NICE National Institute for Health and Care Excellence

**Quality standards advisory committee 2**

**End of life care for infants, children and young people post-consultation meeting**

**Drug misuse prevention prioritisation meeting**

**Minutes of the meeting held on 8 June 2017 at the NICE offices in Manchester**

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| **Attendees** | **Quality standards advisory committee (QSAC) standing members**<br>Michael Rudolf (chair), Moyra Amess, Gillian Baird, Guy Bradley-Smith, Julie Clatworthy, James Crick, Allison Duggal, Jean Gaffin, Corinne Moocarme, Robyn Noonan, Jane Putsey, Ruth Studley, David Weaver, Michael Varrow, Arnold Zermansky.<br><br>**Specialist committee members**<br>End of life care for infants, children and young people: Stacey Curzon, Emily Harrop, Zoe Picton-Howell, Satbir Jassal, Amy Volans<br>Drug misuse prevention: Charlotte Ashton, Rachel Bundock, Paul McArdle, April Wareham<br><br>**NICE staff**<br>Nick Baillie, Gavin Flatt (Items 1-4), Craig Grime (Items 1-4), Stacy Wilkinson (Items 5-7), Shaun Rowark (Items 5-7) |
| **Apologies** | **Quality standards advisory committee (QSAC) standing members**<br>Michael Fairburn, Steve Hajioff, Matthew Sewell, Jane Bradshaw, Malcolm Griffiths.<br><br>**Specialist committee members:**<br>End of life care in children: David Vickers, Lucy Coombes<br>Drug misuse prevention: Pete Burkinshaw |

| 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.<br><br>The Chair informed the committee of the apologies and reviewed the agenda for the day. | |

| Agenda item | Discussions and decisions | Actions |
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| **2. Committee business (public session)** | **Declarations of interest**<br>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 any interests in addition to those previously circulated.. The following interests were declared:<br><br>**Standing committee members**<br>•<br>**Specialist committee members**<br>• Zoe Picton-Howell declared additional interests: involvement in re-writing NHS England guidance on the death of a child and co-authorship of a publication on paediatric end of life care.<br><br>**Minutes from the last meeting**<br>The committee reviewed the minutes of the last meeting held on 9 March 2017 and confirmed them as an accurate record. | |
| **3. Recap of prioritisation exercis** | The NICE team presented a recap of the areas for quality improvement discussed at the first QSAC meeting for end of life care for infants, children and young people:<br><br>**At the first QSAC meeting on 9 February 2017 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:**<br><br>• Advance care planning<br>• Clinical management (managing distressing symptoms)<br>• Emotional and psychological support for the child<br>• Emotional and psychological support for the family<br>• Home care<br>• Key contacts (named medical contact)<br><br>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-qs10031/documents/minutes | |
| **3.2 and 3.3 Presentation and discussion of** | The NICE team presented the committee with a report summarising consultation comments received on end of life care for infants, children and young people. The committee was reminded that this document provided a high level summary of the consultation comments, prepared by the NICE quality standards | NICE team to:<br>• Ensure the term "young adults" is |

| Agenda item | Discussions and decisions | Actions |
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| **stakeholder feedback and key themes/issues raised** | 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.<br><br>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:<br>• Relating to source guidance recommendations<br>• Suggestions for non-accredited source guidance<br>• Request to broaden statements out of scope<br>• Inclusion of overarching thresholds or targets<br>• Requests to include large volumes of supporting information, provision of detailed implementation advice<br>• General comments on role and purpose of quality standards<br>• Requests to change NICE templates<br><br>GF summarised the significant themes from the stakeholder comments received:<br>• Quality standard overall well received<br>• General feedback was that the key areas for quality improvement had been identified.<br>• For most of the measures collecting the data should be technically possible<br>• Use of term young people and young adults<br>• Inclusion of siblings<br>• Data sources<br>• Resource impact | replaced with "young people" throughout the quality standard.<br>• Include health related quality of life of siblings as an additional outcome.<br>• Ensure the term "district nursing" is replaced with "community nurses" throughout the quality standard. |
| **3.4 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.** | |

| Draft statement 1 | Themes raised by stakeholders | Committee rationale | Statement revised (Y/N) |
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| Infants, children and young people with a life-limiting condition and their parents or carers are involved in developing an advance care plan | • Important area of care<br>• Reference to issues regarding young people developing their own advance care plan<br>• Education settings and ambulance trusts included in audience descriptors<br>• Include infants throughout the supporting information<br>• Reference to the fact that an advance care plan is usually developed following a number of discussions and is not a singular activity | • The statement should reflect the need for involvement of the child and family at appropriate stages and that the content may change according to circumstance.<br>• Measures should focus on involvement in development, rather than existence of the plan. They should also reflect importance of parents and include infants.<br>• The rationale and additional supporting information should be amended to reflect that involvement is not a singular activity.<br>• As the statement is focussed on involvement of the child and family, it would not be appropriate to include sharing with ambulance trusts or education settings.<br>• It may be helpful to reference the Child and Young Person's Advance Care Plan Collaborative resources. | Yes.<br>The statement should reflect that the care plan is owned by the child. |
| **Draft statement 2** | **Themes raised by stakeholders** | **Committee rationale** | **Statement revised (Y/N)** |
| Infants, children and young people with a life-limiting condition have a named medical specialist who coordinates their care. | • Reference to a more general key worker or range of appropriate specialists<br>• Services should be local to the children and young person's home<br>• Information for measures already being collected via HES?<br>• Consultation question: can stakeholders suggest who the medical specialist should be? | • The statement should remain focused on named medical specialists, not key workers.<br>• The named medical specialist should be appropriate to the child, therefore may not always be local.<br>• The rationale and supporting information should reflect that the specialist may change if the care or setting changes. | Yes.<br>The statement should specify that the purpose is to "lead on and coordinate medical care". |
| **Draft statement 3** | **Themes raised by stakeholders** | **Committee rationale** | **Statement revised (Y/N)** |
| Children and young people with a life-limiting condition are given information about emotional and | • Major area for quality improvement<br>• This support is best delivered alongside support to parents, siblings, and carers<br>• Emotional and psychological support needs to be defined | • The statement is too narrowly focused and should reflect the importance of involving parents, carers and family.<br>• The statement excludes infants who can benefit from psychological support.<br>• The statement is focused on the provision of information on what psychological support is available and how it can | Yes.<br>Infants and parents and carers to be included. |

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| psychological support and how to access it. | • Rephrased to say that children and young people are 'given access to support'<br>• Information needs to be tailored to needs of individual e.g. learning difficulties<br>• Data could potentially be used to monitor referral patterns<br>• Currently resources are not in place to support this. | be accessed. The measures should be amended to reflect this.<br>• A definition should be included on the types of services that can provide support. | Amendment to wording: "including how to access it". |
| **Draft statement 4** | **Themes raised by stakeholders** | **Committee rationale** | **Statement revised (Y/N)** |
| Infants, children and young people approaching the end of life have any unresolved distressing symptoms assessed by the specialist paediatric palliative care team. | • This should be expanded to include low mood and anxiety<br>• Clear definition of specialist paediatric care team required<br>• Currently there are not enough specialist paediatric care teams available<br>• Consultation question: Can stakeholders suggest how performance would be measured in practice? Are there specific symptoms or timescales that would be more suitable as the focus of quality improvement? | • Current statement cannot be consistently measured to allow comparison of performance. Stakeholders were unable to provide agreed definitions of "unresolved distressing symptoms".<br>• Provision of specialist paediatric palliative care teams was in itself an area for quality improvement. | Yes.<br>Statement to focus on management of all infants children and young people approaching end of life by an MDT that includes specialist paediatric palliative care. |
| **Draft statement 5** | **Themes raised by stakeholders** | **Committee rationale** | **Statement revised (Y/N)** |
| Parents or carers of infants, children and young people approaching the end of life are offered bereavement support when their child is | • Should refer to grief and loss support rather than bereavement support<br>• Siblings should be included<br>• Clear definition of bereavement support was requested.<br>• Process of bereavement support should begin from the point of diagnosis. | • Support before the death of the child should be referred to as "grief and loss support".<br>• A definition of "approaching the end of life" is needed. For measurement purposes the statement could refocus to the period following a prognosis that death is likely to occur within weeks. | Yes.<br>Reference grief and loss support. |

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| nearing the end of their life and after their death. | • Lack of funding currently available for bereavement support. | • For pragmatic purposes the measures could be focused on those children who have died.<br>• Some amendment to rationale terminology would be beneficial eg, autopsy and genetic risk. | |
| **Draft statement 6** | **Themes raised by stakeholders** | **Committee rationale** | **Statement revised (Y/N)** |
| Infants, children and young people approaching the end of life and being cared for at home have 24-hour access to paediatric nursing care and advice from a consultant in paediatric palliative care. | • Should promote greater choice for children and young people<br>• Should a consultant in paediatric palliative care should be specifically referenced<br>• A reference to ambulance trusts should be included | • A definition of "approaching the end of life" is needed. For measurement purposes the statement could refocus to the period following a prognosis that death is likely to occur within weeks.<br>• Appropriate to reference the consultant in paediatric palliative care in line with the NICE guideline.<br>• Paediatric nursing should be re-phrased as children's nursing. | Yes.<br>Amendment to reflect that both services are available 24 hours a day.<br>Amendment to "children's nursing care". |

| **Additional statements suggested** | **Committee rationale** | **Statement progressed (Y/N)** |
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| Short breaks (respite) for children and young people and their parents. | Although respite care can be an important component of support, limited guideline recommendations would support inclusion as an additional quality statement. However, it could be referenced as a component of the care outlined in other statements eg. care plans and psychological support. | No |

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| **3.5. Resource impact** | Concerns were raised as to national and regional service provision. However it was hoped that the quality standard would help focus resource use and promote high quality care. | |
| **3.6. 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. | |

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| **3.7. 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.<br>Additional suggestions of considerations included:<br>• Communication difficulties<br>• Age appropriate information<br>• Service provision at transition between child and adult services<br>• Support for travellers<br>• Reference to the Accessible Information Standard. | |
| **4. Next steps and timescales (part 1 – open session)** | The 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. | |
| **4.1 Close of morning session** | MR thanked the end of life care for infants, children and young people specialist committee members for their input into the development of the quality standard. | |
| **The specialist committee members for the end of life care for infants, children and young people quality standard left and the specialist committee members for the drug misuse prevention quality standard joined.** | | |
| **5. Committee business (public session)** | **Declarations of interest**<br>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. No interests were declared. | |
| **6 and 6.1 Topic overview and summary of engagement responses** | The NICE team presented the topic overview and a summary of responses received during engagement on the topic. | |
| **6.2 Prioritisation of quality improvement areas** | MR and the NICE team led a discussion in which areas for quality improvement were prioritised.<br><br>The QSAC considered the draft areas as outlined in the briefing paper prepared by the NICE team. The 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? |
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| Delivering prevention interventions through existing services | No | The committee discussed comments at topic engagement relating to the importance of delivering prevention interventions to at risk groups within existing services.<br><br>The committee discussed which at risk groups and specific services to focus on to ensure that any statement would be measurable. The committee also discussed what action would be provided to these groups, and felt that the source guideline did not specify an action for this area.<br><br>The committee therefore agreed not to prioritise this area. | **No action** |
| Assessment of vulnerability to drug misuse | Yes | The committee discussed comments at topic engagement relating to the need to assess people at risk at routine appointments and opportunistic contacts to determine whether they are vulnerable to drug misuse.<br><br>The committee agreed the importance of opportunistically assessing those at highest risk. The committee felt that in order for this statement to be measurable, high risk groups and where the assessment would be likely to take place would need to be specified.<br><br>The committee heard from specialist members that children and young people who are looked after or care leavers are high risk and have an annual statutory health assessment where they could be assessed, but this is not currently happening. The committee also heard that children and young people who are in contact with the community-based criminal justice system are a high risk group who are in regular contact with services. | **Assessment of vulnerability to drug misuse for children and young people who are looked after or care leavers**<br><br>**Assessment of vulnerability to drug misuse for children and young people who are in contact with the community-based criminal justice system.** |

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| | | The committee agreed with specialists and prioritised these two populations for inclusion in the draft quality standard. They agreed to prioritise two statements as the two groups are likely to be in contact with different services. | |
| Life skills training | No | The committee discussed comments at topic engagement relating to life skills training for children and young people who are assessed as vulnerable to drug misuse.<br><br>The committee discussed whether this could be progressed as a quality improvement area given that the source recommendations are consider recommendations, inferring that the evidence base was weak. Specialists highlighted that while life skills training is important for this population, the evidence for this preventing drug misuse was found to be poor during the guideline development.<br><br>The committee discussed whether to focus an area for improvement on the components of life skills training. However the committee was unaware of variation in practice for this.<br><br>The committee therefore agreed not to prioritise this area. | **No action** |
| Information and advice | Yes | The committee discussed comments at topic engagement relating to the importance of providing information and advice. Specialist committee members added that this could be signposting to local services as well as written information.<br><br>The committee discussed who would provide this information. They agreed that it should be provided | **Information and advice for people assessed as vulnerable to drug misuse.** |

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| | | when an assessment identifies somebody as being vulnerable to drug misuse.<br><br>The committee discussed which groups this should focus on, and agreed that it should be everybody that is identified through an assessment as vulnerable to drug misuse, as this will be a smaller population than everybody who is at risk of drug misuse.<br><br>The committee therefore agreed to prioritise providing information and advice to people assessed as vulnerable to drug misuse. | |
| Substance misuse services in appropriate community settings | No | The committee discussed comments at topic engagement on providing services, such as provision of information, in settings where people at risk of drug misuse may be, such as nightclubs or festivals.<br><br>The committee felt that given this area was based on consider recommendations it would be difficult to prioritise it as an area for quality improvement. The committee agreed that settings where information is provided could be covered within any draft statement developed on information and advice.<br><br>The committee therefore agreed not to prioritise this area. | **No action** |

| Additional areas suggested | Committee rationale | Area progressed (Y/N) |
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| **Screening at whole population levels** | The committee agreed that universal screening is outside the scope of the quality standard. | **N** |

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| **Research-based prevention programs** | The committee agreed that the role of quality standards is not to review research or evidence and therefore did not progress this area. | **N** |
| **Promoting mental health** | The committee agreed that while promoting mental health may be beneficial in preventing drug misuse, it is not within the scope of this quality standard and is not included in the source guidance. Promoting mental wellbeing is covered by other quality standards. | **N** |
| **Dual diagnosis of mental health problems and drug misuse** | The committee agreed that treating mental health problems as well as drug misuse is outside the scope of the quality standard. | **N** |
| **Competencies and training** | The committee agreed that training and competencies of staff are not addressed by quality standards as it is expected that everyone involved in health and care services should be appropriately trained to deliver services. | **N** |
| **Data sharing systems** | The committee agreed that promoting data sharing systems is not within the remit of quality standards. | **N** |
| **Open access/walk in accessible support / treatment services** | The committee agreed that this area is not within the source guidance for this quality standard and did not want to progress this area for further research. | **N** |
| **Drug misuse prevention in prisons** | The committee agreed that drug misuse in prisons is outside the scope of the quality standard and will be considered by quality standards on physical and mental health in prisons. | **N** |
| **Monitoring of attendance at referral appointments** | The committee agreed that this area focuses on the treatment of drug misuse, which is covered by the quality standard on treating drug misuse. | **N** |

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| **6.3. Resource impact** | The committee considered the resource impact assessment for the source guideline, which suggested that the costs of implementing the guideline would not be significant. The committee were satisfied that none of the areas prioritised for statement development would have a significant impact on resources. | |
| **6.4. Overarching outcomes** | The NICE team explained that the quality standard would describe overarching outcomes that could be improved by implementing a quality standard on drug misuse prevention. It was agreed that the committee would contribute suggestions as the quality standard was developed. | |
| **6.5 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. | |

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| **6.6. QSAC specialist committee members (part 1 – open session)** | The NICE team asked the QSAC to consider the constituency of specialist committee members on the group and whether any additional specialist members were required. The committee did not feel that any additional specialists are needed. | |
| **7. Any other business (part 1 – open session)** | The committee requested that an up-to-date list of all members of QSAC 2 should be sent round with the minutes.<br><br>MR thanked the attendees for their input and closed the meeting.<br><br>**Date of next meeting for drug misuse prevention: 9 January 2018**<br><br>**Date of next QSAC2 meeting: 12 October 2017** | |