressed them?

No additional equality issues were identified by the committee.

3.3 Have the Committee's considerations of equality issues been described in the guideline for consultation, and, if so, where?

The committee's considerations of equality issues have been discussed within the Committee's discussion of the evidence in the reports listed above.

3.4 Do the preliminary recommendations make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

The recommendations drafted by the committee do not present any barriers to, or difficulties with, access for any of the groups mentioned for equalities consideration.

3.5 Is there potential for the preliminary recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

No.

3.6 Are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in questions 3.1, 3.2 or 3.3, or otherwise fulfil NICE's obligation to advance equality?

No.

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Completed by Developer \_\_\_\_\_ Kate Kelley \_\_\_\_\_

Date \_\_\_\_\_ 15/10/2019 \_\_\_\_\_

Approved by NICE quality assurance lead \_\_\_\_\_ Christine Carson \_\_\_\_\_

Date \_\_\_\_\_ 07/08/2019 \_\_\_\_\_