NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE QUALITY STANDARDS

Quality standard topic: Care of dying adults in the last days of life

Output: Equality analysis form – Meeting 1

Introduction

As outlined in the Quality Standards process guide (available from www.nice.org.uk), NICE has a duty to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity, and foster good relations between people from different groups. The purpose of this form is to document the consideration of equality issues in each stage of the development process before reaching the final output that will be approved by the NICE Guidance Executive. This equality analysis is designed to support compliance with NICE's obligations under the Equality Act 2010 and Human Rights Act 1998.

Table 1 lists the equality characteristics and other equality factors NICE needs to consider, i.e. not just population groups sharing the 'protected characteristics' defined in the Equality Act but also those affected by health inequalities associated with socioeconomic factors or other forms of disadvantage. The table does not attempt to provide further interpretation of the protected characteristics. This is because it is likely to be simpler, and more efficient, to use the evidence underpinning the quality standard to define population groups within the broad protected characteristic categories rather than to start with possibly unsuitable checklists created for other purposes, such as social surveys or HR monitoring tools.

The form should be used to:

- confirm that equality issues have been considered and identify any relevant to the topic
- ensure that the quality standards outputs do not discriminate against any of the equality groups
- highlight planned action relevant to equality
- highlight areas where quality standards may advance equality of opportunity.

This form is completed by the NICE quality standards internal team at each stage within the development process:

- Topic overview (to elicit additional comments as part of active stakeholder engagement)
- Quality Standards Advisory Committee meeting 1
- Quality Standards Advisory Committee meeting 2

Table 1

| Protected characteristics |
|---|
| Age |
| Disability |
| Gender reassignment |
| Pregnancy and maternity |
| Race |
| Religion or belief |
| Sex |
| Sexual orientation |
| Other characteristics |
| Socio-economic status |
| Depending on policy or other context, this may cover factors such as social exclusion and deprivation associated with geographical areas or inequalities or variations associated with other geographical distinctions (e.g. the North/South divide, urban versus rural). |
| Marital status (including civil partnership) |

Other categories

Other groups in the population experience poor health because of circumstances often affected by, but going beyond, sharing a protected characteristic or socioeconomic status. Whether such groups are identifiable depends on the guidance topic and the evidence. The following are examples of groups covered in NICE guidance:

- Refugees and asylum seekers
- Migrant workers
- Looked after children
- Homeless people.

Quality standards equality analysis

Stage: Meeting 1

Topic: Care of dying adults in the last days of life

- 1. Have any equality issues impacting upon equality groups been identified during this stage of the development process?
 - Please state briefly any relevant equality issues identified and the plans to tackle them during development.

At topic overview, no specific equality issues were identified. Potential equality issues identified during the development of the primary source guidance were recognised, though.

Following meeting 1, the potential equality issues below were identified:

- People with dementia, cognitive impairments, learning disabilities or language barriers in the last few days of life may have communication difficulties. Draft statements 2 and 4 recognise that discussions about preferences for care and hydration should take account of the person's cognitive status; any speech, language or other communication needs; level of understanding; and whether they would like a person important to them to be present.
- There may be ethnic and cultural issues related to managing pain or other symptoms, and the undesirability of potential sedation in the last few days or hours of life. Draft statement 2 addresses this potential issue by capturing individual preferences for care in the last days of life. Draft statement 4 also ensures that clinically assisted hydration is discussed with people who are dying, and those important to them.
- People who are from traveller communities or who are homeless may have
 particular problems relating to anticipatory prescribing when secure storage of
 medication is needed. No specific measures are proposed in the quality
 standard to address this potential issue. It is noted that during the
 development of the underpinning guideline, the guideline development
 group's experience was that people from traveller communities, or homeless
 people, nearing the end of life are usually brought into a place of care where
 NHS staff can care for them and medication can be offered safely and
 securely.
- Spiritual needs of those in the last few days are important to consider, including non-religion based needs. Draft statement 2 addresses this potential issue by capturing individual preferences for care in the last days of life.

Potential equality issues will continue to be considered during the development of the quality standard.

2. Have relevant bodies and stakeholders been consulted, including those with a specific interest in equalities?

 Have comments highlighting potential for discrimination or advancing equality been considered? Standing members for Quality Standards Advisory Committees (QSACs) have been recruited by open advert with relevant bodies and stakeholders given the opportunity to apply. In addition to these standing committee members, specialist committee members from a range of professional and lay backgrounds relevant to the prevention of falls in older people were recruited.

The first stage of the process saw the topic overview and request for suggested areas for quality improvement published. Stakeholder comments were invited, including from those with a specific interest in equalities. Consultation responses were then considered by the QSAC.

The draft quality standard will be published for a 4 week consultation period for registered stakeholders to express their views on the proposed quality standard statements.

- 3. Have any population groups, treatments or settings been excluded from coverage by the quality standard at this stage in the process? Are these exclusions legal and justified?
 - Are the reasons for justifying any exclusion legitimate?

The quality standard will cover the clinical care of adults aged 18 and over who are dying during the last 2 to 3 days of life. Exclusions are as follows:

Children and young people. The needs of children and young people in the last few days / hours of life are specific. There is a separate quality standard on End of life care for infants, children and young people in the quality standards topic library.

Palliative care before the last few days of life: The focus of this quality standard is the last few days or hours before death. This reflects the focus of the clinical guideline which targeted this period following the Neuberger review of the Liverpool Care Pathway. Care before this period, where different management may be required is not covered in this quality standard. An existing quality standard, End of life care for adults, covers care before the last few days of life.

Service Delivery: This area is excluded from the quality standard. Service delivery was also excluded from the underpinning clinical guideline as it will be covered by a separate guideline (End of life care for adults in the last year of life: service delivery) that is in production.

- 4. If applicable, do any of the quality statements make it impossible or unreasonably difficult in practice for a specific group to access a service or element of a service?
 - Does access to a service or element of a service depend on membership of a specific group?
 - Does a service or element of the service discriminate unlawfully against a group?
 - Do people with disabilities find it impossible or unreasonably difficult to receive a service or element of a service?

The draft quality statements do not make it impossible or unreasonably difficult for a specific group to access a service or element of a service.

5. If applicable, does the quality standard advance equality?

 Please state if the quality standard, including statements, measures and indicators, as described will advance equality of opportunity, for example by making access more likely for certain groups, by tailoring the service to certain groups, or by making reasonable adjustments for people with disabilities?

The quality standard is expected to advance equality of opportunity.