NICE National Institute for Health and Care Excellence

Quality Standards Advisory Committee 4

1. Care of dying adults in the last days of life - post consultation

2. Vaccine uptake in under 19s - post consultation

Minutes of the meeting held on 30 November 2016 at the NICE offices in Manchester

Attendees	**Standing Quality Standards Advisory Committee (QSAC) members** Damien Longson (DL) [Chair], Tim Fielding (TF), Alison Allam, Moyra Amess, Simon Baudouin, Derek Cruickshank, Alison Duggall, Nadim Fazlani, Nicola Hobbs, Zoe Goodacre, John Jolly, Asma Khalil, Annette Marshall, Jane Putsey, Matthew Sewell **Specialist committee members** Sam Ahmedzai [agenda items 1-6], Jayne Kennedy [items 1-6], Gwen Klepping [items 1-6] , Catherine Piggin [items 1-6] and Diana Robinson [items 1-6], Leony Davies [items 7 -11], David Elliman [items 7 -11], Anthony Harnden [items 7 -11], Mary Ramsay [items 7 -11], Krisha Wilson [items 7 -11] **NICE staff** Nick Baillie (NB), Alison Tariq (AT), Paul Daly (PD) [items 1-6], Karyo Angeloudis (KA) [items 7 -11], Helen Vahramian (HV) and Joanne Ekeledo (JE) **NICE Observers** Jane Lynn
Apologies	**Standing Quality Standards Advisory Committee (QSAC) members** Jane Bradshaw, David Weaver, Jane Ingham, Michael Varrow, and James Crick **Specialist committee members** Catherine Heffernan [agenda items 7 -11] Maggie Wearmouth [items 7 -11],

Agenda item	Discussions and decisions	Actions

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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>Specialist committee members</u> **Care of dying adults in the last days of life** • <u>Sam Ahmedzai</u> [agenda item 1-6] 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 auditt on oesophagogastric cancer, chair of National Cancer Research Institute on clinical studies group on supportive and palliative care, member of resuscitation council committee on Emergency Care and Treatment Plan, Elected council member and trustee of British Pain	

Agenda item	Discussions and decisions	Actions
	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. • Diana Robinson [agenda item 1-6] 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. **Vaccine uptake in under 19s** • Anthony Harnden [agenda item 7 -11] Deputy Chairman, Joint Committee of Vaccination and Immunisation • Mary Ramsay [agenda item 7 -11] Immunisation, Hepatitis and Blood Safety Department has provided vaccine manufacturers with post-marketing surveillance reports which the companies are required to submit to the UK Licensing authority in compliance with their Risk Management Strategy. A cost recovery charge is made for these reports. **Minutes from the last meeting** The committee reviewed the minutes of the last meeting held on 28 September 2016 and confirmed them as an accurate record.	
4. QSAC updates	None	

POST CONSULTATION Care of dying adults in the last days of life		
5. Recap of prioritisation exercise	PD(Technical Analyst) and AT (Senior Technical Analyst) presented a recap of the areas for quality improvement discussed at the first QSAC meeting for **Care of dying adults in the last days of life**: **At the first QSAC meeting on 27 July 2016, the QSAC agreed that the following areas for quality improvement should be progressed for further consideration by the NICE team for potential inclusion in the draft quality standard:** • **Recognising someone is in the last days of life** Progress: Emphasis on monitoring signs and symptoms to identify deterioration or improvement • **Communication and shared decision making** Progress: Capture preferences, provide care in accordance with preferences, be responsive to changing preferences • **Managing symptoms and anticipatory prescribing** Progress: Focus on anticipatory prescribing. Drafted using 2 perspectives and sought member views. • **Hydration** Progress: Assessment of hydration needs, and communication of the benefits and risks of assisted hydration • **Access to palliative care** Consider statement based on Rec 1.3.9. Unable to develop robust statement that was person centred, addressed the aims and remained aligned with the underpinning recommendation. No statement produced. The full rationale for these decisions is available in the prioritisation meeting minutes which can be found here: https://www.nice.org.uk/guidance/GID-QS10019/documents/minutes	**5. Recap of prioritisation exercise**

5.2 and 5.3 Presentation and discussion of stakeholder feedback and key themes/issues raised	AT and PD presented the committee with a report summarising consultation comments received on the draft care of adults in the last days of life quality standard. The committee was reminded that this document provided a high level summary of the consultation comments, prepared by the NICE quality standards team, and was intended to provide an initial basis for discussion. The committee was therefore reminded to also refer to the full list of consultation comments provided throughout the meeting. The committee was informed that comments which may result in changes to the quality standard had been highlighted in the summary report. Those comments which suggested changes which were outside of the process, were not included in the summary but had been included within the full list of comments, which was within the appendix. These included the following types of comment: • Relating to source guidance recommendations • Suggestions for non-accredited source guidance • Request to broaden statements out of scope • Inclusion of overarching thresholds or targets • Requests to include large volumes of supporting information, provision of detailed implementation advice • General comments on role and purpose of quality standards • Requests to change NICE templates PD presented a summary of the themes emerging from the general comments made by stakeholders. The 3 main themes emerging from consultation were the QS was generally well supported, comments on the impact of the QS and a need to focus on communication and information sharing preferences for people..	**5.2 and 5.3 Presentation and discussion of stakeholder feedback and key themes/issues raised**
5.4 Discussion and agreement of final statements	The committee discussed each statement in turn and agreed upon a revised set. **These statements are not final and may change as a result of the editorial and validation processes.**	**5.4 Discussion and agreement of final statements**

Draft statement	Themes raised by stakeholders	Committee rationale	Statement revised (Y/N)
1.			

Adults who have signs and symptoms that suggest they may be in the last days of life are monitored for further changes to help determine if they are nearing death, stabilising or recovering.	i. Is daily monitoring appropriate and achievable? ii. Who is responsible for monitoring and should term 'monitoring' have be used? iii. Should focus be communicating that someone is entering the last days of life?	Use of the term "signs and symptoms" should be reconsidered, the rationale should focus on what happens after the point of recognition but the population with the statement should retain 'signs and symptoms'. More clarity is needed in the rationale. The focus of the statement is about monitoring potentially changing needs and symptoms, within the context of diagnostic/prognostic uncertainty, to enable swift and flexible action. This requires an individual care plan that can change. The use of the terms "monitoring" or "review" were discussed, the guideline uses both, stakeholders felt monitoring may solely imply the use of equipment by healthcare professionals. Whichever term is used, it needs to be sufficiently inclusive to encompass both of these scenarios but without excluding a broader range of community-based settings and social care/family roles and judgments, as well as a patient perspective where this is possible. Overall the committee expressed a preference for monitoring as long as its meaning is clear. Although daily monitoring by community-based professionals is achievable, it is unlikely that it will be the same person/ role on a daily basis. It is often family members who are best placed to detect the signs associated with any of the three triage points. Additional resources should not be necessary. The committee confirmed the statement should not focus on communicating that someone is dying.	**N- amend rationale to clarify the focus and clearly define monitoring.**
2.			

Adults in the last days of life are given care that is in accordance with their stated preferences and responsive to their changing preferences.	i. May not be possible to meet all preferences ii. Address needs as well as preferences iii. Ability to make preferences iv. Difficult to start discussions about preferences	The tension between preferences, needs and resources is central to this statement. Many preferences would have to be identified before the last days of life and are not always permissible or achievable. There could be conflicts between the preferences of the patient and those of close family. The role of advocacy in intervening or interpreting on behalf of the patient is also relevant, as are such features as lasting power of attorney. The committee discussed the distinction between preferences within care plans and advanced care statements and terminology used in the Care Act. There was discussion whether to use needs instead of preferences or holistic needs, The guideline uses a number of terms such as needs, wishes, goals. The discussion and shared decision making of the persons preferences or needs and how they may inform future care, in the form of an individualised care plan was determined to be an important factor . The delivery of care in line with that care plan as far as reasonably practical was felt to be the second important aspect. The wording in the Capacity Act 2015 which requires that preferences should be considered, and NHS England Statement on individualized care plans [ID 168], which refers to current and changing needs and preferences, may be helpful in clarifying the wording. The committee considers that two separate statements are needed, as subsequent statements rely on the existence of an individual care plan detailing the person's needs, wishes and options.	**Y - Split to form 2 statements.** **One with focus on discussions to create an individualised care plan that includes capture of needs as well as preferences; the other with a focus on providing care in line with the individualised care plan.**

3. Adults in the last days of life who are likely to need symptom control are prescribed anticipatory medicines with individualised indications for use and dosage.	i. Other factors may affect people being able to have medicines administered without delay ii. Implementation needs to reflect local circumstances iii. Is approach to prescribing anticipatory medicines too restrictive? iv. Statement represents an individualised approach v. What is an individualised approach? vi. Reviewing and stopping existing medications	A challenge for this statement is that the guideline do not fully define what individualised prescribing is. SCMs clarified that individualised prescribing is done by specifying the dose, indication and using the considerations contained in rec 1.6.4. Anticipatory prescribing is early identification of those patients who are likely to need symptom control, especially those at home and in community settings, where prn medications need to be in place and to hand when a health care professional visits. The 5 most common drugs are low cost and can be available in advance, as long as there is a clear understanding of what is available, when, why and how best to use them. There is a need to move on from the negative perceptions of blanket prescribing for end of life symptom control and to focus on reviewing the side-effects and benefits, adjusting the dosage and method of administration and where necessary, stopping medication. This is recurrent process over the last days of life. SCMs confirmed that the RCP audit identifies that individualised prescribing for the last days of life, with different drugs for different indications, is measurable in a hospital setting. The outcome measures are critical since the purpose of anticipatory prescribing is to relieve problematic symptoms. De-prescribing could be a useful measure. Prescriptions should record the intended symptom relief, route and stopping rules.	**N- but clarify what an individualised approach is.**

		Review and stopping existing medication should have occurred prior to the last days of life.	
4. Adults in the last days of life have their hydration status assessed daily, and a discussion about the risks and benefits of clinically assisted hydration.	i. Support for assessment, but ii. What does hydration status cover? iii. Is the frequency right? iv. Is it achievable in the community given resources available? v. Is the focus on clinically assisted hydration appropriate?	Members noted that stakeholders broadly supported the first part of the statement focused on assessment, but recognised that there is no definition of hydration status in the underpinning guideline. Specialist members advised that the focus of the assessment is clinical observation. In terms of frequency, members felt this should be at least daily, but noted the guideline actually says preferably daily. However, it was recognised that hydration status could be assessed when other signs and symptoms are assessed under statement 1. Committee noted stakeholders concerns with the focus of the second part of the draft statement on clinically assisted hydration (CAH). There is limited published evidence of the benefits of CAH, although the RCP audit indicates that it is given in up to 70% of end of life patients in hospital settings. Until such time as there is trial based evidence that CAH has clinical benefits, specific reference to it should not be included in a Quality Statement. Also the ability to meet the statement through stipulating CAH, could limit it to specific settings. The key message in this statement lies in making the patient comfortable and alleviating physical distress. The importance of hydration, in all its forms, including but not singling out CAH, is critical in achieving this. This includes oral hydration, as more than a third of patients are still able to drink. It also includes mouth care and frequent checking. Where practicable, account should be taken of the patient's needs and wishes, which might involve a discussion about the risks and benefits of different types of hydration.	**Y - Retain first part of the statement about assessment, but clarify what assessment of hydration status involves. Amend second part of the statement to focus on discussion about the risks and benefits of various forms of hydration**

Additional statements suggested	Committee rationale	Statement progressed (Y/N)
1. Communicating with the patient, those important to them and professionals that death may be near.	This suggestion partly covered in new statement on individualised care plan	No
2. Attending to the needs of families and carers.	Covered in part by statements 1-4	No
3. Reviewing & discontinuing non-essential medications.	Covered in 5.4.3 on anticipatory prescribing.	No
4. Pain management	Partly covered in 5.4.3 on anticipatory prescribing	Part
5. Individualised care plans	A new statement on individualised care planning is to be included to underpin statements 2, 3 and 4. Discussion of rationale for this is covered in section 5.4.2	Yes

6. Resource impact	The committee agreed the statements prioritised would not have a significant resource impact.	
7. 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.	**Comments invited**
8. 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.	**Comments invited**
9. Next steps and timescales (part 1 – open session)	PD outlined what will happen following the meeting and key dates for the **Care of dying adults in the last days of life** quality standard.	**Comments invited**
POST CONSULTATION **Vaccine uptake in under 19s**		

9. Recap of prioritisation exercise	AT, Senior Technical Analyst and KA, Technical Analyst presented a recap of the areas for quality improvement discussed at the first QSAC meeting for **Vaccine uptake in under 19s.** **At the first QSAC meeting on 29 June 2016, the QSAC agreed that the following areas for quality improvement should be progressed for further consideration by the NICE team for potential inclusion in the draft quality standard:** • Immunisation appointments • Information systems • Targeting groups at risk of low uptake • Contribution of educational settings • The full rationale for these decisions is available in the prioritisation meeting minutes which can be found here: https://www.nice.org.uk/guidance/GID-QS10015/documents/minutes	**9. Recap of prioritisation exercise**
9.2 and 9.3 Presentation and discussion of stakeholder feedback and key themes/issues raised	KA, and AT presented the committee with a report summarising consultation comments received on **Vaccine uptake under 19s**. The committee was reminded that this document provided a high level summary of the consultation comments, prepared by the NICE quality standards team, and was intended to provide an initial basis for discussion. The committee was therefore reminded to also refer to the full list of consultation comments provided throughout the meeting. The committee was informed that comments which may result in changes to the quality standard had been highlighted in the summary report. Those comments which suggested changes which were outside of the process, were not included in the summary but had been included within the full list of comments, which was within the appendix. These included the following types of comment: • Relating to source guidance recommendations • Suggestions for non-accredited source guidance • Request to broaden statements out of scope • Inclusion of overarching thresholds or targets • Requests to include large volumes of supporting information, provision of detailed implementation advice • General comments on role and purpose of quality standards • Requests to change NICE templates KA presented a summary of the general themes from consultation, these were support for the standard, requirement for improvements to national immunization data capture systems and concerns around recording as the records of looked after children often being missing.	**9.2 and 9.3 Presentation and discussion of stakeholder feedback and key themes/issues raised**

9.4 Discussion and agreement of final statements	The committee discussed each statement in turn and agreed upon a revised set. **These statements are not final and may change as a result of the editorial and validation processes.**	**5.4 Discussion and agreement of final statements**

Draft statement	Themes raised by stakeholders	Committee rationale	Statement revised (Y/N)
1. Children and young people who do not attend their immunisation appointment are followed-up with a recall invitation and a phone call or text message.	i. Need for clarity on timing of the actions and who is responsible for doing them. ii. Additional resources will be needed by primary care. iii. Additional equality and diversity considerations. iv. Caution about repeatedly contacting parents who have decided not to have their child immunised	Need to acknowledge instances when the parent/guardian has made a conscious decision not to have the child vaccinated and those who have simply failed to respond to an invitation. The committee recognised the resource required on primary care but felt it to be a fundamental aspect of practice management that it does not require a specific contractual clause and it ought to be happening. Clarity is needed over who does the actions and timing as there are some areas that could potentially confuse the measurement of uptake. It was noted not all practices send an initial appointment, as it is sometimes assumed that the parent/guardian knows when to make an appointment, this should be taken into account in the measures. Clarity is needed as to whether the telephone or text reminder occurs after the reminder, which should be written or whether they can occur simultaneously – this need to be made clear in the rationale.	**Y – amend to specify 'written invitation'**
2.			

Children and young people receiving a vaccination have it recorded in their GP record, their personal child health record and in the child health information system.	i. Difficult to enforce and measure the statement. ii. Add GP contract requirement on providing accurate and timely information on vaccinations given. iii. Need for investment to standardise CHIS across the country and implement a personal child health record for over 5's. iv. Need for a digital personal child health record. v. Parents often do not bring the red book to the appointment. vi. Suggestion to also record vaccinations within the educational records. vii. Add independent schools as they fall short of national reporting requirements.	Accurate recording is a key area for improvement. Often the vaccination has been done but there is a backlog in putting it onto the health records. The intention is to ensure that the records are accurate and consistent whereas current practice is fragmented, inconsistent and delayed. The committee recognized that measurement of entry onto the electronic systems would be easier than recording in the PCHR and felt that this should be recognised within the measures, Although recording in PCHR could be aspirational because of its potential future importance for the young persons' health passport. The committee also felt the order of records should be amended to GP, CHIS, then PCHR. Timeliness of recording is important and whilst acknowledging differing vaccination schedules, should be auditable.	**Y - amend ordering of recording systems.**
3. Young offenders have their immunisation status checked on entry into the secure setting and are offered any outstanding vaccinations.	i. Difficult to measure due to the different providers for health and justice. ii. The focus on young offenders may be at the expense of other at risk groups.	Whilst acknowledging low uptake in other vulnerable groups, the committee decided not to broaden the population covered by this statement. But requested the rationale made it clear why this group had been priortised above others. The acknowledged that young offenders often come from backgrounds where children are least likely to have been immunised.	**N- clarify in rationale why focus is on this group.** **Cover other vulnerable groups in E&D section**

	iii. Broaden the statement to include children in care and those in secure children's homes. iv. Focus on refugee children as they may have unknown vaccination history.	They also agreed the problems of other at risk populations with low uptake and difficulties with recall, should be acknowledged within the Equality and Diversity sections and EQIAs. Since young people can be held in a YOI until the age of 21, NICE team to check if the population covered by the statement. Obtaining past records can present difficulties so there is a risk of repeating vaccinations that have already been done. However, the cost of this will be minimal and out weighed by the benefits of increased overall uptake. The committee also felt that this statement should be last within the pathway.	
4. Children and young people are offered vaccination as soon as it is known that they have missed a routine childhood vaccination.	i. Most stakeholders agreed not to focus on a specific vaccination. ii. Suggestion to use a specific timescale. iii. Need to provide more choice of vaccination venues and times. iv. More types of healthcare professionals to give vaccination. **v.** Funding implications for primary care.	This statement should appear as be statement 2. Vaccination should be offered as soon as it is known that a vaccination has been missed, this should be done opportunistically. Responsibility for the identification can include health care professionals such as GPs, practice nurses, school nurses, paediatricians and health visitors. The term "offer" can extend this group to encompass other professionals who are competent to identify the need or opportunity for a vaccination and to make a correct referral to an appropriate professional. Audience descriptors should be amended to reflect wide range of professionals who can identify missed vaccination and rationale to make it clear that onward referral can be made if	**Y- include the opportunistic nature within the statement**

		missing vaccines cannot be provide at the time of identification.	
5. Developmental statement: Children and young people have their immunisation status checked at key educational stages.	i. Incorporate in to the national specifications for health visiting and school nursing. ii. Unclear how school nurses would access CHIS. iii. The healthy child team would not have access to the child health record or red book. iv. Resource implication for the track down of childhood vaccination data and for the delivery of missed vaccinations. v. Risk of stigma for children singled out for targeted vaccination. Query regarding how religious schools will address this.	This statement has wide public health importance. Because of the fragmented nature of school nursing teams it is not happening as widely as it should. They should be identifying children within their area who need vaccination and making appropriate referrals. There was discussion that where school nurses or healthy child programme teams are in place, they do not all have access or only partial access to the child health information system (CHIS). The access and perception of access was debated but it was felt to be an important requirement of their area responsibilities. An additional complication is accessing records of children who attend school outsider their area of residence.	**N**

Additional statements suggested	**Committee rationale**	**Statement progressed (Y/N)**
1. Identification of those eligible for vaccination.	Partly covered in statement 5	No
2. Uptake of flu vaccine.	No remit to focus on specific vaccinations	No
3. Update records when people change	Covered by statement 4	No

GP practice.		
4. Parental responsibility for monitoring their children's vaccination status.	Not supported by guideline	No
5. Staff training.	Implicit in all Quality Standards that care providers will do this	No
6. Marketing of vaccinations and celebration of vaccine success.	Not supported by guideline	No
7. Electronic vaccination passport for HIV positive people.	Not supported by guideline	No
8. Vaccination passport for all children.	Not supported by guideline	No
9. Check vaccination status of looked after children.	Decision to focus on one specific group – young offenders	No
10. Routine vaccinations of premature neonates	Not supported by guideline	No

9. Resource impact	The committee agreed the statements prioritised would not have a significant resource impact.	
10. Overarching outcomes	The NICE team explained that the quality standard would describe overarching outcomes that could be improved by implementing a quality standard on **Vaccine uptake in under 19s**. It was agreed that the Committee would contribute suggestions as the quality standard was developed.	
11. 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. Although one of the statements focusses on a single at risk group with low uptake, young offenders, reference should be made at an appropriate point in the standard to other vulnerable groups including	Action required

	travellers, children of refugees and recent immigrants.	
12. Next steps and timescales (part 1 – open session)	KA outlined what will happen following the meeting and key dates for the Vaccine uptake in under 19s quality standard.	
13. Any other business (part 1 – open session)	**Date of next QSAC 4 meeting: 16 December 2016 morning session only for: Chronic kidney disease (update)**	