NICE National Institute for Health and Care Excellence

Quality Standards Advisory Committee 2

End of life care for infants, children and young people – prioritisation

Minutes of the meeting held on 9 February 2017 at the NICE offices in Manchester

Attendees	**Standing Quality Standards Advisory Committee (QSAC) members** Michael Rudolf (MR) [Chair], Barry Atwood, Gillian Baird, Ruth Bell, Julie Clatworthy, Michael Fairbairn, Malcolm Griffiths, Jean Gaffin, Ruth Halliday, Tessa Lewis, Corinne Moocarme, Anita Sharma, Amanda Smith, Ruth Studley **Specialist committee members** David Vickers, Emily Harrop, Lucy Coombes, Amy Volans, Zoe Picton-Howell and Stacey Curzon **NICE staff** Nick Baillie (NB), Craig Grime (GG), Gavin Flatt (GF) **Topic expert advisers** None **NICE Observers** None
Apologies	**Standing Quality Standards Advisory Committee (QSAC) members** Anjan Ghosh, Robyn Noonan and Guy Bradley-Smith, **Specialist committee members** Satbir Jassal

Agenda item	Discussions and decisions	Actions
1. Welcome, introductions and plan for the day (private session)	The Chair welcomed the attendees and the Quality Standards Advisory Committee (QSAC) members introduced themselves. The Chair informed the Committee of the apologies and reviewed the agenda for the day.	
2. Welcome and code of conduct for members of the public attending the meeting (public session)	The Chair welcomed the public observers and reminded them of the code of conduct that they were required to follow. It was stressed that they were not able to contribute to the meeting but were there to observe only. They were also reminded that the Committee is independent and advisory therefore the discussions and decisions made today may change following final validation by NICE's guidance executive.	
3. Committee business (public session)	**Declarations of interest** The Chair asked standing QSAC members to declare any interests that were either in addition to their previously submitted declaration or specific to the topic(s) under consideration at the meeting today. The Chair asked the specialist committee members to declare all interests. The following interests were declared: Standing committee members • none Specialist committee members • Lucy Coombes - Invited to co-host a meet the experts session on 'The use of outcome measures in Paediatric Palliative Care' at the EAPC conference in Madrid in May 2017. EAPC are paying the conference fees and accommodation. Had a poster accepted at the European Association of Palliative Care Conference in Madrid in May 2017 entitled 'The Use of Low Dose Morphine in Children with Cancer' • Dr Emily Harrop - Since the last CDG meeting, she has agreed to be involved in two new pieces of work, neither of which provides any financial remuneration (nor any direct personal conflict of interest): Review of the Together for Short Lives Pathway for Neonatal (Perinatal) Palliative care. This was first published in 2009, and is in need of updating; it will be re-published after the NICE guidance, so as to be consistent with it.	

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	Membership of a local group of clinicians looking at patient safety issues related to the use of gastrostomies (with the Oxford Academic Health Services Network) - quality improvement and safety assurance falls naturally within my clinical role • Zoe Picton-Howell - Employed as law tutor by University of York Employed as tutor by University of Edinburgh, Medical School Member Florence Nightingale Foundation Expert Reference Group on Nursing Framework • Dr David Vickers - Employee, Cambridgeshire Community Services NHS Trust Trustee, Royal College of Pediatrics and Child Health Trustee, British Association for Community Child Health Associate Clinical Advisor, Parliamentary and Health Service Ombudsman Wife is an employee, East Anglican Children's Hospices • Dr Amy Volans Chair of London Children's Palliative Care Network Invited to present at Royal Society of Medicine Pediatric Palliative care and Transition study day in January 2017 **Minutes from the last meeting** The Committee reviewed the minutes of the last meeting held on 10 November 2016 and confirmed them as an accurate record	
4. QSAC updates	NB discussed the revised committee model and clarified the schedule for upcoming committee meetings up to June 2017. NB updated the committee on the proposed committee away day and also advised invitations has now been sent out to all committee members inviting them to attend the NICE Conference in May 2017.	
5 and 5.1 Topic overview and summary of engagement responses	GF presented the topic overview and a summary of responses received during engagement on the topic.	
5.2 Prioritisation of quality improvement areas	The Chair and GF led a discussion in which areas for quality improvement were prioritised. The QSAC considered the draft areas as outlined in the briefing paper prepared by the NICE team. The	

Agenda item	Discussions and decisions	Actions
	outcome of discussions is detailed below.	

Suggested quality improvement area	Prioritised (yes/no)	Rationale for prioritisation decision	If prioritised, which specific areas to be included?
Advance care planning	Y	Committee highlighted that advanced care planning should be undertaken for all children and young people with a life limiting condition, not just those approaching the end of life. Committee discussed antenatal diagnoses of life-limiting conditions and ensuring that any statement on advanced care planning included this population. Committee noted the inconsistency around the development of advanced care plans. Committee highlighted the importance of involving children, parents and carers in the development of the advanced care plan. Committee discussed the development of care plans and the importance of sharing and disseminating the plans to all professionals and services involved at each stage.	**Involvement of children and young people with a life limiting condition in the development of their advanced care plan.** Antenatal diagnosis of life-limiting conditions will be included. Supporting information to highlight the importance of shared decision making and the importance of disseminating the care plan to all involved. Based on NICE NG61 recommendations 1.2.5, 1.2.6 and 1.2.10
Clinical management	Y	Committee discussed recognition and management of distressing symptoms in children approaching the end of life, in particular the management of pain and agitation.	**Unresolved distressing symptoms and the involvement of the specialist paediatric palliative care team** Based on NG61 recommendation 1.3.20

		Committee felt the recognition and management of distressing symptoms was not being done consistently well. It was noted that symptom management would be a difficult area in which to measure quality improvement given its individualised nature. Committee discussed involvement of the specialist paediatric palliative care team when the child has unresolved distressing symptoms. Committee proposed including a statement in the draft quality standard for consultation and asking specific questions around the measurability and definition of 'unresolved symptoms'.	
Emotional and psychological support for the child	Y	Committee discussed support for anxiety and depression in all children and young people with a life-limiting condition. It was also noted that emotional and psychological support can be very important for siblings as well. Committee noted variation in the provision of emotional and psychological support to children with a life-limiting condition and that the availability of such support and how to access it was an important area for quality improvement. Committee agreed the statement should include all children and young people with a life limiting condition, not just those approaching the end of life.	**Provision of information on the emotional and psychological support available to the child.** Based on NICE NG61 recommendation 1.2.26.
Emotional and psychological support for the family	Y	Committee discussed bereavement support for parents and carers when the child is approaching end of life, including support for siblings.	**Bereavement support before and after death.** Based on NICE NG61 recommendation 1.4.4.

		Committee highlighted that bereavement support need not always be formal support.	
Home care	Y	Committee discussed care at home and agreed that 24 hour access to paediatric nursing care and advice from a consultant in paediatric palliative care is an area for quality improvement. Committee noted lack in availability of 24 hour access to paediatric nursing care and advice from a consultant in paediatric palliative care. It was agreed this can prevent children and young people from receiving end of life care at home when this was the preferred option. Committee discussed the potential resource impact of this area for quality improvement and agreed it was not significant enough to prevent a statement from being progressed. Committee highlighted the fact that nursing staff should be qualified to support parenteral drug administration. The NICE team agreed to include this within the definitions section and the Committee suggested using NICE NG61 recommendation1.5.11 when drafting the statement to define paediatric nursing care.	**24 hour access to paediatric nursing care and advice from a paediatric palliative care consultant when being cared for at home.** Based on NICE NG61 recommendations 1.5.9 and 1.5.11.
Key contacts	Y	Committee discussed having access to a named worker. Committee noted that the need for this could vary depending on the child's circumstances and the stage of their illness. Committee highlighted the fact that a named medical specialist would be essential to coordinate care and ensure clear communication with the child or young person and their parents/carers.	**A named medical specialist for all children with a life-limiting condition.** Based on NICE NG61 recommendation 1.2.2. Specialist committee members to provide suggestions on whom the named person could be.

		Committee noted that there was currently inconsistency in ensuring all children with a life limiting condition do have a named medical specialist. Committee discussed who, in general, the named specialist should be. Committee suggested that specialist committee members provide suggestions of the range of appropriate specialists once the quality standard is drafted. Committee discussed incorporating access to a level 4 Consultant in the statement. However this was not prioritised as the need for advice from a consultant in paediatric palliative care for children being cared for at home had been addressed by the previous draft statement.	

Additional areas suggested	**Committee rationale**	**Area progressed (Y/N)**
Managed clinical networks	Not within the remit of Quality Standards	**N**
Training for healthcare professionals	Not within the remit of Quality Standards	**N**
Clinical and psychosocial debrief	The committee agreed to prioritise statements specific to the support for children, young people and their families.	**N**

6. Resource impact	Home care – the resource impact was discussed. 2 key aspects to consider: • Rapid Transfer – cost per transfer £1,100 to £2,700, NICE NG61 recommendation 1.5.8	

	- Care at home 24/7 care. The cost would need to be assessed locally, NICE NG61 recommendation 1.5.9 Committee asked if the additional costs associated with home care were affordable. The NICE team advised that home care was affordable as it released pressure on the acute setting. It is anticipated that some of the costs will be met from using existing resources differently.	
6.1 Overarching outcomes	The NICE team explained that the quality standard would describe overarching outcomes that could be improved by implementing a quality standard on end of life care for infants, children and young people. It was agreed that the Committee would contribute suggestions as the quality standard was developed.	
6.2 Equality and diversity	The NICE team explained that equality and diversity considerations should inform the development of the quality standard, and asked the Committee to consider any relevant issues. It was agreed that the Committee would contribute suggestions as the quality standard was developed.	
7. QSAC specialist committee members (part 1 – open session)	NB asked the QSAC to consider the constituency of specialist committee members on the group and whether any additional specialist members were required. **Specialist members**: It was agreed that no additional specialist member are required. The committee did request that the National Perinatal Association could be targeted as a key stakeholder in the development of the statements.	
8. Next steps and timescales (part 1 – open session)	NICE team outlined what will happen following the meeting and key dates for the end of life care for infants, children and young people quality standard. The Chair thanked the specialist committee members for their input into the development of this quality standard.	
10. Any other business (part 1 – open session)	The following items of AOB were raised: - The Chair noted that Amanda Smith was leaving the Committe and that this was her last meeting. He thanked her for her valuable contribution to the Committee. **Date of next meeting for end of life care for infants, children and young people: 8 June 2017** **Date of next QSAC 2 meeting: 9 March 2017**	