**Quality standards advisory committee 1 meeting**

**Date:** 5 July 2018

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

**Morning session:** Child abuse and neglect – prioritisation of quality improvement areas

**Afternoon session:** Serious eye disorders – prioritisation of quality improvement areas

**Minutes:** Draft

**Attendees**

**Quality standards advisory committee 1 standing members:**

Tim Fielding (Chair), Simon Baudouin, Gita Bhutani (vice-chair), Sunil Gupta, John Jolly, Ian Reekie, Anita Sharma, Hugo Van Woerden, Linda Parton, Liz Wigley

**Specialist committee members:**

**Morning session**: Child abuse and neglect
John Altman
Mark Anslow
Gillian Finch
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) {1-16}, Anna Wasielewska (AW) {5-9}, Alison Tariq (AT) {5-9}, Rachel Gick (RG) {12-16}, Julie Kennedy (JK) {12-16}, Jamie Jason (notes)

**NICE observers**
Leslie Hayes, Erin Whittingham

**Apologies** Bee Wee (chair), Phillip Dick, Rhian Last, Tessa Lewis, Teresa Middleton, Hazel Trender, Alyson Whitmarsh, Jane Scattergood, Nicola Hobbs, Maureen Giles (child abuse and neglect)

| **1. Welcome, introductions, objectives of the meeting** |
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| 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 prioritise areas for quality improvement for the child abuse and neglect quality standard.<br><br>The Chair confirmed there were no public observers attending the meeting. |
| **2. Confirmation of matter under discussion and declarations of interest** |
| The Chair outlined that, for the purpose of managing conflicts of interest, the matter under discussion in the morning session was child abuse and neglect, specifically:<br><br>• Working with families<br>• Recognition<br>• Assessment<br>• Response<br>• Ways of working<br><br>The Chair asked standing QSAC members and specialist members to declare verbally any interests that had 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 QSAC1 meeting held on 7 June 2018 and confirmed them as an accurate record.

**4. QSAC updates**

There were no updates from the NICE team.

**5. Prioritisation of quality improvement areas – committee decisions**

AW provided a summary of responses received during the child abuse and neglect topic engagement, referred the committee to the full set of stakeholder and specialist committee members' comments provided in the papers and the committee then discussed each of the areas in turn **(in bold text below)**.

Corinne May-Chahal (CM-C) provided a brief summary of the wider context for the NICE guidance NG76. It was outlined that:

- Statutory guidance on responsibilities of different agencies exists
- Working together to safeguard children outlines responsibilities of different agencies but does not address the quality of the response – this is where NG76 compliments the statutory guideline and adds value to it
- Current financial constraints and capacity within the system make implementing good practice more challenging.

CM-C also clarified the different interpretations of Early help and stressed the importance of preventing further harm.

The committee was asked by GF to consider language used in reference to this topic - using words such as 'Story' should be avoided as it implies fiction/something that is not a true reflection.

**Working with families – Prioritised**

- Communicating with children and young people
- Involving children and young people
- Communicating with parents and carers
- Involving parents and carers

The committee discussed the importance of communicating with children and young people who may be at risk of abuse. Stakeholders were keen to look at recording the voice of children and communicating with them in a safe and effective way and this was discussed.

The committee discussed the importance of capturing the child's voice in their own words. It was felt that accurate recording of children's words and asking them to approve the record of the conversation would drive improvement in children's experiences and build trust. There were concerns about it becoming a tick box exercise as well as children changing their testimonies over time but the committee thought it was important to highlight it as a priority.

The committee also discussed the importance of communicating with children and young people in a safe and effective way. It was agreed that they should agree with the practitioners the ways and forms of communication that is most suitable.

The committee also discussed children who are not brought to appointments as a group that may be at risk of abuse and neglect. Not engaging with services to be considered as one of the risk factors. However, they decided it cannot be used as a definitive sign as some families may struggle to get to appointments due to transport issues, and not being able to get to appointments is not necessarily neglect and some parents could be wrongfully stigmatised due to this. It was noted that wording used for monitoring non-attendances should change from children not attending appointments to children not being brought to appointments.

The committee noted the population for this area may need to be defined further.

The committee agreed that communicating with children and young people is an area for quality improvement.

**ACTION: NICE team to draft two statements based on recommendations 1.1.6 and 1.1.9.**

**Recognition – Prioritised**

- Identifying those at risk

The committee discussed recognising child abuse and neglect alongside assessment and agreed that this is a priority area.

**Assessment – Prioritised (with recognition)**

- Suspected injuries
- Assessing the risk
- Assessing needs

The committee agreed not to prioritise suspected injuries due to lack of available current practice data and guideline recommendations.

The committee discussed the Common Assessment Framework (CAF) as a tool to identify the risks and needs of families. CAF is not mentioned in the guideline but the elements of the assessment are included in some of the recommendations.

The committee discussed the issue of children often not being able or not wanting to speak up and tell others about the abuse and neglect. The committee also discussed abuse and neglect being recognised but then cases being closed or not followed up further.

The committee agreed to focus on alerting features that would lead to an assessment and agreed that children showing marked change in behaviour should be asked further questions and have an initial assessment.

The committee discussed issues with quality of the assessments, lack of effective observations, face to face contact and considering the holistic home/family environment.

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 committee suggested auditing re-referrals to social care to identify how cases are being missed and not dealt with effectively. It was agreed this could be explored as an outcome measure.

The committee agreed that recognising marked change in behaviour which would lead to an assessment should be progressed as a priority area for quality improvement.

**ACTION: NICE team to progress a statement based on recommendations 1.3.12 and 1.3.16.**

**Response – Prioritised**

- Providing support
- Therapeutic interventions

The committee discussed the importance of the response to identified abuse and neglect. Providing suitable interventions was seen as an area which would have the biggest impact on children and young people.

The committee discussed care plans as facilitators of improvements in this area but agreed that a plan does not guarantee the intervention will happen. The committee agreed to focus on ensuring the right interventions are offered and provided.

The committee discussed overlaps with children's attachment and the recommendation from NG26 which covers evaluating the interventions provided. It was noted there is already a quality standard on children's attachment.

The committee agreed that providing suitable therapeutic interventions was an area for quality improvement.

**ACTION: NICE team to progress a statement based on recommendations 1.7.1 and 1.7.3.**

**Ways of working - Prioritised**

- Multi agency working
- Continuity of care

The committee discussed multi agency working and agreed that it was a broad themes which should run through the quality standard rather than be a specific statement. It was discussed that there may not be a recommendation that can help drive improvement of multi-agency working and that it is already covered within legislation.

The committee discussed the importance of continuity of care. The committee agreed that it is very important for children and young people to be supported by a person they can trust. Having multiple and changing people involved in their case can have a detrimental effect and lead to distrust.

The committee discussed that children and young people and their families are usually supported by different agencies so the consistency applies to practitioners who are from those agencies rather than 1 practitioner. Also, the committee agreed that if the practitioners working with children and young people are consistent, it will facilitate better multiagency working.

The committee agreed that continuity of care is an area for quality improvement.

**ACTION: NICE team to progress a statement based on recommendation 1.6.1 and 1.8.1.**

**6. Additional quality improvement areas suggested by stakeholders at topic engagement**

The following areas were not progressed for inclusion in the draft quality standard.

- Maternal mental health
- Mandatory reporting
- Prevention
- Relationships and Sex Education in schools
- Skills, knowledge, training and supervision

The committee members discussed if training could be included as an area for quality improvement. NICE team advised that quality statements focus on actions that demonstrate high quality care or support, not the training to enable these actions.

The committee noted that there had been some inconsistency in the information given about training focused recommendations between the guidelines and the quality standard teams.

**7. Resource impact and overarching outcomes**

The committee considered the resource impact of the quality standard.

The committee noted overarching outcomes:

- Incidence of abuse and neglect
- Duration and impact of abuse and neglect
- Children and young people's health and wellbeing
- Experience of children, young people and their families
- Service outcomes, including:
    - appropriate referrals to health and social care
    - effective multiagency work and established information sharing arrangements
    - appropriate referrals to additional support services

AW requested that the committee submit suggestions to the NICE team relating to the overarching outcomes of the quality standard when it is sent to them for review.

**8. 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

The committee also noted homelessness & temporary accommodation as areas for consideration.

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

**9. 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.**

**10. 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 prioritise areas for quality improvement for the serious eye disorders draft quality standard.

The Chair welcomed the public observers and reminded them of the code of conduct that they were required to follow.

**11. 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:

- Preventing sight loss
- Referral
- Treatment
- Follow up/reassessment
- Support for people with eye disorders

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

**12. Prioritisation of quality improvement areas – committee decisions**

RG provided a summary of responses received during the serious eye disorders topic engagement, referred the committee to the full set of stakeholder comments provided in the papers and the committee then discussed each of the areas in turn. The committee discussed the comments received from stakeholders and specialist committee members at topic engagement **(in bold text below)**.

**Prevention of sight loss – Not prioritised**

- Preventing sight loss

The committee discussed preventing sight loss. It was noted that there is an existing quality standard on smoking cessation. There are no recommendations supporting preventing sight loss in the general population.

The committee agreed not to prioritise this as an area of quality improvement, and instead focus access to treatment and follow-up in relation to relevant eye conditions.

**Referral**

- Referral for cataract surgery – Prioritised
- Glaucoma case-finding – Prioritised
- ECLO referral – Not prioritised
- Urgent referral for suspected late AMD (wet active) – Not prioritised

The committee discussed criteria for referral for cataract surgery and rapid access for wet AMD.

The committee discussed prioritising referral to an Eye Clinic Liaison Officer (ECLO). Although provision varies, it was agreed that the supporting recommendation in the guideline (NG81) does not support uniform provision of this service.

The committee discussed whether there should be 3 statements as the conditions have different referral mechanisms (e.g. for cataracts, direct referral to hospital eye services, or via a GP).

The committee agreed that restricting referrals for cataracts on the basis of visual acuity is an area for quality improvement. The statement will need to focus on criteria other than visual acuity, such as self-reported vision loss, for which measures/tools are available.

The committee agreed that undertaking tests before referral for further investigation and diagnosis of glaucoma and associated conditions is an area for quality improvement. Finding hard-to-reach cases was raised as an issue but this area cannot be progressed by a statement; it will however be highlighted as an equalities issue.

The committee discussed the definition of urgent referral for wet AMD. This varies depending on what is found upon examination. The committee also discussed delays in getting diagnosed can result in vision loss. Delays are associated with the referral being acted upon rather than the referral itself. Some hospitals do not have a fast-track system to get people into an eye clinic at a specified time. The committee agreed to discuss referral for treatment for AMD under' Treatment' (below).

**ACTION: NICE team to progress two statements about referral, for (1) cataracts and (2) glaucoma. These will be based on NG77 recommendations 1.2.1, 1.2.2 and NG81 recommendation 1.1.1**

**Treatment**

- Before cataract surgery – Not prioritised
- Treatment of glaucoma and AMD – Prioritised

The committee discussed using checklists for cataracts. It was agreed they are already widely used.

The committee discussed wrong lens implants. This was not seen as a high priority because it happens in a very small proportion of cases, and typically has minimal impact when it does.

The committee discussed starting treatment for wet AMD within 14 days. The committee agreed that this is a high priority and could deliver benefits for people with wet AMD.

The committee discussed the importance of discussions of the risks and benefits of treatment. This relates to achieving shared understanding, not merely providing a leaflet. It was agreed however that this area relates to all topics, so would not be a priority for this one. It is also covered by the patient experience (2016) NICE quality standard.

The committee also discussed focusing on older people with multi-morbidity, but this area applies to many

conditions. Vision however has a considerable impact on quality of life. There was discussion of whether people who have cataract surgery experience regret that they had not discussed the risks and benefits prior to surgery. It was however noted that a figure for quality of life-gain following cataract surgery was not identified.

The committee agreed that treatment of late AMD (wet active) within 14 days is an area for quality improvement.

**ACTION: NICE team to progress a statement based on NG82 recommendation 1.4.10.**

**Follow-up / reassessment**

- Post-operative care after cataract surgery – Not prioritised
- Follow-up: glaucoma and AMD – Prioritised

The committee discussed follow-up appointments are a high priority especially when there is risk of sight loss when delays occur. It was noted that patients are 8 times more likely to lose vision if the follow-up appointment is delayed. This does not apply to cataracts.

The committee agreed that follow-up appointments being held on time is specific to both glaucoma and AMD, and is an area for quality improvement.

**ACTION: NICE team to progress a combined statement based on NG81 recommendations 1.4.9, 1.4.10 and NG82 recommendation 1.7.8.**

**Support for people with eye disorders**

- Signposting to other sources of support – Not prioritised
- Certificate of Vision Impairment (CVI) - Prioritised

The committee agreed that Certificate of Vision Impairment (CVI) was an important area and enables signposting to and for other services.

The committee discussed whether this statement could apply to all 3 conditions.

The committee agreed that offering CVI registration when eligible is an area for quality improvement.

**ACTION: NICE team to progress a statement based on NG82 recommendation 1.6.4 and investigate whether there are any potentially relevant recommendations in NG81 and NG77.**

**13. Additional quality improvement areas suggested by stakeholders at consultation**

The following areas were not progressed for inclusion in the draft quality standard.

- Audits and registries – data collection is beyond the scope of quality standards. However, methods of data collection may be referred to in the data sources for quality measures.
- Choroidal naevi – no recommendations in the source guidance.
- Concomitant surgical management of primary open angle glaucoma with cataract surgery – no recommendations in the source guidance.
- Delivering services in different ways (AMD) – no recommendations in the source guidance.
- Diabetic macular oedema and diabetic retinopathy – not in the source guidance. Also, there is a national Diabetic Eye Screening programme; screening is outside the scope of NICE guidance.
- Dry eye meibomian gland dysfunction - no recommendations in the source guidance.
- Idiopathic intracranial tension (concerning visual field loss) - no recommendations in the source guidance (NG81).
- Minimally invasive glaucoma surgery (MIGS)/microsurgery - no recommendations in the source guidance (NG81).
- Multifactorial falls risk assessment – covered by Falls in older people (2017), NICE quality standard
- Orthoptic aspects of stroke management - Specific conditions with associated vision problems should be addressed by the quality standard for the condition. The impact of vision problems are

not prioritised in the Stroke in adults (2016) NICE quality standard.
- Pathways across health and social care – Quality statements focus on actions that demonstrate high quality care or support, not the pathways that enable the actions to take place. However, having agreed pathways will be referred to in the measures and audience descriptors where relevant.
- Patient Activation Measures (PAMs) - no recommendations in the source guidance.
- Patient Reported Outcome Measures (PROMS) - no recommendations in the source guidance.
- Regulatory matters – this area is beyond NICE's remit.
- Retinal vein occlusion – no recommendations in the source guidance.
- Retinitis pigmentosa - no recommendations in the source guidance.
- Temporal arteritis - no recommendations in the source guidance.
- Thyroid eye disease – no recommendations in the source guidance.
- Training - Quality statements focus on actions that demonstrate high quality care or support, not the training that enables the actions to take place.
- Use of IT to support care / service delivery - Stakeholders highlighted that the transfer of information between community and hospital eye services can avoid unnecessary duplication of tests. Stakeholders also suggested that investment in an electronic patient record system (but not one confined to transferring digital images) would enable people to access the appropriate point of care through availability of information relating to the health of their eyes. This area was not progressed.
- Uveitis - no recommendations in the source guidance.

**14. Resource impact and overarching outcomes**

The committee considered the resource impact of the quality standard in relation to the following areas:

**Referral (cataract surgery):** Resource impact was deemed acceptable during development of the cataracts guideline and it was felt that improvement in this area could ultimately be cost-effective.

**Treatment (wet AMD)**: There may be a resource impact for some services, but giving treatment in a timely manner would save costs associated with people experiencing vision loss/blindness.

**Follow-up / re-assessment (glaucoma/AMD):** Managing vision loss and blindness, which can result from delayed appointments, has significant costs and as such, has resource impact implications.

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

- Preventable sight loss
- Health-related quality of life for people with long-term conditions
- Proportion of people feeling supported to manage their condition
- Social isolation
- Health-related quality of life for older people
- Preventable sight loss – sight loss certifications.

RG requested that the committee submit suggestions to the NICE team relating to the overarching outcomes of the quality standard when it is sent to them for review.

**15. 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

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| • Sexual orientation<br><br>It was agreed that the committee would continue to contribute suggestions as the quality standard was developed.<br><br>The committee suggested very old people and people with dementia and memory loss.<br><br>Finding hard-to-reach cases in relation to glaucoma (referral statement) was identified as an equalities issue. |
| **16. Any other business** |
| NB informed the standing members that there would be no QSAC on 6 September as planned as there are delays in the topics. |
| **Close of meeting** |