

Quality standards advisory committee 1 meeting

Date: 1 November 2018

Location: NICE office, Level 1a City Tower, Piccadilly Plaza, Manchester, M1 4TD

Morning session: Child abuse and neglect – review of stakeholder feedback

Afternoon session: Serious eye disorders – review of stakeholder feedback

Minutes: Draft

Attendees

Quality standards advisory committee 1 standing members:

Tim Fielding (chair), Simon Baudouin, Gita Bhutani (vice-chair), Phillip Dick, Sunil Gupta, Teresa Middleton, Ian Reekie, Hazel Trender, Hugo Van Woerden, Jane Scattergood, Jane Dale, Liz Wrigley, Linda Parton, Umesh Chauhan, Nicola Hobbs (left 1pm)

Specialist committee members:

Morning session – Child abuse and neglect

John Altman

Mark Anslow

Gillian Finch

Maureen Giles

Danya Glaser

Corinne May-Chahal

Vimal Tiwari

Matthew Turner

Afternoon session – Serious eye disorders

Alexander Foss

Nick Wilson-Holt

Emily Lam

Mary-Ann Sherratt

John Sparrow

Rebecca Turner

NICE staff

Nick Baillie (NB), {1-15} Anna Wasielewska (AW), {5-8} Nicola Greenway (NG), {5-8} Rachel Gick (RG), {11-13} Julie Kennedy (JK), {11-13} Jamie Jason (JJ) Notes {1-15}

NICE observers

Leslie Hayes (pm session)

Apologies Bee Wee (chair), Anita Sharma, John Jolly

1. Welcome, introductions objectives of the meeting

The Chair welcomed the attendees and the quality standards advisory committee (QSAC) members introduced themselves. The Chair informed the committee of the apologies and outlined the objectives of the meeting, which was to review stakeholder comments on the child abuse and neglect quality

standard.

The Chair confirmed that there were no public observers joining the morning session of the committee meeting.

2. Confirmation of matter under discussion and declarations of interest

The Chair confirmed that, for the purpose of managing conflicts of interest, the matter under discussion in the morning session was the child abuse and neglect specifically:

- Alerting features
- Accurate records
- Communication
- Continuity
- Therapeutic interventions

The Chair asked standing committee members and specialist committee members to declare verbally any interests that have arisen since the last meeting and all interests specifically related to the matters under discussion during the morning session.

3. Minutes from the last meeting

The committee reviewed the minutes of the last QSAC1 meeting held on 5 July 2018. On page 5 NICE team to amend the paragraph 'It was also noted that GPs are not clear what the process is once a child is referred and they receive no feedback about what happens to that child.' The paragraph should say that some GPs may not be clear about the local processes and what happens after the referral.

4. QSAC updates

There were no updates from the NICE team.

5. Recap of prioritisation meeting and discussion of stakeholder feedback

AW provided a recap of the areas for quality improvement discussed at the first QSAC meeting for potential inclusion in the child abuse and neglect draft quality standard.

AW summarised the significant themes from stakeholders' comments received on the draft quality standard on child abuse and neglect and referred the committee to the full set of stakeholders' comments provided in the papers.

General note

NB told the committee that NICE would be meeting with Ofsted the following week to discuss their comments on draft quality standard and how this NICE

product fits in with the wider policy and strategy context.

The committee noted pre verbal children as a group that needs to be considered throughout the quality standard.

The committee discussed the implementation of quality standards in light of limited resources and capacity issues. It was noted that the core principles for quality standards are to be aspirational yet achievable. The committee agreed to discuss the document with those principles in mind.

5.1 Discussion and agreement of amendments required to quality standard

<p>Draft statement 1: Alerting features</p> <ul style="list-style-type: none"> • Children and young people who display marked changes in behaviour or emotional state are asked about anything that may be causing those changes in a private conversation. 	<p>The committee agreed that stakeholders supported a statement on identifying alerting features and that it should be progressed to the final quality standard.</p> <p>The committee agreed that following amendments and issues should be explored by the NICE team:</p> <p>Marked changes in behavior – the committee wished to clarify that the changes may include improved behaviour, not just bad behaviour; it should be clarified that a change in a child or young person is the relevant feature.</p> <p>The committee discussed why it had been decided to focus on marked changes in behaviour. The committee agreed that changes in a child or young person were a very specific and important opportunity to identify abuse or neglect and which was commonly missed. The committee acknowledged that there were many other important indicators in the guideline which should be mentioned in the quality standard if possible.</p> <p>The committee agreed that the emphasis of the statement was to identify children who were being abused but not recognized.</p> <p>The committee discussed stakeholders’ concerns with the term private conversation. Stakeholders suggested that children could find this intimidating and professionals may not be comfortable speaking to children in private.</p>
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	<p>The committee discussed who would be having this conversation and agreed that it could be teachers or nursery staff, someone who would notice a change in the child because they have had an existing relationship with the child.</p> <p>The committee also discussed whether “children are asked” used in the statement may seem coercive. The committee agreed that better term should be identified and suggested influence, sensitive enquiry, exploring the child’s understanding or asking about their lives.</p> <p>The committee agreed that the numerators and denominators needed some work. It was noted that being referred to social services was not a measure of quality.</p> <p>The committee also noted that having a conversation would exclude younger children and children with communication difficulties which should be recognized and addressed in the EIA.</p> <p>ACTION: NICE team to progress a statement with the suggested amendments.</p>
<p>Draft statement 2: Accurate records</p> <ul style="list-style-type: none"> • Children and young people talking to practitioners about abuse or neglect have their experiences recorded in their own words. 	<p>The committee agreed that stakeholders supported a statement on accurately recording children’s words and that it should be progressed to the final quality standard.</p> <p>The committee agreed that following amendments and issues should be explored by the NICE team:</p> <p>The committee discussed scenarios when some children and young people asked about abuse may deny it which may cause issues at a later date. However the committee agreed that the statement was about the child being heard rather than improving the legal system.</p> <p>The committee discussed that having to sign a document could cause distress. The importance of this statement was to capture the child’s words and give them the opportunity to reflect on what they had said if it was appropriate.</p>

	<p>The committee suggested re-ordering the statements so this was not coming straight after statement 1.</p> <p>The committee also suggested changing the statement heading to take the focus away from “records”. It was suggested the conversation could be recorded in quotation marks to capture the child’s words.</p> <p>Again the committee agreed that obtaining feedback from pre verbal children and children who cannot communicate due to disability should be recognized and addressed in the EIA.</p> <p>ACTION: NICE team to progress a statement with the suggested amendments.</p>
<p>Draft statement 3: Communication</p> <ul style="list-style-type: none"> • Children and young people talking to practitioners about abuse or neglect agree with them how they will communicate with each other. 	<p>The committee agreed that stakeholders supported a statement on communication and that it should be progressed to the final quality standard.</p> <p>The committee agreed that following amendments and issues should be explored by the NICE team:</p> <p>The committee discussed the need to involve parents or carers where children are too young to talk if it is appropriate but also acknowledged that the focus of the statement was specifically aimed at children and young people who were able to communicate with practitioners.</p> <p>The committee agreed that this should be highlighted as a two way communication; the practitioners should know how to contact children and young people (preferences and safety) but also for the children to be able to get in touch with the practitioner when they need/want to. This arrangement was perceived as giving children and young people control of the communication.</p> <p>The committee agreed that the measures should be more descriptive.</p> <p>ACTION: NICE team to progress a statement with the suggested amendments.</p>

<p>Draft statement 4: Continuity</p> <ul style="list-style-type: none"> Children and young people who have experienced abuse or neglect receive support from a consistent group of practitioners 	<p>The committee agreed that stakeholders supported a statement on continuity and that it should be progressed to the final quality standard.</p> <p>The committee supported stakeholders' comments and agreed that this a very important statement.</p> <p>The committee noted that the statement may appear to be too focused on social workers and asked the NICE team to explore the wording to ensure all people involved in supporting children and young people are included.</p> <p>The committee wanted to clarify that this statement was focused on continuity within the various professions/services that children and young people had regular contact with rather than a concept of a keyworker or lead professional.</p> <p>ACTION: NICE team to progress a statement with the suggested amendments.</p>
<p>Draft statement 5: Therapeutic interventions</p> <ul style="list-style-type: none"> Children and young people who have experienced abuse or neglect are offered a choice of therapeutic interventions based on a detailed assessment. 	<p>The committee agreed that stakeholders supported a statement on therapeutic interventions and that it should be progressed to the final quality standard.</p> <p>The committee agreed that following amendments and issues should be explored by the NICE team:</p> <p>The committee discussed the issue of choice highlighted by stakeholders. The committee noted there was a lack of choice of interventions in the system and that the quality statement has a potential to drive improvement in commissioning. They agreed that the choice should be interpreted as an opportunity for joint decision making rather than choice of interventions. The emphasis was on child's choice to accept the offered intervention.</p> <p>The committee also agreed that the statement should specifically say that it's assessment of therapeutic need rather than a generic assessment.</p> <p>The committee also discussed the outcome and what</p>

	<p>happens after assessment.</p> <p>ACTION: NICE team to progress a statement with the suggested amendments and revisit the wording.</p>
<p>5.2 Additional quality improvement areas suggested by stakeholders at consultation</p>	
<p>No additional areas.</p>	
<p>6. Resource impact and overarching outcomes</p>	
<p>The committee considered the resource impact of the quality standard.</p> <p>The committee noted the support plans for investment around children’s mental health.</p> <p>The committee confirmed the overarching outcomes are those presented in the draft quality standard.</p> <ul style="list-style-type: none"> • Incidence of abuse and neglect. • Children and young people’s health and wellbeing. • Experience and views of children, young people and their families. • Service outcomes, including: <ul style="list-style-type: none"> – appropriate referrals to health and social care – timely and appropriate referral to additional support services – reducing repeated referrals. <p>The committee would like to remove incidence.</p> <p>The committee would like to include recognition and management of abuse and neglect.</p>	
<p>7. Equality and diversity</p>	
<p>The committee agreed the following groups should be included in the equality and diversity considerations:</p> <ul style="list-style-type: none"> • Age • Gender reassignment • Pregnancy and maternity • Religion or belief • Marriage and civil partnership • Disability • Sex 	

- Race
- Sexual orientation

It was agreed that the committee would continue to contribute suggestions as the quality standard was developed.

The committee noted:

- Pre verbal children
- Children with disabilities and communication issues
- Transient groups
- Homeless children

8. Close of morning session

The specialist committee members for the child abuse and neglect quality standard left and the specialist committee members for the serious eye disorders quality standard joined.

9. Welcome, introductions and objectives of the afternoon

The Chair welcomed the serious eye disorders specialist committee members and QSAC members introduced themselves. The Chair informed the committee of the apologies and outlined the objectives of the afternoon, which was to review stakeholder comments on the serious eye disorders quality standard.

The Chair confirmed that there were no public observers joining the morning session of the committee meeting.

10. Confirmation of matter under discussion and declarations of interest

The Chair confirmed that, for the purpose of managing conflicts of interest, the matter under discussion in the afternoon session was serious eye disorders specifically:

- Referral for cataract surgery
- Referral – chronic open angle glaucoma and related conditions
- Treatment - late AMD (wet active)
- Monitoring of late AMD (wet active)
- Reassessment – chronic open angle glaucoma and related conditions
- Supporting adults with visual impairment

The Chair asked both standing and specialist members to declare verbally all interests specifically related to the matters under discussion during the afternoon session.

11.1 Recap of prioritisation meeting and discussion of stakeholder feedback

RG provided a recap of the areas for quality improvement prioritised at the first QSAC meeting for potential inclusion in the serious eye disorders draft quality standard.

RG summarised the significant themes from the stakeholder comments received on the serious eye disorders draft quality standard and referred the committee to the full set of stakeholder comments provided in the papers.

11.2 Discussion and agreement of amendments required to quality standard

Draft statement 1: Referral for cataract surgery

- Adults with cataracts are not refused surgery based on visual acuity alone.

The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard, with the following amendments and issues to be explored by the NICE team:

The committee discussed the wording of this statement and discussed whether it could be worded in a more positive way.

It was suggested that the statement could refer to adults with symptoms of cataract. However, the committee expressed concern that this may lead to commissioners using different criteria to restrict access to surgery. The committee agreed to keep the current form of wording. It was decided that reference to symptomatic, clinically operable cataracts would be added in the supporting information to counteract the statement's negative phrasing.

The committee supported the suggestion that 'first and second eye' is referred to for clarity.

It was suggested that measures relating to quality of life are added so that services can refer to the impact on quality of life when discussing access to cataract surgery with commissioners. It was highlighted that a quality of life measure is being piloted for the National Ophthalmology Database Cataract Audit.

ACTION: NICE team to progress amending the

	<p>supporting information for the statement.</p> <p>ACTION: NICE team to review existing process measures and consider adding measures relating to quality life.</p>
<p>Draft statement 2: Referral – chronic open angle glaucoma and related conditions</p> <ul style="list-style-type: none"> Adults have case-finding tests in primary care before referral for further investigation and diagnosis of chronic open angle glaucoma (COAG) and related conditions. 	<p>The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard, with the following amendments and issues to be explored by the NICE team:</p> <p>The committee noted that community optometrists, not GPs, perform these case-finding/referral filtering tests.</p> <p>The committee discussed that the term case-finding, to optometrists, means services that are not included in the routine sight test, as defined in the General Ophthalmic Services contract. It was also felt that ‘case-finding’ was felt to have a different meaning, which may cause confusion regarding the focus of the statement.</p> <p>The aim of the statement is to target inappropriate referrals into hospital eye services if raised eye pressure is detected. The additional tests referenced in the statement are carried out as part of ‘referral refinement’. They are supported by complex commissioning arrangements in England.</p> <p>The committee confirmed the supporting information should refer to ‘optometrists’ – no additional detail is needed.</p> <p>The committee confirmed they are happy with the measures.</p> <p>Reference to anxiety should be removed from the rationale and audience descriptors as the committee felt that the emphasis should be on avoiding unnecessary tests.</p> <p>ACTION: NICE team to progress this statement, with amended wording.</p>

<p>Draft statement 3: Treatment – late age-related macular degeneration (wet active)</p> <ul style="list-style-type: none"> Adults with late age-related macular degeneration (AMD) (wet active) start treatment within 14 days of referral to the macular service. 	<p>The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard.</p> <p>Concerns were raised about the resource impact required to achieve the timescale. The committee heard that this was investigated during development of the source guideline and was considered to be achievable.</p> <p>The committee discussed there are plans to extend the National Ophthalmology Database audit to include AMD. Data, including those for outcomes, is collected electronically and aligns with NHS Digital policies. The statement would support these developments.</p> <p>Referring to obtaining consent to treatment is beyond of the scope the statement and the suggestion was not progressed.</p> <p>ACTION: NICE team to progress this statement.</p>
<p>Draft statement 4: Monitoring late age-related macular degeneration (wet active)</p> <ul style="list-style-type: none"> Adults with late age-related macular degeneration (AMD) (wet active) have ongoing monitoring for both eyes. 	<p>The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard, with the following amendments and issues to be explored by the NICE team:</p> <p>The committee discussed the aim of this standard was to support timely monitoring appointments. This has been a long-standing issue, and there is strong support for this statement.</p> <p>Stakeholder suggestions to make reference to clinically appropriate intervals more prominent and to define timescales were discussed.</p> <p>The NICE team noted that using the word appropriate in the statement does not aid measurement, but that reference to having appointments at intervals identified by clinicians could be included in the rationale.</p> <p>The committee noted there is a relevant process</p>

	<p>measure from the National Elective Care Transformation (NECT) Programme. The committee heard that NHS Digital has introduced this data field for some conditions.</p> <p>The committee agreed to add an outcome measure from the NECT Programme.</p> <p>The committee discussed the suggestion that OCT could be used for monitoring, and that it was becoming more widespread in optical practices. It was also suggested that text referring to the role of allied health professionals delivering this care should be added to the supporting information. This would reflect the current direction of travel in this area of care.</p> <p>ACTION: NICE team to amend the rationale.</p> <p>ACTION: NICE team to investigate referencing the role of allied health professionals in delivering OCT monitoring.</p> <p>ACTION: NICE team to review the measures.</p>
<p>Draft statement 5: Reassessment – chronic open angle glaucoma and related conditions</p> <ul style="list-style-type: none"> Adults with chronic open angle glaucoma (COAG) and related conditions have reassessment at specific intervals. 	<p>The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard, with the following amendments and issues to be explored by the NICE team:</p> <p>The suggestion to include reference to risk progression in the statement was discussed. It was suggested that the relevant information from the source guideline is highlighted in the quality standard’s supporting information.</p> <p>ACTION: NICE team to add information about risk progression from the source guideline.</p>
<p>Draft statement 6: Supporting adults with visual impairment</p> <ul style="list-style-type: none"> Adults with 	<p>The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard, with the following amendments and issues to be explored by the NICE team:</p>

<p>AMD or COAG are given a certificate of vision impairment (CVI) as soon as they are eligible.</p>	<p>The committee discussed the statement. It was questioned why the statement concerned only 2 serious eye disorders. The NICE team said that this is because the underpinning recommendations are from the NICE guidelines for AMD and glaucoma.</p> <p>It was suggested that the statement’s wording is changed to ‘Adults with serious eye disorders’. The conditions would be defined as AMD and COAG in the supporting information.</p> <p>It was noted the ophthalmologist has to sign the certificate, but that typically, other health professionals identify adults who are eligible for a CVI (optometrists, ECLOs).</p> <p>It was highlighted to the committee that registration is a voluntary process, which involves choice and shared decision-making. It was agreed that reference to these factors should be included, but the word ‘given’ should remain in the statement, to aid measurability. It was also explained, by the NICE team, that allowance is made for people who decline the CVI (as applies to other interventions), and that thresholds for measures aren’t specified.</p> <p>ACTION: NICE team to amend the statement wording and define the conditions in the supporting information.</p> <p>ACTION: NICE team to review the supporting information to emphasise the role of choice and shared decision-making.</p>
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11.3 Additional quality improvement areas suggested by stakeholders at consultation

The following area was not progressed for inclusion in the final quality standard as the committee agreed that it was out of the scope of this quality standard:

- 1. Other serious eye disorders:** these are not covered by the source guidelines that are in the scope of this quality standard.
- 2. Improving data collection for wet AMD:** this area was not progressed as it is beyond the scope of a quality standard. Progressing statement 3

will however highlight the importance of ongoing work in this area.

3. **Implementation of the Accessible Information Standard:** the committee felt this was an equalities issue, and is a cross-cutting area so a statement on it was not progressed.
4. **Access to minimally invasive glaucoma surgery (MIGS):** this area was not progressed because the source guidance does not support a statement on this.
5. **Provision of ECLOs:** it was agreed that the supporting recommendation in NICE's guideline on [glaucoma](#) does not support uniform provision of this service.

The committee suggested that the quality standard should refer to diabetic retinopathy. It was agreed that the NICE team will link to relevant information about this. This may include information about the screening programme.

ACTION: NICE team to investigate linking to information relating to diabetic retinopathy within the standard.

12. Resource impact and overarching outcomes

The committee considered the resource impact of the quality standard. There were no additional comments in this part of the meeting.

The committee confirmed the overarching outcomes are those presented in the draft quality standard.

- Avoidable sight loss.
- Health-related quality of life.
- Patient safety incidents reported.
- Social isolation.

13. Equality and diversity

The committee agreed the following groups should be included in the equality and diversity considerations:

- Age
- Gender reassignment
- Pregnancy and maternity
- Religion or belief
- Marriage and civil partnership
- Disability
- Sex
- Race
- Sexual orientation

It was agreed that the committee would continue to contribute suggestions as the quality standard was developed.

Also noted:

- Prisoners
- Learning disabilities
- It was agreed that the quality standard would support older people; the eye conditions covered by the standard are particularly prevalent among older people.

14. Any other business

None.

15. Close of meeting