

**National Institute for Health and Care Excellence**  
Clinical Guideline: End of life care for infants, children and young people  
Stakeholder Scoping Workshop  
Friday 3<sup>rd</sup> October 2014

**Presentations**

The group were welcomed to the meeting and informed about the purpose of the day. The Stakeholder Scoping Workshop is an opportunity for stakeholders to review the draft scope and give their input into whether it is clinically appropriate.

The group received presentations about NICE's work, the work of the National Collaborating Centre for Women's and Children's Health (NCC-WCH) and the work of the patient and public involvement programme. The Chair of the guideline development group also presented the key elements of the draft scope.

Following questions, the stakeholder representatives were then divided into five groups which included a facilitator and a scribe. Each group had a structured discussion around the key issues. Mark Baker (Clinical Adviser, NICE) and David Vickers (Chair, guideline development group) circulated between groups to observe discussions.

In summary, the main points raised by the groups at the end of the group discussions included the following which are described in more detail in the sections below:

- Transitional care is needed for those up to the age of 25
- The definition of end of life care vs palliative care – the title may need amending to reflect the understanding of these terms.
- Parallel planning
- This was the opportunity to come up with relevant service delivery guidance including the education and training of staff involved in the care of infants, children and young people covered by this guideline and the setting of care
- The importance of communication and support for families/carers after death
- Symptom management
- Sudden and unexpected death

**Scope**

**General comments**

Stakeholders felt very strongly that the title of the guideline is misleading as 'end of life care' tended to be identified as the last weeks and days of life. They felt that the term 'palliative care' would be more appropriately identified in the title to convey the scope of the guideline to clinicians. The stakeholders felt that the period of time referred to needs

to be contextualised throughout the scope; end of life care is part of palliative care.

- Palliative care – from diagnosis through death and beyond
- End of life care – final weeks and days

### **Section 3.1**

One group suggested that the child mortality rate is not accurate. Another group felt that community nursing should be mentioned.

### **Section 4.1 Population**

The stakeholders were in agreement that the transitional work that is done with young people in the 18 – 25 year old group is much closer to paediatric work and there is not always a 'neat' transition to adult care at age 18.

The stakeholders also suggested subgroups which they would like to see included.

These were infants, children and young people with:

- HIV/AIDS
- Acute life threatening conditions and sudden and unexpected death; noting that there may be overlap with guidance (such as emergency care and meningitis) as their care is more likely to be short-term.
- non-verbal communication
- learning disabilities
- Ventilation
- Intensive care (in particular neonates)

### **Equalities**

The stakeholders felt that the equalities section should be expanded to include:

- refugees and asylum seekers, migrant workers/infants, children and young people born abroad
- looked-after infants, children and young people
- homeless infants, children and young people
- children and young people with cognitive impairment, communication and learning disabilities
- Socio – economic groups

### **Section 4.2 Setting**

It was discussed by the stakeholders that the charitable, voluntary and private sectors play a key role in the delivery of care outlined in this scope. The groups were reminded that this guideline will only cover NHS and government funded social care. However the

stakeholders noted that much of the care provided in hospices and educational settings may be NHS commissioned care and the stakeholders felt that it would be more accurate to include 'NHS commissioned care in a non NHS setting' in this part of the scope.

## **Section 4.3 Management**

### **Issues that will be covered**

The areas to be covered in the guideline were discussed at length in all groups.

Stakeholders felt that it needed to be defined in all places if the area or question was addressing palliative care or end life care. One group felt the need to replace "with life limiting conditions" in all places where appropriate instead of "end of life care".

Below is a summary of points raised (by topic area):

- a) needs to be adapted to include throughout life with a life limiting illness.
- d) Needs to include regular reviews to adapt accordingly to circumstances. Additionally this could be updated to include 'achieving'.
- k) Transition work is only applicable to young people in palliative care and not those experiencing end of life. Additionally it was noted that transitional work methods differ between younger and older adolescents and needs to increase over time.
  - One group wanted 'treatment limiting decisions' to be included in this area.
- j) One group would like this to include 'information in decision making'. One group would like to see guidance on whether a post-mortem examination is required/appropriate. One group stated that the information provided would differ based on the type of death i.e. circulatory or brain death.
- n) One group suggested that the wording needs to be clear that this is short term as long term bereavement support would be outside of the scope.
- m) One group reasoned that this area should include the manner of care in addition to place of care
- l) One group thought this could be a repetition of a palliative care guideline in development. One group wanted this area to also include 'delivery of technology'.
- c), g) and h) – stakeholders suggested that these areas should ideally cover children and young people, parents, carers, family members, and significant others (such as partners of young people)
- Stakeholders noted that there is a need to cover the parallel planning of care/ advance planning.

### **Issues that will not be covered**

Stakeholders suggested that the scope must clearly define the areas of bereavement

which this guideline covers e.g. length of time, subsequent mental health issues.

#### **Section 4.4 Main outcomes**

Stakeholders suggested the following changes for the main outcomes:

- One group noted that for a) quality of death is also an important factor.
- Two groups suggested that b) should be amended to include reference to patient satisfaction.
- One group pointed out that c) needs to be taken with caution as there may be good reason for the desired and actual places of death to differ.
- One group said that d) should include positive aspects as well as depression and anxiety (such as resilience). One group reasoned that d) should include emotional well-being as well as psychological (such as feeling empowered).
- Two groups suggested that it might be helpful if access to education and the choice to continue in education was included as an outcome.

#### **Section 4.5 Review questions**

The stakeholders did not discuss the review questions in depth. Their general suggestions are listed below:

- A distinction needs to be made in all questions when this is addressing palliative care or end life care.
- Question c – one group were unsure how efficacy would be defined in this context.
- Question f – As is clear from this question as it stands, there is no defined composition for an MDT – suggested improvement for this question is “what is the best composition for an MDT”?
- Question f - Shared decision making with the MDT vs parental only – does this improve the quality of the decision in terms of patient satisfaction?
- Question l - to be updated to include ‘decision making’.
- Question o – to be updated to weight decision making in favour of the child or young person and to find the views of patients on the care decisions which are made by parents.
- Is there a significant impact on patient wellbeing from the use of complementary therapies (from example hydrotherapy, massage)?

#### **Section 4.6 Economic aspects**

One group discussed this area and raised that staff is the most costly in this area. If the

recommendations change the structure of the MDT and out of hours working there would be an impact on the health economics.

### **GDG composition**

There was a great deal of discussion in all groups with respect to GDG composition.

#### **Stakeholders made the following recommendations for the proposed members of the Guideline Development Group:**

- Paediatric palliative care consultant - stakeholders noted that there are less than 10 positions in the UK for this specific role. This may limit the applications to this position. They felt it could be expanded to include community paediatricians as for many infants, children and young people the care they receive in the community crosses into palliative care.
- Nurse – Various specialties were put forward for inclusion on the GDG. Stakeholders explained that the majority of palliative care is provided by nursing staff. These included: community nurse (with experience in end of life care); palliative care nurse (with experience in the community); specialist nurse in organ donation; oncology outreach nurse; neonatal nurse (due to the pace of care provided)
- Youth worker –this role could perhaps be expanded to include play therapist/ activity co-ordinator/ social worker/key workers/ young people’s support workers/educational support worker
- Psychologist – could be amended to include ‘mental health practitioner’ with experience in end of life care or mental health support worker
- Lay members – one group suggested that it would be helpful if these members could have had direct experience of palliative care in a close family member e.g. parent or sibling.
- One group raised that perhaps the ethicist and the spiritualist could be changed to expert advisors. One group felt that it was necessary that the ethicist and the spiritualist were dedicated roles. Two groups felt that the ethicist role could be covered by a member with experience and training in palliative care as this is often a required skill.

Stakeholders thought that the final title/remit of the guideline would influence the positions required.

One group felt that when advertising, the positions should be broad enough as to not alienate possible applicants who are based outside of a medical setting.

**Stakeholders made the following recommendations for additional members of the Guideline Development Group:**

- A representative from the wider MDT – such as occupational therapist or physiotherapist
- An expert in transitional care

**Stakeholders also made the following recommendations for expert advisers:**

- Paediatric pain specialist
- Specialist in organ donation
- Child death overview panel member
- Undertaker
- Young people experiencing end of life care