

Quality standards advisory committee 2 meeting

Date: 10 April 2018

Location: NICE office, Level 1a City Tower,

Piccadilly Plaza, Manchester, M1 4TD

Morning session: Endometriosis – review of

stakeholder feedback

Minutes: Final

Attendees

Quality standards advisory committee 2 standing members:

Michael Rudolf (chair), Gillian Baird, Robyn Noonan, Steve Hajioff, Moyra Amess, Jean Gaffin, David Weaver, Corinne Moocarme, Julie Clatworthy

Specialist committee members (SCMs for endometriosis):

Anita Sharma Deborah Panes Amy Wilbraham Lynda Harrison

NICE staff

Mark Minchin (MM) Eileen Taylor (ET) Craig Grime (CG) Jamie Jason (notes)

Apologies Michael Varrow, James Crick, Guy Bradley-Smith, Jane Bradshaw, Allison Duggal, Ruth Studley, Malcolm Griffiths, Mathew Sewell, Jane Putsey, Geeta Kumar (SCM)

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 endometriosis quality standard.

The Chair confirmed that there were no public observers joining 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 was the endometriosis quality standard: specifically:

- Clinical examination for suspected endometriosis
- Referral if initial treatment for endometriosis is not effective, not tolerated or contraindicated
- Referral for deep endometriosis
- Coordinated care through a managed clinical network

The Chair explained that a new declarations of interest register would be tabled at the meetings from now on and asked that anyone who had not yet filled this in to do so.

3. Minutes from the last meeting

The committee reviewed the minutes of the last QSAC 2 meeting held on 13 February 2018 and confirmed them as an accurate record.

4. Recap of prioritisation meeting and discussion of stakeholder feedback

ET provided a recap of the areas for quality improvement prioritised at the first QSAC meeting for potential inclusion in the endometriosis draft quality standard.



ET summarised the significant themes from the stakeholder comments received on the endometriosis draft quality standard and referred the committee to the full set of stakeholder comments provided in the papers.

Discussion and agreement of amendments required to quality standard

Draft statement 1: Clinical examination for suspected endometriosis

 Women presenting with suspected endometriosis have an abdominal and pelvic

examination.

The committee considered this statement with statement 4. See statement 4 below for more details.

The committee discussed having a timescale from presentation to examination of 4-6 weeks. It was discussed that patients may not want an examination when they first present and it might be better to return to have the examination. The committee heard that endometriosis cannot be ruled out if the examination is normal.

The committee discussed the stakeholder comment that the definition of suspected endometriosis may have a resource impact and lead to unnecessary examinations. However, the committee also felt that given the length of time from presentation to diagnosis this is a necessary step and the definition is appropriate. It was also noted that clinical judgement should be used when deciding whether the assessment should be carried out.

The committee also discussed patient choice and who would carry out the examination. The committee discussed the merit of identifying a sub-group of women for whom uptake of the pelvic examination may be low, for example younger girls or women who may not want this for cultural reasons.

In view of concerns about the appropriateness of this draft statement, the committee agreed to discuss it further alongside draft statement 4.

Draft statement 2: Referral if initial treatment for endometriosis is not effective, not tolerated or contraindicated

 Women receiving initial hormonal treatment for endometriosis are referred to a gynaecologist if it is not effective, not tolerated or contraindicated. 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:

ACTION:

- NICE team to change the wording to say referred to 'gynecology services' and explain under definitions.
- NICE team to explore the measures and reduce from 3 to 1.

The committee agreed that using 'gynecology services' would allow for a wider scope of treatment. Gynecology services can be defined under the definitions.

The committee discussed how to differentiate between the 3 measures in this statement and felt using just 1 would be more beneficial.

The committee were content with the use of a 6 month timescale in the measure for referral if initial hormonal treatment is ineffective.

Draft statement 3: Referral for deep endometriosis

 Women with suspected or confirmed deep endometriosis The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard.

It was noted that not all areas in the country have access to a specialist service.



involving the bowel, bladder or ureter are referred to a specialist endometriosis service.			
Draft statement 4: Coordinated care through a managed clinical network • Community services are part of a managed clinical network providing coordinated care for women with suspected or confirmed endometriosis.	The committee discussed draft statement 1 and draft statement 4 together. A common aim for each of these statements was to reduce the length of time taken to receive a diagnosis. It was agreed that these statements would be replaced by one statement on endometriosis being diagnosed promptly. ACTION: NICE team to replace statements 1 and 4 with a statement on prompt diagnosis. The committee noted that pain management teams are included in the definitions of gynecology services. The main aim to drive quality improvement within statements 1 and 4 is to diagnose endometriosis in an appropriate time and to have a pathway that can be followed. The committee discussed the steps involved in doing this and the difficulties of a measurable statement. It was agreed that the NICE team would try to draft a quality statement on diagnosing endometriosis in a timely way, including measures on parts of the pathway such as physical examination, ultrasound and laparoscopy.		
5. Additional quality improvement areas suggested by stakeholders at consultation			
No additional areas were sugg	No additional areas were suggested.		

No additional areas were suggested.

6. Resource impact and overarching outcomes

The committee considered the resource impact of the quality standard.

The committee suggested that the following be added to the overarching outcomes of the quality standard:

Raising awareness

ET 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.

7. Equality and diversity

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

Age Disability Gender reassignment Sex Pregnancy and maternity Race

Religion or belief Sexual orientation

Marriage and civil partnership

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

The committee emphasised the need to have gynaecology expertise for people with learning disabilities.



The committee discussed unequal access of services based on geographical location. It was also agreed that transgender men would be included in the equalities considerations of all of the quality statements.

8. Any other business

The committee expressed views on having half day committee meetings and also having meetings on the Tuesday after a bank holiday. The NICE Team will look into the possibility of rearranging future meetings that fall near bank holidays.

The Chair reported that Michael Fairburn had resigned from QSAC and that he had written to thank him for his contribution to the committee's work.

Appendix 1: Declarations of interest

Name	Membership	Declaration
Geeta Kumar	Specialist	Appointed lead for NGA's guidelines on ectopic pregnancy as part of revision of multiple obstetrics guidelines
		Appointed Deputy Hospital Medical Director for Quality and Safety at Wrexham Maelor hospital, BCUHB, North Wales
		NICE Fellow
		Chair of RCOG's Patient information committee
		Lead reviewer on behalf of RCOG's Guideline committee for RCOG's Green top guidelines on Ectopic pregnancy published
		Member of BCUHB NICE liaison committee and All Wales NICE liaison group
		Editorial board member of "Ultrasound" Journal of British medical ultrasound society (BMUS)
		Invited Specialist committee member for NICE "Quality Standards on menopause"
		Represent RCOG in "Tommy's" pregnancy advisory board-charity promoting pregnancy related advice for women
		Health board representative in "All Wales Endometriosis Task and Finish group"-working to improve care provision for women with endometriosis in Wales
		Clinical Advisor for Public services Ombudsman Wales, providing clinical expert opinion on complaints to PSOW
		As a member of NICE Specialist advisory committee, I provide expert opinion on new interventional procedures in gynaecology



		MRCOG examiner UK and International
		Principal investigator for randomised controlled multicentre trial: GAP3 to evaluate the role of Gabapentin for chronic pelvic pain
		Principal investigator for randomised controlled multicentre trial: GEM 3 for management of ectopic pregnancy: awaiting site initiation study
		Principal investigator for randomised controlled multicentre trial -UCON comparing Ulipristal acetate with hormonal coil in the management of heavy menstrual bleeding
		Authored OSCE's for MRCOG part 3 for text book to be published by Oxford University press
		Authored chapter on "Prescription in pregnancy" in Fetal Medicine textbook published by Cambridge University press in May 2016
		Co-authored article entitled "Bullying at work" published in "The Obstetrician and Gynaecologist (TOG)"
		Co-authored textbook: "Early pregnancy issues for MRCOG and Beyond" published by RCOG-Cambridge University Press. Included in the Best-seller list
Anita Sharma	Specialist	Is a standing QSAC 1 member
Deb Panes	Specialist	Lead Research Nurse for University Hospitals Bristol undertaking the Abbvie Solstice Endometriosis Clinical Drug Trail.
		Lead Research Nurse for University Hospitals Bristol for the SPIRIT 2 Endometriosis Clinical Drug Trial
Amy Wilbraham	Specialist	None
Lynda Harrison	Specialist	Member of Endometriosis UK.
		Member of the Northern Ireland Endometriosis Support group.
		Acts as a patient representative for the Patient Client Council representing patients with Endometriosis.