

**Quality standards advisory committee 2 meeting**

**Date:** 14 December 2017

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

**Morning session:** Endometriosis –  
prioritisation of quality improvement areas

**Minutes:** Final

**Attendees**

**Quality standards advisory committee 2 standing members:**

Michael Rudolf (chair), Moyra Amess, Gillian Baird (vice-chair), Guy Bradley-Smith, Michael Fairbairn, Jean Gaffin, Malcolm Griffiths, Corinne Moccarme, Robyn Noonan, Jane Putsey, Michael Varrow, David Weaver, Arnold Zermansky.

**Specialist committee members:**

**Morning session – Endometriosis:**

Lynda Harrison  
Geeta Kumar  
Deb Panes  
Anita Sharma  
Amy Wilbraham

**NICE staff**

Nicola Cunliffe (NC), Mark Minchin (MM), Shaun Rowark (SR), Eileen Taylor (ET)

**NICE observers**

Olivia Crane and Rachel Gick

**Apologies**

Jane Bradshaw, Julie Clatworthy, James Crick, Allison Duggal, Steven Hajioff, Mathew Sewell, Ruth Studley.

**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 prioritise areas for quality improvement for the endometriosis quality standard

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

**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 endometriosis quality standard: specifically, symptoms and diagnosis; management; organisation of care; information and support.

The Chair asked standing QSAC 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. The Chair asked the specialist committee members to verbally declare all interests. Interests declared are detailed in appendix 1.

**3. Minutes from the last meeting**

The committee reviewed the minutes of the last QSAC1 meeting held on 12 October 2017. It was highlighted that the minutes for developmental follow-up of babies and young people born pre-term should be clear that the two assessments in the first year should focus on developmental assessment. Other than this amendment the minutes were confirmed as an accurate record.

#### 4. QSAC updates

There were no updates from the NICE team.

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

ET provided a summary of responses received during the endometriosis 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**).

The following areas were prioritised for inclusion in the draft quality standard.

##### Symptoms and diagnosis

- **Recognition of symptoms and prompt diagnosis** – prioritised.
- The committee agreed this is a key area for quality improvement and heard it can take up to 7 ½ years for endometriosis, which is a common disease, to be diagnosed.
- The committee progressed a statement on women who present with suspected endometriosis being offered an abdominal and pelvic examination based on endometriosis: diagnosis and management (NG73) recommendation 1.3.3. The effects of this not happening can have an impact on the time taken to diagnose.
- The committee agreed to ask a question at consultation about whether this will make a significant difference in the diagnosis of endometriosis.

##### Management

- **Pain management. hormonal treatments** - prioritised
- The committee prioritised a statement on women who do not respond to hormonal treatment being offered a referral to secondary care based on NG73 recommendation 1.8.7.
- As the guideline does not have a timeline it was agreed that at consultation NICE would ask stakeholders if this should be 3 months from starting treatment or 6 months from starting treatment.
- **Laparoscopy** – prioritised
- The committee heard that not all gynaecologists in general endometriosis services have undertaken specialist training or have enough experience in identifying endometriosis.
- The committee prioritised a statement on general gynaecological services having access to a multi-disciplinary team who have a special interest in endometriosis based on NG73 recommendation 1.1.3.

##### Organisation of care

- **Treatment pathways & coordinated care and access to services** – prioritised
- The committee agreed that it is important that women with suspected or confirmed deep endometriosis are referred to a specialist services and have access to a specialist MDT. A statement was prioritised based on NG73 recommendation 1.4.2.
- The committee noted that setting up a clinical network with a focus on community services would be beneficial in raising awareness, particularly in younger women. A statement was prioritised based on NG73 recommendation 1.1.1.

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

##### Recognition of symptoms and diagnosis

- **Specialist diagnosis** – not prioritised.
- The committee focussed on general practice as the best way to improve initial identification and, as detailed above, a statement was prioritised on abdominal and pelvic examination. Other recommendations on recognition were 'consider' recommendations and therefore could not be used to underpin a quality statement.

##### Management

- **Fertility care** – not prioritised.
- The committee agreed this issue is sufficiently covered by the NICE quality standard on fertility

<p>problems (QS73).</p> <p><b>Information and support</b></p> <ul style="list-style-type: none"> <li>• <b>Support service role, psycho-social support, culturally sensitive information and support and education and literature for people with endometriosis</b> – not prioritised.</li> <li>• The committee agreed that although these were important areas most of these issues are covered in the NICE quality standard on patient experience in the NHS (QS15).</li> <li>• The committee did highlight that an important issue is younger people and teenagers being managed by adult services, this will be highlighted in equality and diversity considerations.</li> </ul>
<p><b>6. Additional quality improvement areas suggested by stakeholders at topic engagement</b></p>
<p>The following areas were not progressed for inclusion in the draft quality standard because:</p> <ul style="list-style-type: none"> <li>• <b>Equalities</b> – are considered in separate document and a consideration for each statement.</li> <li>• <b>Awareness in the population</b> – is not the purpose of quality standards.</li> <li>• <b>Psycho-social impact research and new guidance</b> - are not within the remit of quality standards.</li> </ul>
<p><b>7. Resource impact and overarching outcomes</b></p>
<p>The committee considered the resource impact of the quality standard.</p> <p>The committee confirmed the overarching outcomes are those presented in the draft quality standard. The committee suggested time away from school or work be added.</p> <p>ET requested that the committee submit additional suggestions to the NICE team relating to the overarching outcomes of the quality standard when it is sent to them for review.</p>
<p><b>8. Equality and diversity</b></p>
<p>ET provided an outline of the equality and diversity considerations included so far and requested that the committee submit suggestions when the quality standard is sent to them for review.</p>
<p><b>9. Any other business</b></p> <p>QSAC 2018 dates to be sent to committee. NICE team are trialling a new way of compiling minutes, members can feedback next month.</p>

**Appendix 1: Declarations of interest**

**Table 1: Morning session**

Name	Membership	Declaration
Lynda Harrison	SCM	<p>I am a member of Endometriosis UK.            I am a member of the Northern Ireland Endometriosis Support group.            I act as a patient representative for the Patient Client Council representing patients with Endometriosis.            I was a lay member on the NICE endometriosis Guideline.            I was a lay member on the NICE patient decision making aid for endometriosis.</p>
Deb Panes	SCM	<p>Lead Research Nurse for University Hospitals Bristol undertaking the Abbvie Solstice Endometriosis Clinical Drug Trail. 2013 – present            Lead Research Nurse for University Hospitals Bristol for the SPIRIT 2 Endometriosis Clinical Drug Trial 2017 – present</p>
Geeta Kumar	SCM	<ul style="list-style-type: none"> <li>• Appointed lead for NGA’s guidelines on ectopic pregnancy as part of revision of multiple obstetrics guidelines: Nov 2017</li> <li>• Nov 2017: Appointed Deputy Hospital Medical Director for Quality and Safety at Wrexham Maelor hospital, BCUHB, North Wales</li> <li>• NICE Fellow: 2017 -2020</li> <li>• Chair of RCOG’s Patient information committee since May 2016</li> <li>• Lead reviewer on behalf of RCOG’s Guideline committee for RCOG’s Green top guidelines on Ectopic pregnancy published: 2017</li> <li>• 2017: Member of BCUHB NICE liaison committee and All Wales NICE liaison group</li> <li>• 2017: Editorial board member of “Ultrasound” Journal of British medical ultrasound society (BMUS)</li> <li>• 2016: Invited Specialist committee member for NICE “Quality Standards on menopause” published in Jan 2017.</li> <li>• 2016: Represent RCOG in “Tommy’s” pregnancy advisory board-charity promoting pregnancy related advice for women</li> <li>• 2016-17: Health board representative in “All Wales Endometriosis Task and Finish group”-working to improve care provision for women with endometriosis in Wales</li> <li>• 2016-17: Clinical Advisor for Public services Ombudsman Wales, providing clinical expert opinion on complaints to PSOW</li> <li>• 2013-ongoing: As a member of NICE Specialist advisory committee, I provide expert opinion on new interventional procedures in gynaecology</li> <li>• 2012 onwards: MRCOG examiner UK and International</li> </ul> <p><b>Research:</b></p> <ul style="list-style-type: none"> <li>• 2017: Principal investigator for randomised controlled multicentre trial: GAP3 to evaluate the role of Gabapentin for chronic pelvic pain</li> <li>• 2017: Principal investigator for randomised controlled multicentre trial: GEM 3 for management of ectopic pregnancy: awaiting site initiation study</li> <li>• 2016 ongoing: Principal investigator for randomised controlled</li> </ul>

multicentre trial -UCON comparing Ulipristal acetate with hormonal coil in the management of heavy menstrual bleeding

**Publications:**

- 2017: Authored OSCE's for MRCOG part 3 for text book to be published by Oxford University press
- 2016: Authored chapter on "Prescription in pregnancy" in Fetal Medicine textbook published by Cambridge University press in May 2016
- 2012: Co-authored article entitled "Bullying at work" published in "The Obstetrician and Gynaecologist (TOG)"
- 2011: Co-authored textbook: "Early pregnancy issues for MRCOG and Beyond" published by RCOG-Cambridge University Press. Included in the Best-seller list