NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1 Quality standard title

Endometriosis

Date of quality standards advisory committee post-consultation meeting:
10 April 2018

2 Introduction

The draft quality standard for endometriosis was made available on the NICE website for a 4-week public consultation period between 16 February and 16 March 2018. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 15 organisations, which included service providers, national organisations, professional bodies and others.

This report provides the quality standards advisory committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the committee as part of the final meeting where the committee will consider consultation comments. Where appropriate the quality standard will be refined with input from the committee.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the committee should read this summary alongside the full set of consultation comments, which are provided in appendix 1.

3 Questions for consultation

Stakeholders were invited to respond to the following general questions:

1. Does this draft quality standard accurately reflect the key areas for quality improvement?

2. Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be to be for these to be put in place?

3. Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

Stakeholders were also invited to respond to the following statement specific questions:

4. For draft quality statement 2: Quality statements need to be measurable. In process measure b, we have therefore included a timescale of 6 months from the start of initial hormonal treatment. Is this a reasonable timescale? Please give reasons for your answer.

5. For draft quality statement 4: Quality statements usually focus on a single concept to achieve quality improvement. By focussing this statement on one community service, improvements in coordinated care and greater awareness of endometriosis can be achieved. Which community service (contained in the definitions) should this statement focus on? Please confirm reasons for your response.

4 General comments

The following is a summary of general (non-statement-specific) comments on the quality standard.

- Support for the quality standard and general agreement that the quality standard accurately reflects the key areas for quality improvement
- Ensuring treatment can be accessed in the appropriate setting provides a positive and much needed step forward in supporting the diagnosis and management of endometriosis
- The quality standard has a specialist perspective focussing on severe disease
- Focusing on reducing delayed diagnosis could lead to unintended consequences
- It is important that women are informed about their condition, treatment routes and options
- Suggestion to measure the impact of the quality standard by measuring how many people present with late diagnosis of endometriosis

Consultation comments on data collection (question 2)

- Data collection for a confirmed diagnosis of endometriosis would be easier than suspected endometriosis due to the way this is recorded on IT systems

Consultation comments on resource impact (question 3)

- Further specialist pain services are needed in endometriosis centres to ensure expertise in pelvic pain. This may need funds but there will be savings from reduced admissions, GP visits and optimal medication use. Social care requirements will also fall
- Each of the statements in the draft quality standard are achievable by local services

- Endometriosis centres, specialist transgender and adolescent gynaecology services are not available in some areas so some of the statements may not be easily achievable
- Several of the quality statements relate to primary care where resources are currently stretched. Full implementation and monitoring of the quality standard will require significant additional resources

5 Summary of consultation feedback by draft statement

5.1 Draft statement 1

Women presenting with suspected endometriosis have an abdominal and pelvic examination.

Consultation comments

Stakeholders made the following comments in relation to draft statement 1:

- This statement was welcomed as it will assist women to access timely support
- Women should be informed if endometriosis is suspected
- Supporting information should note that endometriosis cannot be ruled out if an abdominal and pelvic examination is normal
- Rationale should match the audience descriptor which states that the examination should take place the first time a woman visits a healthcare professional to discuss the symptoms
- Examination at first visit is not always best practice. Many women will have abdominal/pelvic pain and constipation or IBS as a comorbidity or primary diagnosis and it may not be possible to examine the woman at the time
- Statement should note that adolescent women must be managed without an internal pelvic exam. It can be fear of an internal exam that stops parents and adolescent women seeking medical advice and the primary presentation of endometriosis in adolescent women does not warrant this
- The broad definition of suspected endometriosis may lead to over-diagnosis and over-treatment of endometriosis which is not severe
- One stakeholder felt the definition of suspected endometriosis recommends underage sex because a 17 year old with 12 months of infertility is probably having sex below 16 years old
- Suggestion to make it clearer in the equalities section that, in addition to a chaperone, a relative or friend could be present

Comments on measures and resource impact:

- Systems and structures are not in place for data collection. Free text is usually used to record when a pelvic and abdominal examination has been performed
- This can be measured from the clinical records in the hospital notes as details are recorded on paper when people are seen in the gynaecology clinic
- It is good to see working diagnoses of endometriosis being supported and measured
- Minimal resources are needed for abdominal and pelvic examination so this is realistically achievable. Follow up is potentially difficult in sexual and reproductive health services

5.2 Draft statement 2

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

Consultation comments

Stakeholders made the following comments in relation to draft statement 2:

- Suggestion to change the statement title to include ‘hormonal’ treatment as initial treatment is usually analgesics
- Finding an effective treatment is difficult for many women. This statement should enable them to receive specialist support if initial treatment is not acceptable
- Suggestion that all women with endometriosis are seen by a gynaecologist to improve their quality of life, especially for pain management
- Suggested additional statement on a working diagnosis of endometriosis being given if initial hormonal treatment is effective and women being supported to get a definitive diagnosis via a gynaecology referral, should they want it
- Supporting information should make it clear that infertility, or the woman trying for a baby, is a contraindication to hormonal treatment
- A stakeholder noted that if there are adverse effects with one hormonal treatment, the clinician would try another before referral
- Definition of gynaecology services should note that specialist imaging for endometriosis may involve more than one health care professional

Comments on measures:

- It may be difficult to collect data for this statement as it is not routinely collected
- This can be measured from the gynaecology clinic record

Consultation question 4

Quality statements need to be measurable. In process measure b, we have therefore included a timescale of 6 months from the start of initial hormonal treatment. Is this a reasonable timescale? Please give reasons for your answer.

Stakeholders made the following comments in relation to consultation question 4:

- Stakeholders felt a 6 month timescale is reasonable because:
    - in clinical practice, an effect of treatment within 4–6 months would be expected
    - a number of women will try more than one hormonal therapy
    - this supports a 6 month follow up of women with suspected endometriosis and referral to secondary care if required so it should reduce diagnostic delay for women needing secondary care diagnosis
- Stakeholders felt that it should be clear 6 months is not the minimum length of time. GPs should refer as soon as it is evident hormonal treatment is not effective
- Suggestion to use a 3 month timescale as treatments should not take 6 months to have an effect on pain symptoms. Hormone treatments are usually effective in suppressing pain symptoms but not preventing disease progression

5.3 Draft statement 3

Women with suspected or confirmed deep endometriosis involving the bowel, bladder or ureter are referred to a specialist endometriosis service.

Consultation comments

Stakeholders made the following comments in relation to draft statement 3:

- Statement welcomed as it ensures access to a specialist endometriosis service for women with complex symptoms or confirmed endometriosis
- Suggestion to add ‘with access to a team of additional specialists as necessary’ to sentence 2 in rationale
- Specialist endometriosis services are essential for the care of women with deep endometriosis but this is a difficult diagnosis for primary care clinicians to make
- Pathways should be established between gynaecology units to ensure that appropriate numbers of specialist services are available on a Sustainability and Transformation Partnership (STP) footprint
- In specialist services the role of the clinical nurse specialist (CNS) is varied. All women diagnosed with endometriosis who need support should have access to a CNS as they can be the key for good care pathways

Comments on measures:

- GP referral data is not currently available in a collectable format
- Data is submitted to the British Society for Gynaecological Endoscopy (BSGE) database. This data only includes women referred to specialist centres
- Outcome measure on centres working towards accreditation as specialist endometriosis services suggests there is a shortage of these services
- ‘Diagnosis rates of deep endometriosis involving the bowel, bladder or ureter’ is not the correct outcome. Women with suspected deep endometriosis should be referred to a specialist centre but some of them will not have deep endometriosis

5.4 Draft statement 4

Community services are part of a managed clinical network providing coordinated care for women with suspected or confirmed endometriosis.

Consultation comments

Stakeholders made the following comments in relation to draft statement 4:

- This statement will be fundamental in ensuring seamless patient travel between community, primary care, secondary and tertiary level care
- Pain management services should be included in the rationale and audience descriptors so that women with suspected or confirmed endometriosis suffering from chronic pain have access to pain management
- The practicality of the statement was queried because GPs and their teams can manage less severe endometriosis. Participating in a managed clinical network is too bureaucratic and time consuming for school nursing and GPs
- There are administrative costs in running a managed clinical network including primary care staff time and it will be difficult to recruit general practice representation

Comments on measures and resource impact:

- Include an outcome on the length of time from presenting to a healthcare professional to diagnosis
- Focus on improving education and awareness of endometriosis for all clinicians and evidence of referral pathways
- Outcome on work and school absences is unrealistic as this information is not recorded
- Additional resources would be needed to implement this effectively

Consultation question 5

Quality statements usually focus on a single concept to achieve quality improvement. By focussing this statement on one community service, improvements in coordinated care and greater awareness of endometriosis can be achieved. Which community service (contained in the definitions) should this statement focus on? Please confirm reasons for your response.

Stakeholders made the following comments in relation to consultation question 5:

- Stakeholders felt the statement should focus on all community services because:
  - delays in diagnosis are usually within community services, so it is important to have an effective managed clinical network in all areas
  - focusing on one element of the community service will not achieve service wide improvement
  - focusing on the whole community service could significantly improve patient management, early intervention and the need for higher level services
- Stakeholders felt the statement should focus on general practice because:
  - general practice provides the majority of health care to women of reproductive age and endometriosis may present with a variety of cross-disciplinary symptoms
  - GPs and practice nurses are the first point of contact for most women and girls with suspected endometriosis
  - young women missing school on a regular basis won't be picked up by school health services
- It was also noted that school nurses are a good point of contact, increasing awareness and support

Appendix 1: Quality standard consultation comments table – registered stakeholders

ID	Stakeholder	Statement number	Comments[1]
1	Boston Scientific	General	It is of paramount importance that women are informed about their conditions and also treatment routes and options. It is necessary for them to access services early and that they are referred promptly to specialist services.
2	Endometriosis UK	General	The draft QS is welcomed and provides a positive and much needed step forward in supporting the diagnosis and management of endometriosis, and ensuring treatment can be accessed in the appropriate setting. Please note that numbers (eg 1.2.3) refer to the NICE Guideline - Endometriosis: diagnosis and management.
3	Royal College of General Practitioners	General	This has been written very much from a specialist perspective, with the focus on more severe disease. There was also a preoccupation with delays in diagnosis without any consideration of the unintended consequences of steps taken to reduce delays.
4	The Centre for Reproduction Research	General	The Centre for Reproduction Research hosts a programme of research and development work focused on endometriosis. Because our work focuses on the social and psychological aspects of the condition, we are only able to comment in response to question 1 'does this draft quality standard accurately reflect the key areas for quality improvement?' We support the four quality statements, and agree they are priority areas for improvement.
5	The Society and College of Radiographers	General	The Society and College of Radiographers wonder if there is something missing re. measuring the quality standards to some extent. Endometriosis is notoriously difficult to diagnose with / without imaging, but maybe there needs to be some measure of how many women / transgender present with late diagnosis of endometriosis? This is something the standards are trying to reduce, but if it is not being monitored how we will we know if there are improved outcomes for patients?
6	World Endometriosis Society	General	WES would recommend that a steering committee is established to ensure the next steps towards implementation / compliance.
7	Royal College of General Practitioners	Q1	Yes
8	Royal College of Obstetricians and Gynaecologists	Q1	The draft quality standard does accurately reflects the key areas for quality improvement.
9	The Faculty of Sexual and Reproductive Healthcare (FSRH)	Q1	Yes

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[1] PLEASE NOTE: Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its staff or its advisory committees.

ID	Stakeholder	Statement number	Comments[1]
10	The Faculty of Sexual and Reproductive Healthcare (FSRH)	Q2	Data collection for those with a confirmed dx of endometriosis would be easier than those just suspected due to the way diagnoses are recorded on IT systems.
11	Faculty of Pain Medicine	Q3	It is achievable with reinvestment of savings used to develop areas currently underdeveloped. This includes formal links to specialist pain services. There will also be a requirement to develop further specialist pain services in specialised endometriosis centres to develop an appropriate expertise in pelvic pain. This may need priming of funds but the savings come with reduced admissions, GP visits and optimal medication use. Social care requirements will also fall.
12	Royal College of Obstetricians and Gynaecologists	Q3	Each of the statements in the draft quality standard are achievable by local services. However, endometriosis centres, specialist transgender and adolescent gynaecology services are not readily available in some areas and therefore, some of the standards may not be easily achievable in those areas.
13	Royal College of Obstetricians and Gynaecologists	Q3	Several of the quality statements relate to primary care, for which resources are currently stretched. Full implementation of the standard and monitoring will require significant additional resources across services.
14	Royal College of Obstetricians and Gynaecologists	Q6	No specific example cases.
15	Boston Scientific	S1	We welcome this statement, as this will assist women suffering from this condition to access the timely support that is required for a long term condition such as Endometriosis. NG 47 also states “Do not exclude the possibility of endometriosis if the abdominal or pelvic examination, ultrasound or MRI are normal. If clinical suspicion remains or symptoms persist, consider referral for further assessment and investigation.” This is important as reports suggest that women suffering from endometriosis are not adequately managed.
16	Endometriosis UK	S1	One of the big issues women face in getting a diagnosis is endometriosis being suspected, a key factor behind the average 7.5 years to diagnosis, with women often being told their symptoms are normal. Many women also report not hearing the word ‘endometriosis’ until after a laparoscopy as it has never been considered by healthcare professionals. It is vital that women who present with one or more symptoms are suspected of having endometriosis and are informed of this, and provided with the information they need to understand the condition, route to diagnosis and possible treatments (NICE Guideline – 1.2.3). This is outlined in the *Rationale*, *Quality measures* and *What the quality statement means for different audiences* for Statement 1. This could be achieved by amending Statement 1 to: Women presenting with one or more of the symptoms or signs of endometriosis are suspected as having endometriosis and have an abdominal pelvic examination.
17	Endometriosis UK	S1	Whist it was agreed that with the systems and structures available it would be possible to collect the data for the proposed quality measures, it was noted that: • the systems and structures are not currently in place. They will need span community, general gynaecology and specialist endometriosis services.

ID	Stakeholder	Statement number	Comments[1]
			- there should be a way to capture patients with musculoskeletal/neuropathic pain from suspected endometriosis patients as they need a different approach to treat their pain.
18	Endometriosis UK	S1	It should be noted in the rational that a woman may still have endometriosis even if nothing is noted in a abdominal and pelvic exemption; endometriosis cannot be ruled out on this alone (1.5.1)
19	Endometriosis UK	S1	Under process, denominator – suggest this would be clearer if amended to: the number of women presenting with one or more of the signs or symptoms of endometriosis.
20	Endometriosis UK	S1	Outcomes – It is very good to see working diagnoses of endometriosis being supported and measured. Too many women wait many years (on average 7.5 years) without a name for what they are suffering from, which can have a significant detrimental impact on their education or employment, and quality of life. Having a working diagnosis is especially important for women who may need to take time off work, due to their symptoms, investigations and treatments, as if these are not linked as one condition they could lose pay or even their jobs as missing too much unexplained time off work. For those in education, a diagnosis also makes a significant difference in terms of support and recognition of time off.
21	Endometriosis UK	S1	Women with 1 or more symptoms: recommend that the full list of signs and symptoms are put in here rather than just a selection. Therefore include gastrointestinal and urinary problems, and trouble getting pregnant to the list in brackets.
22	Endometriosis UK	S1	Women with 1 or more symptoms: it is welcomed that this descriptor includes that the examination of their pelvis or abdomen should be done the first time they visit a healthcare professional to discuss these symptoms. It should be added to the 'rational' at the start of this section that the examination should be done on the first visit so this is clear to healthcare professionals.
23	Pelvic Pain Support Network	S1	GP audits mentioned, however such data is not currently collected. Links with school health and sexual health services are poor and currently difficult to collect data of this type.
24	Primary Care Women's Health Forum	S1	To prevent complications from endometriosis the condition needs to be diagnosed and treatment started early. This is dependant on the history of cyclical pain and concerns – the clinical findings of ovarian cysts and reduced pelvic organ mobility are later findings. Although examination is important the measure should be one of increasing recognition of symptoms through education and awareness raising and early commencement of treatment.
25	Royal College of General Practitioners	S1	We welcome the statement encouraging abdominal and pelvic examination but the statement of examination at first visit (line 21, page 6) is not best practice necessarily. So many of these women will have nonspecific abdominal/pelvic pain and constipation or IBS as a co- or primary diagnosis. In addition, it may not be possible to examine the woman at the time due to staff skills, patient preference, time, woman's periods so to make this more amenable to actual GP practice. An abdominal and PV examination within 4 to 6 weeks with patient consent, earlier if serious alternate pathology is possible. Delaying an abdominal and vaginal examination in endometriosis is not life threatening but ensuring good diagnostic data gathering and skills is important. The difficulty with this statement is the phrase 'suspected endometriosis'. On page 7 it says that endometriosis should be suspected in women presenting with 'period-related pain (dysmenorrhoea) affecting daily activities and quality of life'. Following this advice would lead GPs to suspect endometriosis in every woman presenting with dysmenorrhoea severe

ID	Stakeholder	Statement number	Comments[1]
			enough to make them spend an hour or two lying down. They should then do an abdominal & pelvic examination on all of them (including teenage women without any sexual experience). Does the committee really think that? Finding no abnormality on examination, but still suspecting endometriosis, the conscientious GP should then order US scan, and presumably if that were negative, then refer for laparoscopy. There is then the possibility of overdiagnosing endometriosis of trivial severity and over treating it. What conclusions has the NICE impact assessment arrived at? This quality statement carries a real risk of encouraging bad medicine.
26	Royal College of General Practitioners	S1	Systems are not in place for data collection. Data collection showing that pelvic and abdominal examination had been performed is difficult as these are usually recorded in free text and not Read coded in general practice. A manual sample of records would be required.
27	Royal College of General Practitioners	General	Page 17 there are issues with a standard that recommends underage sex. As a 17 year old with 12 months of infertility is having sex probably below 16 years old (and a national desire to reduce teenage pregnancies due to increased mortality and morbidity in babies and teens) and yet the statement information suggests that is a group. We suggest looking at the infertility statement in more depth for under 17 year olds
28	Royal College of Nursing	S1	We are unsure how this standard will be measured effectively, we are aware that in some areas, often women have not been examined by anyone in general practice before referral. The standard would also need a campaign to increase awareness of endometriosis within primary care and for the women themselves so they can be more aware of the condition and also be made aware of available services.
29	Royal College of Obstetricians and Gynaecologists	S1	The rationale behind this statement is that delays in the diagnosis and treatment of endometriosis can be reduced if healthcare professionals carry out an abdominal and pelvic examination. Most women with endometriosis will not have the signs described, so it is important that the clinician is not falsely reassured by a normal examination.
30	The Centre for Reproduction Research	S1	Research suggests that women can face barriers in receiving investigations for symptoms (Culley et al., 2013a) and statement 1 should assist with this Culley et al (2013a) The social and psychological impact of endometriosis on women's lives: a critical narrative review, *Human Reproduction Update* 19(6): 625–639. With regard to our initial submission, we do reiterate the need for enhanced GP information and training, to ensure the NICE 2017 guideline is implemented fully; for fertility and endometriosis care to be better joined up; for the role of the endometriosis Clinical Nurse Specialist to be recognised as a primary role; and for support services to be inclusive of relationships, sex and intimacy.
31	The Faculty of Sexual and Reproductive Healthcare (FSRH)	S1	Minimal resources needed for abdominal and pelvic exam, therefore realistically achievable. However, there may be differences in SRH services across the country in terms of patient mix. We don't have an official remit for "community gynaecology" and whilst we may see those self referring, follow up is potentially more difficult
32	The Society and College of Radiographers	S1	The Society and College of Radiographers feel this is a reasonable suggestion. A consideration is would further training be needed for some of these practitioners in relation to clinical examination?

ID	Stakeholder	Statement number	Comments[1]
33	The Society and College of Radiographers	S1	Re. equality and diversity: The Society and College of Radiographers feels that this statement does not relate well to advice on the use of chaperones in health care. Maybe it could be reworded to suggest that in addition to a chaperone a relative or friend could be present? 'In these cases, suggesting they have a friend or relative as a chaperone and a female practitioner carrying out the examination may be helpful'
34	York Teaching Hospital NHS Foundation Trust	S1	This is a good standard to justify thorough history taking and examination of patients with chronic pelvic pain. This standard will be easy to measure from the clinical records in the hospital notes. History and clinical examination are still recorded on paper when patients are seen in the Gynaecology clinic as diagnosed or suspected case of endometriosis.
35	World Endometriosis Society	S1	This statement must be modified to acknowledge that adolescents must be managed without requirement of an internal pelvic exam. It can be fear of an internal exam that keeps parents and adolescent patients from seeking medical advice for pelvic pain. The primarily SPE presentation of endometriosis in adolescent does not warrant an internal exam. The NASPAG guidelines should be followed regarding indications for and circumstances under which internal pelvic exams should be performed for adolescents.
36	Boston Scientific	S2	We welcome this statement, but we would also like to respectfully suggest that they are seen by a gynaecologist. This would help to improve the quality of life of the patient, especially in reference to pain management, and daily activities.
37	British Fertility Society	S2	It should be made clear that Infertility, or if the woman is trying for a baby, is a contra-indication to hormonal treatment. Women with suspected or diagnosed endometriosis who are trying for a baby should be referred to a specialist fertility service
38	Endometriosis UK	S2	We have strong concerns that a side effect of this QS would be that women for whom hormonal treatments *does* manage symptoms will not be given a working diagnosis of endometriosis, and denied the opportunity for referral to secondary care and a definitive diagnosis of endometriosis. Without a diagnosis they will not receive appropriate monitoring and support, nor know about the potential detrimental impact this could have on disease progression and their future choices including fertility; and of deep endometriosis not being referred to a specialist centre. The NICE guidelines highlight that diagnosis '*delays can affect quality of life and result in disease progression*' (1.1.2), and it is vital that the QS does not inadvertently result in delayed diagnosis. Sadly, a very common situation is women with some of the main symptoms of endometriosis (chronic pelvic pain; period related pain) being immediately prescribed hormonal (contraceptive) treatments, and if the symptoms improve then nothing further is done - with no consideration nor mention at all of endometriosis during this time. It is only years later, for example when they come off the pill and symptoms return or when they are trying to get pregnant, that endometriosis investigations may start. Women may also be unaware that other symptoms they are experiencing such as gastrointestinal symptoms could be linked, resulting in misdiagnosis of other conditions and impacting on employment or education. It is vitally important that women receive a diagnosis of endometriosis, so they can be aware of their condition, the potential for disease progression and the impact this could have eg on fertility, employment and quality of life. They also need a diagnosis to enable and empower their self-management of the disease, and to be aware of additional symptoms to look out for.

ID	Stakeholder	Statement number	Comments[1]
			Very importantly, a woman could have deep endometriosis with the symptom of pelvic pain. If this is managed by hormonal treatment and not referred to gynaecology they could be denied the diagnosis of deep endometriosis and not referred for appropriate investigations, treatment and management. A definitive diagnosis can only be via laparoscopy and biopsy. The Quality Standards must be clear that a working diagnosis of endometriosis can and should be given if hormonal treatment is effective but that women should be supported to get a definitive diagnosis via a gynaecology referral, should they want it. It is proposed an additional QS is added: Women receiving initial hormonal treatment for one or more of the symptoms of endometriosis that is effective in managing symptoms are given a working diagnosis of endometriosis, made aware of the short and long term implications of the disease (including fertility), its management and treatment, and of other potential symptoms to be aware of. How to get a definitive diagnosis must be explained and supported, should the patient wish for this. . The narrative should include under the rationale: • that a woman may have deep endometriosis which a GP may not be able to identify and so progression to a formal diagnosis by a gynaecologist should be supported. • ensuring the woman receives effective information about the disease. • clarity that the patient should be supported through the appropriate pathway for a diagnosis of endometriosis, including referral to a gynaecologist, in a timely manner; if having had clear information about the disease and in discussion with their GP the patient decides at this point that she will not pursue a formal diagnosis at this point, that a working diagnosis is recorded on her records. Should she wish to pursue a formal diagnosis at a later point and/or if other symptoms are noted, a referral to secondary care should be made.
39	Royal College of Nursing	S2	We would support this statement but would like it to include a time limit, as it takes on average, about seven and half months to get a diagnosis. Women should be referred sooner.
40	Royal College of Nursing	S2	Again it may be difficult to collect data for this statement, as it is not currently being collected as a matter of course.
41	Royal College of Obstetricians and Gynaecologists	S2	Suggest change the title to ‘Referral if initial hormonal treatment for endometriosis is not effective, not tolerated or contraindicated’. Initial treatment is usually analgesics, but this quality statement relates to hormonal treatments. Process a) – Unable to think of any woman who would have contraindications to all of the hormonal treatments. Process c) – If a woman has adverse effects to one hormonal treatment, the clinician would usually try another before referral.
42	The Centre for Reproduction Research	S2	Research also suggests that finding an effective treatment is an ongoing battle for many women and statement 2 should enable women to receive specialist support if initial treatment is not acceptable (Culley et al., 2013b). Culley et al (2013b) Endometriosis: improving the wellbeing of couples; www.dmu.ac.uk/endopart.

ID	Stakeholder	Statement number	Comments[1]
43	The Society and College of Radiographers	S2 & 3	Specialist imaging for endometriosis may involve more than one HCP, as some radiologists specialise in gynaecology imaging including MRI, but not always ultrasound. It may be a specialist imaging team which includes a sonographer with a special interest/expertise in endometriosis 'a healthcare professional with specialist expertise in gynaecological imaging of endometriosis'
44	York Teaching Hospital NHS Foundation Trust	S2	This standard can be measured from Gynaecology clinic record. York Teaching hospital has a dedicated endometriosis clinic where new and follow-up patients are seen. This clinic will be able to collect the data from new referrals from GP. Six months is a reasonable time scale from the start of initial treatment. Women with endometriosis are asked to keep record of pain and periods and their analgesic requirements. It takes over 3 months before they notice any improvement and decide to continue with the treatment or stop it.
45	Endometriosis UK	S2 - Q4	The aim of this QS is welcomed and will support prompt diagnosis of endometriosis. The 6 month timescale is considered reasonable, and with the added clarity that this refers to initial/first hormonal treatment it is hoped will ensure that women are not 'kept' in primary care trying multiple different hormonal treatments for too long a period of time, whilst the disease progresses. However it was noted that it must be clear 6 months should not be considered the 'minimum' length of time ie GPs should refer as soon as it is apparent hormonal treatment is not effective, not wait for at least 6 months, and this should be clarified in the narrative.
46	Pelvic Pain Support Network	S2 - Q4	Is 6 months from the start of treatment reasonable? would suggest 3 months as treatments should not take 6 months to have an effect on pain symptoms. Hormone treatments are usually effective in suppressing pain symptoms but not necessarily effective in preventing progression of the disease thereby providing just temporary relief. There needs to be provision for those who get relief but in whom symptoms recur on ceasing treatment.
47	Primary Care Women's Health Forum	S2 - Q4	6 months is appropriate time to determine whether a hormonal treatment is effective but an early follow up would be more appropriate if there is no improvement or deteriorating symptoms
48	Royal College of General Practitioners	S2 - Q4	The timescale of 6 months is appropriate in clinical practice as this is realistic as a number of women will try more than one hormonal therapy due to acne, mood, period changes etc. and so this gives GPs a proper go at therapy. In addition, it supports a 6 month follow up of women in whom this is the provisional likely diagnosis and referral to secondary care if required so should reduce diagnostic delay for those needing secondary care diagnosis
49	Royal College of General Practitioners	S2 - Q4	6 months is reasonable allowing for adequate menstrual cycles to assess effectiveness.
50	Royal College of Obstetricians and Gynaecologists	S2 - Q4	Regarding draft quality statement 2, a timescale of 6 months seems entirely reasonable. In clinical practice, we would expect to see an effect of treatment within 4–6 months.
51	The Faculty of Sexual and Reproductive Healthcare (FSRH)	S2 - Q4	Again this may be difficult within SRH due to limited remit to follow patients up. Perhaps easier in primary care.

ID	Stakeholder	Statement number	Comments[1]
52	Boston Scientific	S3	We welcome this statement, as this ensures expertise of healthcare professionals working in a specialist endometriosis service is consulted, when managing a woman that presents with complex symptoms or confirmed endometriosis.
53	Endometriosis UK	S3	We are pleased to see and fully support this statement.
54	Endometriosis UK	S3	Sentence two: suggest adding at the end of this sentence 'with access to a team of additional specialists as necessary'.
55	Endometriosis UK	S3	Data Source; suggest adding in recorded cases of deep endometriosis diagnosed in general gynaecology, and timely referral to a specialist centre; and deep endometriosis operations undertaken in non-specialist gynaecology departments.
56	Pelvic Pain Support Network	S3	GP referral data currently inaccessible in a collectable format. Diagnosis data depends on consistent ICD coding in general practice and secondary/tertiary care. ICD 11 needs piloting and there have been issues around coding for endometriosis and other pelvic pain conditions which to my knowledge are still not sorted
57	Primary Care Women's Health Forum	S3	Specialist endometriosis centres are essential to improve the care of women with deep endometriosis however this is an extremely difficult diagnosis for primary care clinicians to make. The pathways should be established between gynaecology units to ensure appropriate care and to ensure that appropriate numbers of specialist centres are commissioned on an STP footprint.
58	Royal College of General Practitioners	S3	This should not affect GPs. They should refer to the local gynaecology services as per their local referral pathways who would refer on to these specialist endometriosis service.
59	Royal College of Nursing	S3	In specialist centres the role of the Clinical Nurse Specialist (CNS) is varied. The RCN have produced a document on the CNS role: *Clinical nurse specialist in Endometriosis* (2015) which informs this. The RCN Women's Health Nursing Forum consider that all women with endometriosis who need support should have access to a CNS as they can be the key for good care pathways.
60	Royal College of Nursing	S3	There are systems and processes in place for collecting this data via the British Society for Gynaecological Endoscopy (BSGE) and the data should be accessible, however, the data does not include that of women who have not been referred to the centres.
61	Royal College of Obstetricians and Gynaecologists	S3	The relevance of quality measure b) Evidence of services working towards accreditation as specialist endometriosis services is unclear. Is there a shortage of accredited endometriosis centres? Outcome a) (page 13 of 21) – We are unsure that 'diagnosis rates of deep endometriosis involving the bowel, bladder or ureter' is the correct outcome. It is important that women with *suspected* deep endometriosis are referred to a specialist centre but it is recognised that a proportion of them will not have deep endometriosis confirmed. Outcome b) is entirely relevant.
62	The Centre for Reproduction Research	S3	In relation to statement 3 we support the referral of women with deep endometriosis involving the bowel, bladder or ureter to specialist endometriosis care, but furthermore reiterate that ideally access to specialist endometriosis care and to an endometriosis Clinical Nurse Specialist should be available to all diagnosed women.
63	York Teaching Hospital NHS Foundation Trust	S3	This standard will be easy to measure as York is accredited BSGE endometriosis centre. Cases of deep endometriosis of bowel bladder and ureter are operated as Joint cases with Urologist and colorectal surgeons along with a Gynaecologist. The data is submitted to BSGE Endometriosis centre database as a requirement for endometriosis centre.

ID	Stakeholder	Statement number	Comments[1]
64	Boston Scientific	S4	We also welcome statement 4, as a multidisciplinary team is of paramount importance in the management of Endometriosis; we welcome the patient centric approach in the disease management.
65	Endometriosis UK	S4	We welcome the inclusion of this statement; given the multidisciplinary nature needed to diagnose, treat and manage endometriosis a managed clinical network to coordinate care is vital. We welcome the inclusion of women with suspected, as well as confirmed, endometriosis.
66	Endometriosis UK	S4	The major symptom of endometriosis is chronic pain. Access to pain management is therefore vital and can support women in improving their quality of life. Pan management services should be included in the rational to clearly signal that women with suspected or confirmed endometriosis should have access to pain management, where they are suffering from chronic pain.
67	Endometriosis UK	S4	Due to the important of pain management, which sadly is often omitted despite women suffering chronic pain, should also be added into: • the 'What the quality statement means for different audiences' – Service providers, healthcare professionals and Women who have, or might have, endometriosis • the definition of community services • under the description of the Managed clinical network
68	Endometriosis UK	S4	Add in an outcome: length of time from presenting to a healthcare professional to diagnosis.
69	Faculty of Pain Medicine	S4	This will be fundamental in ensuring seamless patient travel between community, primary care, secondary and tertiary level care. If not achieved the real benefits will be lost as the more complex cases utilise the greatest amount of health care resource.
70	Primary Care Women's Health Forum	S4	A managed clinical network for endometriosis will not be a commissioned service. This measure would be more appropriate if focused on improving education and awareness of all clinicians (school nurses, GPs, SRH clinicians etc) of endometriosis and clear evidence of referral pathways.
71	Royal College of General Practitioners	S4	We are unsure about the practicality of this statement about community network. This would appear to follow a specialist agenda. GPs and their teams are quite capable of managing mild degrees of endometriosis on their own. Managing a community network requires leadership, support, resources and sustained interagency communications at multiple levels. The school nursing services and primary care are under considerable workload pressure in parts of the UK. In the current financial and time pressed climate it is unclear what the resources implications and impact for patients are likely to be. The requirement to participate in a managed clinical network is overly bureaucratic and time consuming. It makes no allowance that GPs are just that – generalists – with responsibility to manage the whole range of medical problems. An evaluation of a pilot network would be useful
72	Royal College of General Practitioners	S4	There are administrative costs involved in running a managed clinical network including payment for primary care staff time. There will be difficulties in recruiting general practice representation due to pressures from other clinical areas and lack of general practice staff.

ID	Stakeholder	Statement number	Comments[1]
73	Royal College of Nursing	S4	We would welcome and support this quality statement, however, the statement would need a lot of input, education and coordinated working to enable it to be implemented effectively as a routine care. There would potentially be an increase in resources for the standard to be achievable. The provision of centres is not equitable throughout the country so this would need to be addressed.
74	Royal College of Obstetricians and Gynaecologists	S4	Outcome a) 'Number of days lost at school and work because of symptoms of endometriosis' seems to be entirely unrealistic. This sort of information is not recorded.
75	The Centre for Reproduction Research	S4	In relation to statement 4, we recognise that disjointed care disadvantages many women and therefore support the need for coordinated care (Culley et al., 2013b). Culley et al (2013a) The social and psychological impact of endometriosis on women's lives: a critical narrative review, *Human Reproduction Update* 19(6): 625–639.
76	World Endometriosis Society	S4	Bloating should be added to the list of symptoms (it is actually more common than pain on defecation).
77	York Teaching Hospital NHS Foundation Trust	S4	Vale of York has endometriosis and pelvic pain guideline which GPs follow and refer patients accordingly to York Hospital. I am not sure how we collect data retrospectively regarding satisfaction of women regarding management of endometriosis. At present hospital collect British Society of Gynaecological Endoscopy validated questionnaire before and after the surgery. This is submitted to BSGE regularly. A patient satisfaction survey could be done prospectively in primary care as well as secondary care by a validated questionnaire. It will be helpful if NICE suggest specific endometriosis related quality of life questionnaire which can be given to patients in the clinic and can be sent to them 6months after the treatment if they had agreed to receive the questionnaire. My concern is that all endometriosis centres already collect the questionnaires from deep endometriosis patients for BSGE endometriosis database which is a national database. it may become duplicate for the patients who have deep endometriosis and were treated surgically.
78	Endometriosis UK	S4 – Q5	With a 7.5 year average length of time to diagnosis of endometriosis, the majority of time generally within community services, it is important that an effective managed clinical network is commissioned in all areas and covers all aspects of care. This is the first recommendation in the NICE guidelines (1.1.1). If only one community service is included in the Quality Standard there is risk that the others are omitted as not seen as important. It would be preferable if this QS remains as it is, referring to all community services. If it is decided to narrow the focus, despite the comment above, then the service should be 'General Practice' – this covers both GPs and practice nurses. At present, if a women is prescribed contraception, they generally discuss menstrual issues with the practice nurse. Should the patient have other issues they see as non-related to menstrual issues, such as gastrointestinal problems, they present to a G. The lack of communication between these healthcare professionals, and the lack of awareness of symptoms that might be related to endometriosis, can cause significant delay in diagnosis, along with misdiagnosis and potentially wrong treatments along the way.

ID	Stakeholder	Statement number	Comments[1]
79	Faculty of Pain Medicine	S4 – Q5	Focusing on one element of the community service will struggle to achieve a service wide improvement. Some of the data sources (example school attendance levels and employment sickness rates) may struggle to pick up potential cases of endometriosis due the nature of the disease and understandable reluctance to discuss personal matters with employers and use other reasons for absence. If the focus is on the whole community service (school nurses, GPs, practice nurses and sexual health services) along with their integration (referral, cross service communication, follow-up) and monitoring a proportion of patients pathways, then there is potential to significantly improve patient management, gain early intervention and potentially reduce some of the longer term complications and need for higher level services
80	Pelvic Pain Support Network	S4 – Q5	Which community service should this focus on? Young women missing school on a regular basis is unlikely to be picked up by sexual or school health services which tend to be disjointed, therefore would suggest this focusses on GP/practice nurses.
81	Royal College of General Practitioners	S4 – Q5	General practice provides the majority of health care to women of reproductive age and therefore should be the focus, especially as endometriosis may present with a variety of cross-disciplinary symptoms.
82	Royal College of Obstetricians and Gynaecologists	S4 – Q5	I believe that this statement should focus on general practice (GPs would be the first point of contact for most women and girls with suspected endometriosis) and practice nurses. School nurses would also be a good point of contact and will help increase awareness and support.
83	The Faculty of Sexual and Reproductive Healthcare (FSRH)	S4 – Q5	General practice for the reasons listed above
84	Department of Health and Social Care	No comment	Thank you for the opportunity to comment on the draft for the above quality standard. I wish to confirm that the Department of Health and Social Care has no substantive comments to make, regarding this consultation.

Registered stakeholders who submitted comments at consultation

- Boston Scientific
- British Fertility Society
- Department of Health and Social Care
- Endometriosis UK
- Faculty of Pain Medicine
- Pelvic Pain Support Network
- Primary Care Women's Health Forum
- Royal College of General Practitioners
- Royal College of Nursing
- Royal College of Obstetricians and Gynaecologists
- The Centre for Reproduction Research
- The Faculty of Sexual Health and Reproductive Healthcare (FSRH)
- The Society and College of Radiographers
- World Endometriosis Society
- York Teaching Hospital NHS Foundation Trust