Quality Standards Advisory Committee 4

Care of dying adults in the last days of life – prioritisation meeting

Minutes of the meeting held on Wednesday 27th July 2016 at the NICE offices in Manchester

Attendees	**Standing Quality Standards Advisory Committee (QSAC) members** Tim Fielding (TF) [Chair], Alison Allam, Moyra Amess, Simon Baudouin, James Crick, Nadim Fazlani, Zoe Goodacre, John Jolly, Asma Khalil, Annette Marshall, Jane Putsey and David Weaver **Specialist committee members** Sam Ahmedzai, Jayne Kennedy, Catherine Piggin and Diana Robinson **NICE staff** Nick Baillie (NB), Tony Smith (TS), Paul Daly (PD) and Lisa Nicholls (LN) **NICE Observers** Helen Vahramian
Apologies	**Standing Quality Standards Advisory Committee (QSAC) members** Damien Longson, Allison Duggal, Michael Varrow, Jane Bradshaw, Nicola Hobbs, Derek Cruickshank and Jane Ingham **Specialist committee members** Gwen Klepping

Agenda item	Discussions and decisions	Actions
Discussion on hip fracture	The NICE team presented the latest iteration of the hip fracture quality standard, seeking the views of the standing committee. The standing members acknowledged the quality standard had changed significantly since consultation. They were therefore unsure whether the statements accurately reflect the wider	**NICE team to keep the committee updated on the next steps for the hip**

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	stakeholders priorities for quality improvement. Concerns regarding the conduct of attendees at the meeting were discussed. It was agreed to run a further consultation with specific questions.	**fracture quality standard.**
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: <u>Standing committee members</u> • None <u>Specialist committee members</u> • Sam Ahmedzai – is the NIHR National speciality Lead for cancer outside the acute hospital, clinical lead of Royal College of Physicians national audit of end of life care, clinical adviser to NICE guideline development on service delivery in last year of life and chair of NICE guideline development group for care of dying adult in the last days of life. NIHR HTA research grant, prostate cancer UK research grant, MRC research grant, royalty fees from Oxford University Press, lecture fees on palliative care and PhD external examiner in Denmark. Also received funding for university and NHS trust R&D. Is a member of NICE guideline group on multiple myeloma, royal college of surgeons national confidential adult on oesophagogastric cancer, chair of national cancer research institute on clinical studies group on supportive and palliative care,	

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	member of resuscitation council committee on Emergency Care and Treatment Plan, Elected council member and trustee of British Pain Society, Member of target ovarian cancer scientific board, member of professional advisory board and scientific committee of Maggie's centre, steering group member of British Thoracic Oncology Group and chair of respiratory study group of multinational association for supportive care in cancer. • Jayne Kennedy – member of Association of Palliative Medicine and member of London End of Life Clinical Leadership Group • Diana Robinson – has a small shareholding in Reckitt Benckiser and Indivior. PPI work which may pay expenses and or honoraria for meetings, workshops or conference attendance and for reviewing research proposals: National Institute for Health Research, PGfAR funding panel, occasional lay peer reviews, National Cancer Research Institute, University of Leeds (IMPACCT study), CQC, NICE.SCIE older people with long terms conditions GDG, NICE.RCP care of dying adults GDG, SCIE co-production group, NHS England New Care Models team, public participation, Marie Curie Expert Voices and Research Expert Voices Groups, QMUL/Bart's Patient and Public Advisory Group. Personal family interest, sister in law works for UCL in credit control section. **Minutes from the last meeting** The committee reviewed the minutes of the last meeting held on 29th June 2016 and confirmed them as an accurate record.	
4. QSAC updates	None	
5 and 5.1 Topic overview and summary of engagement responses	PD and TS 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 PD 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. Recognising someone is in the last days of life Communication Shared decisions	

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	Managing hydration Managing symptoms Anticipatory prescribing Access to specialist palliative care Additional areas	
5.3 Prioritised area – recognising someone is in the last days of life	The committee discussed stakeholder suggestions for quality improvement areas relating to recognising when someone is in the last days of life. The committee noted the importance of recognising signs that a person may be about to die, but emphasised the importance of monitoring signs and symptoms (often with specialist input) to identify deterioration or improvement. It was seen as an important aspect of care in all settings, noting that the extent of monitoring can vary, for example if someone is in a critical care setting the level of monitoring may routinely be greater. The committee agreed that a quality statement should be drafted relating to people who have signs or indications that they might be entering the last days of life, in all settings. The important action would be to provide effective monitoring of signs and symptoms with specialist input as required.	**NICE team to draft a statement relating to people who have signs or indications that they might be entering the last days of life, in all settings**
5.3 Prioritised area – communication and shared decision making	The committee discussed stakeholder suggestions for quality improvement areas relating to communication and shared decision making. The committee agreed the importance of capturing a person's preferences in the event of imminent death, recognising that the person's condition may improve and that death may not follow. In the last 2-3 days of life, healthcare professionals should act in accordance with preferences stated, but should continue to be responsive to changing preferences towards the end of life. The committee agreed that the communication of the likelihood of death to the person and their family was highly important (and distinct from any earlier delivery of a terminal prognosis), and agreed that preferences recorded should be shared with all relevant healthcare and other care practitioners to inform care planning and care delivery in the last days of life. The committee agreed that a quality statement should be drafted to cover the capture of a person's preferences and shared decisions when the likelihood of imminent death was recognised, drawing on preferences stated in advance. The action could be undertaken as part of the communication of likely death and would form the basis for the sharing of information on preferences to inform care planning and	**NICE team to draft a statement to cover the capture of a person's preferences and shared**

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	delivery in the last few days of life. The committee discussed the possibility of an additional quality statement about individualised care planning, but felt that this would be a rationale of the capture of preferences and that the details would be covered by the areas of anticipatory prescribing and symptom management discussed below.	**decisions when the likelihood of imminent death was recognised, drawing on preferences stated in advance.**
5.3 Prioritised area – managing symptoms and anticipatory prescribing	The committee discussed stakeholder suggestions for quality improvement areas relating to symptom management and anticipatory prescribing. It was suggested that there can be differences in access to medication to symptom management depending on the setting: in hospitals patients may have to wait for a doctor to provide prescriptions for symptom management. The committee agreed that the key area for quality improvement was to ensure that anticipatory prescribing and symptom management was individualised, not provided on a blanket basis, and suggested that this should form the basis for a quality statement. The NICE team agreed to consider drafting the statement from the perspective of individualised care planning (with anticipatory prescribing to alleviate symptoms as a component), or from the perspective of anticipatory prescribing based on individual assessments, with the type of medicine, dose and when to use it stated for individual patients.	**NICE team to draft a statement from the perspective of individualised care planning (with anticipatory prescribing to alleviate symptoms as a component), or from the perspective of anticipatory prescribing based on individual assessments, with the type of medicine, dose and when to use it stated for individual patients.**
5.3 Prioritised area – hydration	The committee discussed stakeholder suggestions for quality improvement areas relating to hydration in the last few days of life. The committee agreed that this was a very important area of care, with wide variation in quality across different settings. The committee felt it was important to emphasise that clinicians weigh up the risks and benefits of clinically assisted hydration on a case by case basis for any dying person. They wanted to emphasise that open and honest discussions should take place around the decision making process, ensuring that the dying person and those important to them are aware of the uncertainty about its benefits and the effect on survival The committee agreed that a quality statement should cover the assessment and recognition of hydration needs, and communication with families of the potential benefits and risks of assisted hydration.	**NICE team to draft a statement to cover the assessment and recognition of hydration needs, and**

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	The committee agreed that other aspects of hydration, including mouth care, should be routine aspects of good clinical and nursing practice.	**communication with families of the potential benefits and risks of assisted hydration.**
5.3 Prioritised area – access to palliative care	The committee discussed stakeholder suggestions for quality improvement areas relating to access to specialist palliative care, in particularly out of hours. The committee noted variation in the provision of specialist palliative care services among trusts, and noted a potentially significant resource impact associated with extending this level of provision. However it was also noted that access could relate to availability, rather than use, and that access to palliative care support does not always need to be face to face. The committee noted that the potential source recommendations in NICE guideline NG31 did not specifically refer to patient access to specialist palliative care; rather they often refer to the availability of such specialists, along with other specialists, to support healthcare professionals who are caring for people in the last few days of life. The NICE team was asked to consider drafting a quality statement for consultation based on recommendation 1.3.9 of NICE guideline NG31, which refers to the availability of experienced staff (including palliative care) to support shared decision making. In developing the quality standard, the NICE team would be mindful of forthcoming guidance on service delivery relating to end of life care (and the possibility of access to specialist palliative care being covered by a future quality standard), as well as the potential resource impact issues associated with any draft quality statement in this area.	**NICE team to consider a statement for consultation based on NG31 recommendation 1.3.9, which refers to the availability of experienced staff (including palliative care) to support shared decision making.**
5.3 Additional areas	The committee discussed stakeholder suggestions relating to other quality improvement areas that were not covered by NICE guideline NG31, or where considered by the NICE team to be out of the scope of this quality standard. These included: complementary therapies, earlier intervention, care of the deceased and service delivery. The committee did not identify areas from these suggestions that could be prioritised for inclusion in the current quality standard.	
5.4 Overarching outcomes	The NICE team explained that the quality standard would describe overarching outcomes that could be improved by implementing a quality standard on care of dying adults in the last days of life. It was agreed that the Committee would contribute suggestions as the quality standard was developed.	

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5.5 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. In relation to equality issues the committee noted a recent CQC report on end of life issues and a report by Marie Curie relating to LGBT groups. The NICE team agreed to take account of any relevant aspects of these reports in noting equality considerations for the current quality standard.	
6. Next steps and timescales (part 1 – open session)	The NICE team outlined what will happen following the meeting and key dates for the care of dying adults in the last days of life quality standard.	
6. Any other business (part 1 – open session)	The following items of AOB were raised: • None raised **Date of next meeting for care of dying adults in the last days of life: 30th November 2016** **Date of next QSAC 4 meeting: Wednesday 28th September 2016 – osteoporosis and falls prevention**	