# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## Health and social care directorate

## Quality standards and indicators

## Briefing paper

**Quality standard topic:** Endometriosis

**Output:** Prioritised quality improvement areas for development.

**Date of Quality Standards Advisory Committee meeting:** 14 December 2017

## Contents

# 1 Introduction

This briefing paper presents a structured overview of potential quality improvement areas for endometriosis. It provides the committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

## *1.1 Structure*

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development source below are included to help the committee in considering potential statements and measures.

## *1.2 Development source*

The key development source referenced in this briefing paper is:

Endometriosis: diagnosis and management (2017) NICE guideline NG73.

Published September 2017. Next review September 2019.

# 2 Overview

## *2.1 Focus of quality standard*

This quality standard will cover the diagnosis and management of endometriosis in women, including young women aged 17 and under.

## *2.2 Definition*

Endometriosis is the growth of endometrial-like tissue (the womb lining) outside the womb. Endometriosis is mainly a disease of the reproductive years and, although its exact cause is unknown, it is hormone related and is associated with menstruation.

## *2.3 Incidence and prevalence*

Endometriosis is typically associated with symptoms such as pelvic pain, painful periods and subfertility. Pain can be frequent, chronic and/or severe and is associated with tiredness and more sick days. It has a significant physical, sexual, psychological and social impact. Endometriosis is an important cause of subfertility which has a significant effect on quality of life.

Women may also have endometriosis without symptoms, so it is difficult to know how common the disease is in the population. Endometriosis UK[1] reported that it is estimated to affect around 2 million women in the UK, which is around one in ten, though some health bodies suggest that this figure is much higher and possibly as many as one in every five women.

## *2.4 Management*

Women with endometriosis typically present with pain to community services, including GPs, practice nurses, school nurses and sexual health services. They may then be referred to gynaecology services for diagnosis and management. Some women may present directly to fertility services.

Diagnosis can only be made definitively by laparoscopic visualisation of the pelvis, but other, less invasive methods may be useful in assisting diagnosis, including ultrasound. Management options for endometriosis include pharmacological, non-pharmacological and surgical treatments.

Endometriosis is an oestrogen-dependent condition. Most drug treatments for endometriosis work by suppressing ovarian function, and are contraceptive. Surgical treatment aims to remove or destroy endometriotic lesions. The choice of treatment depends on the woman's preferences and priorities in terms of pain management and fertility.

Complex surgical treatment is carried out in specialist endometriosis services (endometriosis centres), which incorporate a multidisciplinary team.

Endometriosis can be a chronic condition affecting women throughout their reproductive lives, and sometimes beyond. Women's priorities and preferences may change over time, and management strategies should change to reflect this.

See appendix 1 for the associated care pathway from NICE clinical guideline NG73.

## *2.5 Resource impact*

We do not expect this quality standard to have a significant impact on resources. When the endometriosis: diagnosis and management guideline was developed, a resource impact statement was produced which noted that:

- the resource impact of implementing any single guideline recommendation will be less than £1 million per year in England (or £1,800 per 100,000 population) **and**
- the resource impact of implementing the whole guideline in England will be less than £5 million per year (or £9,100 per 100,000 population).

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[1] Diagnosis Survey. Endometriosis UK. February 2011.

This is because improvements in care will be achieved by using existing resources differently. No initial investment is required.

The guideline focuses on the organisation of care to improve diagnosis and treatment for women who have endometriosis. By increasing awareness of endometriosis, this may reduce multiple GP consultations and emergency department admissions; ensure treatment is given by appropriately trained providers and improve outcomes for women.

Endometriosis services are commissioned by clinical commissioning groups and NHS England (specialist services). Providers are NHS hospital trusts and primary care services.

## *2.6 National outcome frameworks*

Table 1 shows the outcomes, overarching indicators and improvement areas from the national outcome frameworks that the quality standard could contribute to achieving.

**Table 1 NHS outcomes framework 2016–17**

| **Domain** | **Overarching indicators and improvement areas** |
|---|---|
| 2 Enhancing quality of life for people with long-term conditions | ***Overarching indicator***<br>2 Health-related quality of life for people with long-term conditions**<br>***Improvement areas***<br>**Ensuring people feel supported to manage their condition**<br>2.1 Proportion of people feeling supported to manage their condition<br>**Improving functional ability in people with long-term conditions**<br>2.2 Employment of people with long-term conditions*, ** |
| 4 Ensuring that people have a positive experience of care | ***Overarching indicators***<br>4a Patient experience of primary care<br>i GP services<br>4b Patient experience of hospital care<br>***Improvement areas***<br>**Improving people's experience of outpatient care**<br>4.1 Patient experience of outpatient services<br>**Improving people's experience of integrated care**<br>*4.9 People's experience of integrated care*** |
| **Alignment with Adult Social Care Outcomes Framework and/or Public Health Outcomes Framework**<br>* Indicator is shared<br>** Indicator is complementary<br>Indicators in italics in development | |

# 3 Summary of suggestions

## *3.1 Responses*

In total 8 stakeholders responded to the 2-week engagement exercise 19/10/17 – 2/11/17. We also received comments from 4 specialist committee members.

Stakeholders and specialist committee members were asked to suggest up to 5 areas for quality improvement. The responses have been merged and summarised in table 2 for further consideration by the Committee.

Full details of all the suggestions provided are given in appendix 3 for information.

**Table 2 Summary of suggested quality improvement areas**

| Suggested area for improvement | Stakeholders |
|---|---|
| **Symptoms and diagnosis**<br>• Recognition of symptoms<br>• Prompt diagnosis<br>• Specialist diagnosis | CRR, EUK, RCGP, RCN, RCOG, SCM |
| **Management**<br>• Pain management<br>• Laparoscopy<br>• Fertility care | BPS, CRR, RCOG, SCM |
| **Organisation of care**<br>• Treatment pathways and coordinated care<br>• Access to services | CRR, EUK, RCGP, RCN, RCOG, SCM |
| **Information and support**<br>• Support service role<br>• Psycho-social support<br>• Culturally sensitive information and support<br>• Education and literature for people with endometriosis | CRR, PHL, RCOG, SCM |
| **Additional areas**<br>• Equalities<br>• Awareness in the population<br>• Psycho-social impact research<br>• New guidance | RCN, SCM, CRR, RCGP, RCOG, RCPath |
| BPS, British Pain Society<br>CRR, Centre for Reproduction Research<br>EUK, Endometriosis UK<br>PHL, Prime Health London<br>RCN, Royal College of Nursing<br>RCGP, Royal College of General Practitioners<br>RCOG, Royal College of Obstetricians and Gynaecologists<br>RCPath, Royal College of Pathologists<br>SCM, Specialist Committee Member | |

### *3.2 Identification of current practice evidence*

Bibliographic databases were searched to identify examples of current practice in UK health and social care settings; 153 papers were identified for endometriosis. In addition, 41 papers were suggested by stakeholders at topic engagement and 3 papers internally at project scoping.

Of these papers, 5 have been included in this report and are included in the current practice sections where relevant. Appendix 2 outlines the search process.

# 4 Suggested improvement areas

## *4.1 Symptoms and diagnosis*

### 4.1.1 Summary of suggestions

**Recognition of symptoms**

Stakeholders felt that often GPs and other community healthcare professionals were unaware of endometriosis and that they may not recognise potential signs and symptoms. In addition they may not understand when and where to refer women. Improving early identification of symptoms would reduce misdiagnosis and delays in diagnosis.

**Prompt diagnosis**

Stakeholders noted that the length of time to diagnosis is can be lengthy for women who present in general practice with 1 or more symptoms of endometriosis. Women should receive timely referrals for ultrasound scans or gynaecological opinion if initial therapy in primary care has been ineffective, if recurrent symptoms occur or if there are pelvic signs of endometriosis. Endometriosis should be diagnosed using diagnostic laparoscopy but delays in referrals can cause women significant prolonged ill health and distress. A stakeholder felt that women should be encouraged to keep a symptom diary and it is noted that when women are unaware of a diagnosis they are unable to self-manage their symptoms.

**Specialist diagnosis**

A stakeholder commented that women with suspected or confirmed deep endometriosis involving the bowel, bladder or ureter should not be seen in a general gynaecological service, but in a specialist endometriosis centre. Specialist endometriosis services should provide specialist expertise in the gynaecological imaging of endometriosis.

### 4.1.2 Selected recommendations from development source

Table 3 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 3 to help inform the committee’s discussion.

**Table 3 Specific areas for quality improvement**

| **Suggested quality improvement area** | **Selected source guidance recommendations** |
|---|---|
| Recognition of symptoms | **Endometriosis symptoms and signs**<br>NICE NG73 Recommendations 1.3.1 and 1.3.2 |
| Prompt diagnosis | **Referral for women with suspected or confirmed endometriosis**<br>NICE NG73 Recommendation 1.4.2<br>**Diagnosing endometriosis**<br>NICE NG73 Recommendation 1.5.1 |
| Specialist diagnosis | **Referral for women with suspected or confirmed endometriosis**<br>NICE NG73 Recommendation 1.4.2<br>**Diagnostic laparoscopy**<br>NICE NG73 Recommendation 1.5.11 |

### Endometriosis symptoms and signs

NICE NG73 Recommendations 1.3.1 and 1.3.2

1.3.1 Suspect endometriosis in women (including young women aged 17 and under) presenting with 1 or more of the following symptoms or signs:

- chronic pelvic pain
- period-related pain (dysmenorrhoea) affecting daily activities and quality of life
- deep pain during or after sexual intercourse
- period-related or cyclical gastrointestinal symptoms, in particular, painful bowel movements
- period-related or cyclical urinary symptoms, in particular, blood in the urine or pain passing urine
- infertility in association with 1 or more of the above.

1.3.2 Inform women with suspected or confirmed endometriosis that keeping a pain and symptom diary can aid discussions.

### Referral for women with suspected or confirmed endometriosis

NICE NG73 Recommendation 1.4.2

Refer women to a specialist endometriosis service (endometriosis centre) if they have suspected or confirmed deep endometriosis involving the bowel, bladder or ureter.

#### Diagnosing endometriosis

NICE NG73 Recommendation 1.5.1

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.

**Diagnostic laparoscopy**

NICE NG73 Recommendation 1.5.11

During a diagnostic laparoscopy, a gynaecologist with training and skills in laparoscopic surgery for endometriosis should perform a systematic inspection of the pelvis.

### 4.1.3 Current UK practice

#### Recognition of symptoms

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience. However, the detail contained within the sections below on prompt and specialist diagnosis suggests that symptoms are not well recognised.

#### Prompt diagnosis

In 2011, 2890 women with endometriosis took part in a public awareness survey on diagnosis for Endometriosis UK[2]. The survey found that the average time from symptoms to diagnosis was 7.5 years, down from 11 years in 2005. Approximately 20% of those who responded in 2011 received a diagnosis within two years, 33% of respondents waited at least 10 years to be diagnosed.

#### Specialist diagnosis

The All-Party Parliamentary Group on Women's Health carried out an internet survey[3] in early 2017 for women with endometriosis or fibroids. They received 2367 responses to the endometriosis survey.[4] This survey found that 40% of women with endometriosis who responded were seen by their GP at 10 or more appointments before being referred to a specialist.

The Endometriosis UK diagnosis survey[5] found that it took GPs on average 4 years to make a referral to a specialist.

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[2] Diagnosis Survey. Endometriosis UK. February 2011.

[3] Informed Choice? Giving women control of their healthcare, All-Party Parliamentary Group on Women's Health. March 2017

[4] Informed Choice? Giving women control of their healthcare, All-Party Parliamentary Group on Women's Health. March 2017.

[5] Diagnosis Survey. Endometriosis UK. February 2011.

## *4.2 Management*

### 4.2.1 Summary of suggestions

**Pain management**

A stakeholder felt women should have multidisciplinary assessment and management of pain associated with endometriosis to prevent avoidable distress and disability associated with chronic pain.

Stakeholders commented that, depending on the degree of symptom and disease severity, a short trial of analgesia, anti-inflammatory drugs and/or hormonal treatment, should be considered. This can offer effective symptom and disease control at a primary care level, delaying or preventing the need for further gynaecological referral.

**Laparoscopy**

A stakeholder commented that during a diagnostic laparoscopy, a gynaecologist with training and skills in laparoscopic surgery for endometriosis should perform a systematic inspection of the pelvis. They highlighted the importance of diagnostic laparoscopy findings relating to the extent of disease being documented in a standardised format, with image storage and transfer facility, to prevent multiple laparoscopies when care is transferred to another provider.

Additionally a stakeholder suggested surgical treatment should be undertaken at laparoscopy if peritoneal endometriosis does not involve the bowel, bladder or ureter. There should be a full discussion of the risks and benefits of laparoscopy, including a plan if the findings are negative.

**Fertility care**

Stakeholders suggested that fertility should form part of the management of endometriosis. Specifically they suggested that laparoscopic ovarian cystectomy with excision of the cyst wall should be undertaken where fertility is a priority for women who have an endometrioma (ovarian cyst lined by endometriotic tissue) and that the risks and benefits of hysterectomy should be discussed.

### 4.2.2 Selected recommendations from development source

Table 4 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 5 to help inform the committee’s discussion.

**Table 4 Specific areas for quality improvement**

| Suggested quality improvement area | Selected source guidance recommendations |
|---|---|
| Pain management | **Pharmacological pain management**<br>NICE NG73 Recommendation 1.8.1 – 1.8.2<br>**Hormonal treatments**<br>NICE NG73 Recommendation 1.8.6<br>**Surgical management**<br>NICE NG73 Recommendation 1.10.1 |
| Laparoscopy | **Diagnostic laparoscopy**<br>NICE NG73 Recommendation 1.5.13<br>**Surgical management**<br>NICE NG73 Recommendations 1.10.2 - 1.10.3 |
| Fertility care | **Hysterectomy in combination with surgical management**<br>NICE NG73 Recommendation 1.10.10<br>**Surgical management if fertility is a priority**<br>NICE NG73 Recommendation 1.11.2 |

### Diagnostic laparoscopy

NICE NG73 Recommendation 1.5.13

If a full, systematic laparoscopy is performed and is normal, explain to the woman that she does not have endometriosis, and offer alternative management.

### Pharmacological pain management

NICE NG73 Recommendation 1.8.1 – 1.8.2

1.8.1 For women with endometriosis-related pain, discuss the benefits and risks of analgesics, taking into account any comorbidities and the woman's preferences.

1.8.2 Consider a short trial (for example, 3 months) of paracetamol or a non-steroidal anti-inflammatory drug (NSAID) alone or in combination for first-line management of endometriosis-related pain.

### Hormonal treatments

NICE NG73 Recommendation 1.8.6

Offer hormonal treatment (for example, the combined oral contraceptive pill or a progestogen)[6] to women with suspected, confirmed or recurrent endometriosis.

### Surgical management

NICE NG73 Recommendations 1.10.1 - 1.10.3

1.10.1 Ask women with suspected or confirmed endometriosis about their symptoms, preferences and priorities with respect to pain and fertility, to guide surgical decision-making.

1.10.2 Discuss surgical management options with women with suspected or confirmed endometriosis. Discussions may include:

- what a laparoscopy involves
- that laparoscopy may include surgical treatment (with prior patient consent)
- how laparoscopic surgery could affect endometriosis symptoms
- the possible benefits and risks of laparoscopic surgery
- the possible need for further surgery (for example, for recurrent endometriosis or if complications arise)
- the possible need for further planned surgery for deep endometriosis involving the bowel, bladder or ureter.

1.10.3 Perform surgery for endometriosis laparoscopically unless there are contraindications.

### Hysterectomy in combination with surgical management

NICE NG73 Recommendation 1.10.10

For women thinking about having a hysterectomy, discuss:

- what a hysterectomy involves and when it may be needed
- the possible benefits and risks of hysterectomy
- the possible benefits and risks of having oophorectomy at the same time
- how a hysterectomy (with or without oophorectomy) could affect endometriosis symptoms
- that hysterectomy should be combined with excision of all visible endometriotic lesions
- endometriosis recurrence and the possible need for further surgery

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[6] At the time of publication (September 2017), not all combined oral contraceptive pills or progestogens have a UK marketing authorisation for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

- the possible benefits and risks of hormone replacement therapy after hysterectomy with oophorectomy (also see the NICE guideline on menopause). Perform surgery for endometriosis laparoscopically unless there are contraindications.

**Surgical management if fertility is a priority**

NICE NG73 Recommendation 1.11.2

Offer laparoscopic ovarian cystectomy with excision of the cyst wall to women with endometriomas, because this improves the chance of spontaneous pregnancy and reduces recurrence. Take into account the woman's ovarian reserve. (Also see ovarian reserve testing in the NICE guideline on fertility problems.)

### 4.2.3 Current UK practice

**Pain management**

The All-Party Parliamentary Group on Women's Health survey[7] found that, at diagnosis, 63% (1395/2220) of women with endometriosis received pain killers, 15% (268/1814) were referred to a pain clinic and 23% (414/1825) had pain management. The survey did not record whether women were satisfied with the options they received, nor does it note whether they received more than one form of treatment. In addition, 67% (1524/2262) of women with endometriosis received hormonal treatment. The survey did not record whether the other women had discussed and decided not to receive hormonal treatment.

**Laparoscopy**

The All-Party Parliamentary Group on Women's Health survey found that, at diagnosis, 77% (1704/2217) of women with endometriosis underwent laparoscopic surgery. The survey did not record whether women had discussed and decided not to undergo this surgery, nor does it record whether the reason for the surgery was to confirm the diagnosis, remove endometriosis or both.

**Fertility care**

ENDOPART[8] was a research study funded by the UK Economic and Social Research Council. The overall aims of the study were to explore the impact of endometriosis on couples and to contribute to improving the well-being of people living with endometriosis by providing an evidence base for improving couple support. It took place 2012 – 2013 and involved 22 heterosexual couples where the

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[7] Informed Choice? Giving women control of their healthcare, All-Party Parliamentary Group on Women's Health. March 2017.

[8] The ENDOPART study, De Montfort University 2013

female partner had endometriosis. Eighteen out of the 22 couples who took part reported that endometriosis had in some way affected their plans to have children. Half of these couples had sought and/or received medical fertility investigations or treatment.

No other published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience.

## *4.3 Organisation of care*

### 4.3.1 Summary of suggestions

**Treatment pathways and coordinated care**

Stakeholders highlighted that there is regional variation in care planning and referral pathways for women with endometriosis. There needs to be clear pathways from primary to secondary care and access to diagnostics such as MRI and ultrasound. A managed clinical network consisting of community services including GPs, practice nurses, school nurses and sexual health services, gynaecology services and specialist endometriosis services should be in place for women with suspected or confirmed endometriosis. This would help with prompt diagnosis and treatment, including management of pain and fertility.

**Access to services**

Stakeholders commented that all women with endometriosis should have access to a clinical nurse specialist. Additionally general gynaecological service multidisciplinary teams should include a psychiatrist, a gynaecologist with a special interest in endometriosis, pain management and fertility services if applicable.

A stakeholder felt the use of a multidisciplinary team and information provision for women who will be made medically or surgically menopausal is also important.

Stakeholders commented that some gynaecology units do not have healthcare professionals with the specialist knowledge or skills to manage complex cases of endometriosis. These cases should be managed by dedicated specialist centres. However, access to specialist endometriosis services, including specialist centres, is not available to all women.

### 4.3.2 Selected recommendations from development source

Table 5 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 5 to help inform the committee's discussion.

**Table 5 Specific areas for quality improvement**

| Suggested quality improvement area | Suggested source guidance recommendations |
|---|---|
| Treatment pathways and coordinated care | **Organisation of care**<br>NICE NG73 Recommendations 1.1.1 and 1.1.2 |

| | |
|---|---|
| Access to services | **Gynaecology services for women with suspected or confirmed endometriosis**<br>NICE NG73 Recommendation 1.1.3<br>**Specialist endometriosis services (endometriosis centres)**<br>NICE NG73 Recommendation 1.1.4 |

**Organisation of care**

NICE NG73 – Recommendations 1.1.1 and 1.1.2

1.1.1 Set up a managed clinical network for women with suspected or confirmed endometriosis, consisting of community services (including GPs, practice nurses, school nurses and sexual health services), gynaecology services and specialist endometriosis services (endometriosis centres).

1.1.2 Community, gynaecology and specialist endometriosis services (endometriosis centres) should:

- provide coordinated care for women with suspected or confirmed endometriosis
- have processes in place for prompt diagnosis and treatment of endometriosis, because delays can affect quality of life and result in disease progression.

**Gynaecology services for women with suspected or confirmed endometriosis**

NICE NG73 – Recommendation 1.1.3

Gynaecology services for women with suspected or confirmed endometriosis should have access to:

- a gynaecologist with expertise in diagnosing and managing endometriosis, including training and skills in laparoscopic surgery
- a gynaecology specialist nurse with expertise in endometriosis
- a multidisciplinary pain management service
- a healthcare professional with an interest in gynaecological imaging
- fertility services.

**Specialist endometriosis services (endometriosis centres)**

NICE NG73 – Recommendation 1.1.4

Specialist endometriosis services (endometriosis centres) should have access to:

- gynaecologists with expertise in diagnosing and managing endometriosis, including advanced laparoscopic surgical skills
- a colorectal surgeon with an interest in endometriosis
- a urologist with an interest in endometriosis

- an endometriosis specialist nurse
- a multidisciplinary pain management service with expertise in pelvic pain
- a healthcare professional with specialist expertise in gynaecological imaging of endometriosis
- advanced diagnostic facilities (for example, radiology and histopathology)
- fertility services.

### 4.3.3 Current UK practice

#### Treatment pathways and coordinated care

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience.

#### Access to services

The British Society for Gynaecological Endoscopy[9] (BSGE) are responsible for the accreditation of specialist endometriosis centres. The requirements to be a BSGE specialist endometriosis centre include: having a dedicated consultant lead endometriosis service run within a specialist outpatient clinic; a named colorectal surgeon to support the service; a dedicated endometriosis specialist nurse and a support network including urologists and pain management specialists. Accreditation is reviewed annually.

The BSGE website lists 46 accredited specialist endometriosis centres in England. These centres are not available in all areas of the country.

No published studies on current practice were highlighted for the availability of clinical nurse specialists in general gynaecology services or the composition of MDTs; this area is based on stakeholder's knowledge and experience.

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[9] British Society for Gynaecological Endoscopy website

## *4.4 Information and support*

### 4.4.1 Summary of suggestions

**Support service role**

A stakeholder commented that support services should include relationship, sex and intimacy advice as endometriosis can affect these areas significantly. For women or couples who report an impact on sex and intimacy, access to psychosexual support should be facilitated.

Stakeholders also suggested that, at diagnosis, healthcare professionals should discuss planning for and having children, allowing women and couples to consider this and receive evidence-based information, advice and support.

**Psycho-social support**

A stakeholder commented that endometriosis affects women in the reproductive age group, some of whom will have complex needs which need a psychological and social support network to meet their long term needs.

**Culturally sensitive information and support**

A stakeholder felt that culturally sensitive information on endometriosis should be made available and that there should be culturally sensitive support in primary and secondary care for women diagnosed with endometriosis and their family members.

**Education and literature for people with endometriosis**

Stakeholders felt information and support should be provided to women with suspected or confirmed endometriosis to help them understand the condition and therefore use appropriate self-management strategies. Stakeholders felt that this education should be provided by community and secondary care but commented that there is variability in the quality of available literature for women with endometriosis and its distribution.

### 4.4.2 Selected recommendations from development source

Table 6 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 6 to help inform the committee’s discussion.

**Table 6 Specific areas for quality improvement**

| Suggested quality improvement area | Selected source guidance recommendations |
|---|---|
| Support service role | **Endometriosis information and support**<br>NICE NG73 Recommendation 1.2.2 |
| Psycho-social support | **Endometriosis information and support**<br>NICE NG73 Recommendations 1.2.1 – 1.2.3 |
| Culturally sensitive information and support | **Endometriosis information and support**<br>NICE NG73 Recommendation 1.2.1 – 1.2.4 |
| Education and literature for people with endometriosis | **Endometriosis information and support**<br>NICE NG73 Recommendations 1.2.2 and 1.2.3 |

**Endometriosis information and support**

NICE NG73 Recommendations 1.2.1 – 1.2.4

1.2.1 Be aware that endometriosis can be a long-term condition, and can have a significant physical, sexual, psychological and social impact. Women may have complex needs and require long-term support.

1.2.2 Assess the individual information and support needs of women with suspected or confirmed endometriosis, taking into account their circumstances, symptoms, priorities, desire for fertility, aspects of daily living, work and study, cultural background, and their physical, psychosexual and emotional needs.

1.2.3 Provide information and support for women with suspected or confirmed endometriosis, which should include:

- what endometriosis is
- endometriosis symptoms and signs
- how endometriosis is diagnosed
- treatment options
- local support groups, online forums and national charities, and how to access them.

1.2.4 If women agree, involve their partner (and/or other family members or people important to them) and include them in discussions. For more guidance on providing information to people and involving family members and carers, see the NICE guideline on patient experience in adult NHS services.

### 4.4.3 Current UK practice

**Support service role and psycho-social support**

The ENDOPART[10] study noted that, of the 22 couples that took part, many couples reported they did not receive enough information from healthcare practitioners about endometriosis or its treatment and management and did not have sufficient opportunity to discuss their condition and in particular its impact on their relationship.

Participants were asked whether they thought increased information or support for male partners and for couples would be valuable. Overall participants were in favour of the development of resources and support aimed at couples.

### Culturally sensitive information and support

The ENDOCUL study[11], which explored the ways in which minority ethnic women experience endometriosis and its treatment, was conducted in 2008. Twenty-nine women were interviewed as part of the study. It found that some of the negative experiences they experienced with healthcare professionals were related to cultural insensitivity or misunderstandings and women were also concerned with health professionals' general insensitivity to their symptoms

### Education and literature for people with endometriosis

No published studies on providing education to women with endometriosis on managing their condition were highlighted. However, the All-Party Parliamentary Group on Women's Health internet survey [12] reported that sixty-eight per cent of respondents said they got information about their condition from the internet, 41% from their gynaecologist and 22% from their GP (please note that some women received information from more than one of these sources and all responses were included).

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[10] The ENDOPART study, De Montfort University 2013

[11] The ENDOCUL study, De Montfort University 2008

[12] Informed Choice? Giving women control of their healthcare, All-Party Parliamentary Group on Women's Health. March 2017

## *4.5 Additional areas*

### Summary of suggestions

The improvement areas below were suggested as part of the stakeholder engagement exercise. However they were felt to be either unsuitable for development as quality statements, outside the remit of this particular quality standard referral or require further discussion by the committee to establish potential for statement development.

There will be an opportunity for the committee to discuss these areas at the end of the session on 14 December 2017.

#### Equalities

Stakeholders felt consideration should be given to religious or minority ethnic groups, where talking about periods is more of a taboo than in the general population, so that there are ways to reach women from these groups who may not visit their GP with these problems. In addition, younger patients should be listened to by healthcare professionals and steps should be in place to ensure transgender people with endometriosis can access services in an appropriate and sensitively handled way.

Equality and diversity issues will be considered for each quality statement in the quality standard, including the issues which have been raised by these stakeholders. In addition, an equality impact analysis is updated at different stages throughout quality standard development.

#### Awareness in the population

Stakeholders felt awareness of endometriosis is needed amongst the general population, including teenagers. Women are not often aware of the symptoms and this means they do not seek help. Increasing knowledge of what is an acceptable period and talking about menstruation will increase the number of women seeking help. Often young women are told it is normal and not offered help.

Quality standards focus on areas for quality improvement that can be addressed by local commissioners. National awareness campaigns are outside the scope of quality standards.

#### Psycho-social impact research

A stakeholder felt that endometriosis in adolescents and young women, and the psychosocial impact of the condition, should be a priority area for future research.

Areas for research are outside of the scope of quality standards.

**New guidance**

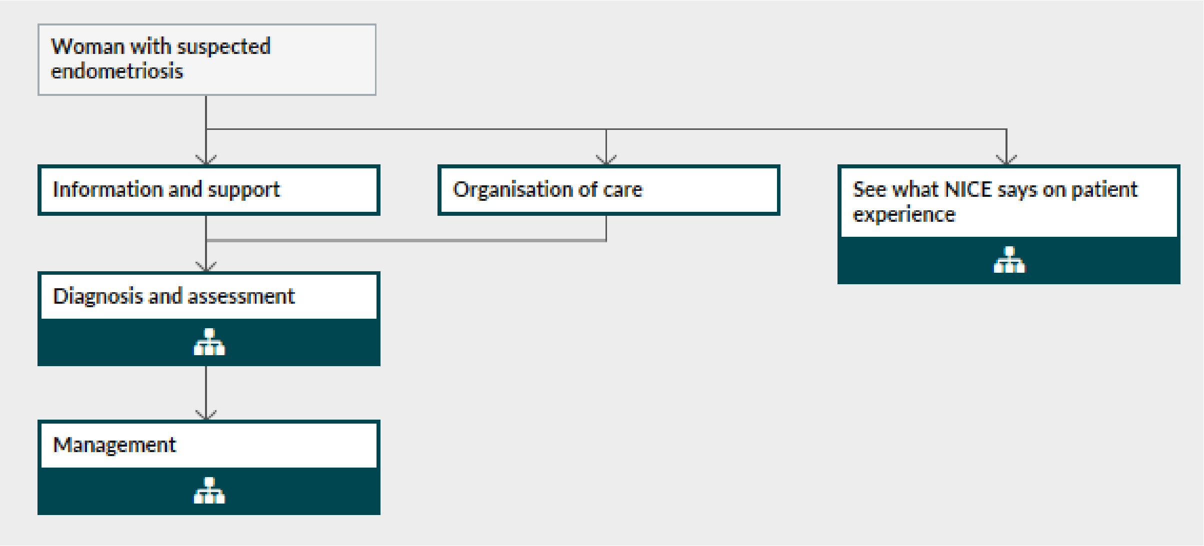
A stakeholder felt there should be clear guidance on primary care management of endometriosis.

A stakeholder felt a new guideline addressing endometriosis and infertility, and how to treat women when these two issues co-exist, should be developed which would help patients and healthcare providers make informed decisions about their care.

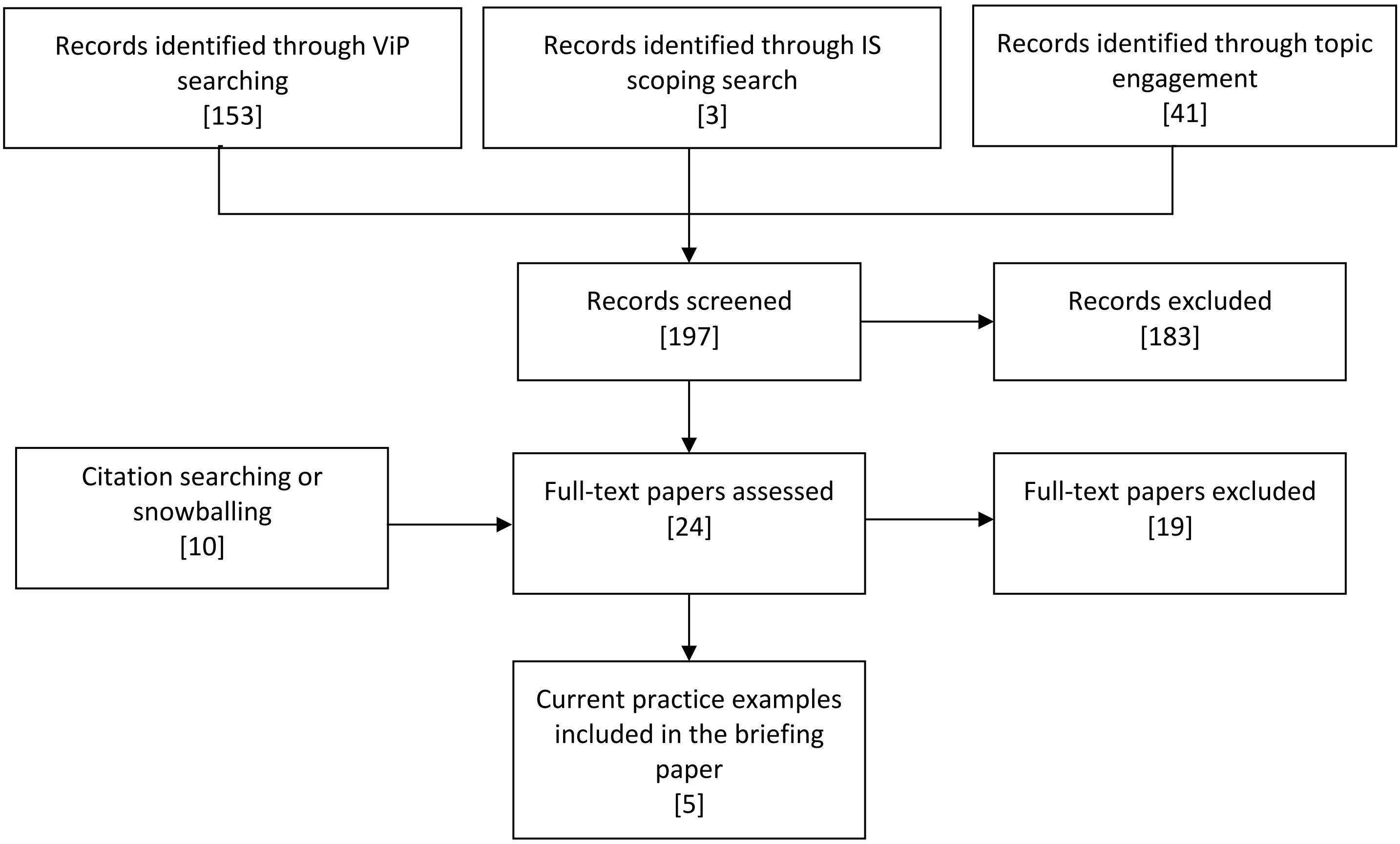
A stakeholder commented that as there is a risk of neoplasia arising in endometriosis, there should be guidelines on when conservative management should not be pursued.

Additional guidance is outside of the remit of quality standards. Suggestions for additional guidance will be passed on to the NICE centre for guidelines.

## Appendix 1: Endometriosis pathway



## Appendix 2: Review flowchart



# Appendix 3: Suggestions from stakeholder engagement exercise – registered stakeholders

| ID | Stakeholder | Suggested key area for quality improvement | Why is this important? | Why is this a key area for quality improvement? | Supporting information |
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| **Symptoms and diagnosis** | | | | | |
| 1 | Centre for Reproduction Research | GP training and information for GPs on endometriosis: recognising potential signs and symptoms, and when and how to refer women to be improved to reduce delays in diagnosis | Women with endometriosis frequently experience significant delays from symptom onset to diagnosis (Cox et al., 2003a; Denny, 2004a, b; Denny and Mann, 2008; Sepulcri and do Amaral, 2009; Fourquet et al., 2010; Bernuit et al., 2011; Nnoaham et al., 2011), ranging from 5 (Sepulcri and do Amaral, 2009) to 8.9 years (Fourquet et al., 2010). While patient level delays (i.e. delays seeking help) account for some of this time, factors relating to the medical profession also contribute. Several papers suggest that prior to diagnosis, women commonly experience repeated visits to doctors where symptoms are normalized, dismissed and/or trivialized, resulting in women feeling ignored and disbelieved (Cox et al., 2003a, b; Denny, 2004a, b, 2009; Jones et al., 2004; Ballard et al., 2006; Denny and Mann, 2008; Manderson et al., 2008; Markovic et al., 2008). Women are often initially referred to inappropriate secondary care, or misdiagnosed, most commonly with irritable bowel syndrome or pelvic inflammatory disease (Jones et al., 2004; Ballard et al., 2006; Denny and Mann, 2008). General practitioners are reported as lacking knowledge, awareness and sympathy and displaying attitudes that perpetuate myths about endometriosis (Cox et al., 2003b; Denny, 2004b; Jones et al., 2004; Denny and Mann, 2008). | However, diagnosis can provide not only a sense of relief, legitimation (i.e. confirmation that their symptoms were genuine), liberation and empowerment, (Cox et al., 2003a; Denny, 2004b; Huntington and Gilmour, 2005; Ballard et al., 2006; Manderson et al., 2008; Seear, 2009b) and a language with which to explain their experiences (Ballard et al., 2006), but crucially it also provides access to a range of treatment and support services to facilitate effective management of the condition.<br>The NICE guideline states that 'delayed diagnosis is a significant problem for women with endometriosis. Patient self-help groups emphasise that healthcare professionals often do not recognise the importance of symptoms or consider endometriosis as a possibility … Delays of 4 to 10 years can occur between first reporting symptoms and confirming the diagnosis. Many women report that the delay in diagnosis leads to increased personal suffering, prolonged ill health and a disease state that is more difficult to treat.' The guideline also has a strong focus on monitoring, referral and diagnosis. | Ballard K, Lowton K, Wright J. (2006) What's the delay? A qualitative study of women's experiences of reaching a diagnosis of endometriosis. Fertil Steril, 5:1296–1301.<br>Bernuit D, Ebert AD, Halis G, Strothmann A, Gerlinger C, Geppert K, Faustmann T. (2011) Female perspectives on endometriosis: findings from the uterine bleeding and pain women's research study. J Endometriosis, 2:73–85.<br>Cox H, Ski C,Wood R, Sheahan M. (2003a) Endometriosis, an unknown entity: the consumer's perspective. Int J Consum Stud, 3:200–209.<br>Cox H, Henderson L, Andersen N, Cagliarini G, Ski C. (2003b) Focus group study of endometriosis: struggle, loss and the medical merry-go-round. Int J Nurs Pract, 1:2–9.<br>Denny E. (2004a) Women's experience of endometriosis. J Adv Nurs, 6:641–648.<br>Denny E. (2004b) 'You are one of the unlucky ones': delay in the diagnosis of endometriosis. Divers Health Social Care, 1:39–44.<br>Denny E, Mann CH. (2008) Endometriosis and the primary care consultation. Eur J Obstet Gynecol Reprod Biol, 1:111–115.<br>Fourquet J, Gao X, Zavala D, Orengo JC, Abac S, Ruiz A, Laboy |

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| | | | | | J, Flores I. (2010) Patients' report on how endometriosis affects health, work, and daily life. Fertil Steril, 7:2424–2428.<br>Jones G, Jenkinson C, Kennedy S. (2004) The impact of endometriosis upon quality of life: a qualitative analysis. J Psychosom Obst Gyn, 2:123–133.<br>Manderson L,Warren N, Markovic M. (2008) Circuit breaking: pathway of treatment seeking for women with endometriosis in Australia. Qual Health Res, 4:522–534.<br>Markovic M, Manderson L,Warren N. (2008) Endurance and contest: women's narratives of endometriosis. Health, 3:349–367.<br>Nnoaham KE, Hummelshoj L,Webster P, d'Hooghe T, de Cicco Nardone F, de Cicco Nardone C, Jenkinson C, Kennedy S, Zondervan K. (2010) Impact of endometriosis on quality of life and work productivity: a multicenter study across ten countries. Fertil Steril, 2:366–373.<br>Sepulcri RD, do Amaral VF. (2009) Depressive symptoms, anxiety, and quality of life in women with pelvic endometriosis. Eur J Obstet Gyn R B, 1:53–56. |
| 2 | Endometriosis UK | Length of time to diagnosis: women are diagnosed promptly, following presenting to a GP with 1 or more symptoms of endometriosis | The current average time to diagnosis is 7.5 years. As an average, this masks very different lengths of time, from just a few months to over 15 years. Prompt diagnosis is recommended in NICE guidance.<br><br>Not having a diagnosis and so not having treatment or management of the | The cost of endometriosis in the UK is estimated at £8.2 billion/year.<br><br>The All Party Parliamentary Group on Women's Health found that 40% of women with endometriosis needed 10 or more GP appointments before being referred to a specialist. | • All Party Parliamentary Group on Women's Health report – *Informed Choice? Giving women control of their healthcare* https://static1.squarespace.com/static/5757c9a92eeb8124fc5b9077/t/58d8c98b1b10e366b431ba06/1490602405791/APPG+Womens+Health+March+2017+web+title.pdf |

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| | | | condition can have significant impact, in lost education/work; in progression of the disease; with mental health, for example by being told what you have is 'normal' and not being believed. As one of the leading causes of infertility, not diagnosing women can take away their choice about having children as they are not aware of the risks. | When reviewing the areas for quality improvement, we discussed whether 'length of time to diagnosis' was an area for quality improvement, or whether it should be a measured outcome of other quality improvement areas. Due to the detrimental impact a lack of diagnosis can have and its importance to women with the condition we believe it should be an area for quality improvement. | • Endometriosis costs the UK approximately £8.2bn per annum in lost working time and healthcare costs. Source: Simoens S, Dunselman G, Dirksen C, et al. The burden of endometriosis: costs and quality of life of women with endometriosis and treated in referral centres. Hum Reprod 2012; 27(5):1292-9.<br>NICE guidelines on endometriosis – call for prompt diagnosis: https://www.nice.org.uk/guidance/ng73 |
| 3 | Endometriosis UK | Specialist endometriosis centres available to all patients that need access to them. No woman with suspected or confirmed deep endometriosis involving the bowel, bladder or ureter should be seen in a general gynaecological service. | The NICE guidelines state that all women should be referred to a specialist endometriosis service (endometriosis centre) if they have suspected or confirmed deep endometriosis involving the bowel, bladder or ureter. This should be available to all women who need it irrespective of where they live.<br>Due to the serious nature of the condition, no women with such endometriosis should be operated on in a general gynaecological setting. | Whilst there are specialist endometriosis centres across the country, not all women who need to be are referred to them, and individuals report different levels of access dependent on where they live.<br><br>Specialist centres provide a multidisciplinary team approach to treatment and management of endometriosis, vital to treating endometriosis effectively. | NICE guidelines on endometriosis |
| 4 | Endometriosis UK | GP's have undertaken structured education in endometriosis and are aware of the symptoms, diagnosis pathway (including referral to secondary care when appropriate) management and treatments. | The (unacceptable) 7.5 years average length of time to diagnosis is mainly due to the symptoms of endometriosis not being recognised nor considered in general practice. GPs must be provided with structured education (eg online CPD provided by the RCGP) and their awareness of the condition and its management measured.<br><br>GPs should know what diagnosis stages and treatments can be undertaken in primary care, and when a woman with endometriosis or potential | The cost of endometriosis in the UK is estimated at £8.2 billion/year.<br>The All Party Parliamentary Group on Women's Health found that 40% of women with endometriosis needed 10 or more GP appointments before being referred to a specialist.<br>Without prompt treatment and management of endometriosis, the condition may progress, making it harder to treat in future.<br>Symptoms of endometriosis overlap with several other conditions, however the first time a woman hears 'endometriosis' should not in the recovery room following a laparoscopy. | NICE Guidelines state "endometriosis can be a long-term condition, and can have a significant physical, sexual, psychological and social impact. Women may have complex needs and require long-term support"<br><br>All Party Parliamentary Group on Women's Health report – *Informed Choice? Giving women control of their healthcare* |

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| | | | endometriosis should be referred to secondary care, and to do so promptly. | Patients with symptoms that may be endometriosis eg chronic pelvic pain should also include patients be provided with clear, succinct information about the possible causes of the symptoms they are experiencing and the investigations that may be undertaken, so they are informed about the route to diagnosis. | |
| 5 | RCGP | Reassurances that overdiagnosis and overinvestigation are considered and minimalised | | | |
| 6 | Royal College of Nursing | Easier routes to an accurate diagnosis. | Women on average take seven years to get a diagnosis. | Endometriosis presents itself in a variety of ways and shares symptoms with other conditions, resulting to difficulty in diagnosis and often delays.<br>Whilst diagnosis is delayed, women are suffering and we are wasting valuable NHS resources which also leads to businesses suffering from women taking time off work due to ill health. | Getting diagnosed with Endometriosis: Endometriosis UK |
| 7 | Royal College of Nursing | Access to secondary care for prompt diagnosis | Many women are not referred on to gynaecologists and are kept in primary care, | This results to variation in practice as access to secondary care differs in different areas. | Getting diagnosed with Endometriosis: Endometriosis UK |
| 8 | RCOG | - Keeping of a symptom diary<br>- Diagnosing endometriosis using diagnostic laparoscopy | | | |
| 9 | SCM | Knowledge and awareness of endometriosis amongst community based HCP | It would reduce misdiagnosis of endometriosis and reduce delays in diagnosis | Delayed diagnosis and treatment of endometriosis can affect quality of life and result in disease progression. | |
| 10 | SCM | Key area for quality improvement 1<br>Suspecting endometriosis in primary care settings. | Delays of 4 – 10 years can occur before women receive a diagnosis of endometriosis. The Royal College of Obstetricians and Gynaecologists (RCOG) recognise that women living with chronic pelvic pain caries a heavy economic and social burden. | The NICE guidance states that the average time from symptom onset to diagnosis is 8 years in the UK. Women during this time often start to normalise their symptoms which can make diagnosis more difficult and cause delays in treatment.<br>Healthcare professionals use of tools to aid diagnosis differs, so leading to an inconsistent | The Endometriosis UK Diagnosis Survey highlights data on delays in diagnosis and delays in referrals to specialist services.<br>The Royal College of Nursing (RCN) Endometriosis factsheet has a tick box table to aid women and healthcare professionals in |

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| | | | Women can often experience a misdiagnosis of Irritable Bowel Syndrome due to the overlap of symptoms (RCN fact sheet).<br>The NICE guidance suggests that endometriosis should be suspected in women presenting with 1 or more if a specified symptom or sign (section 1.3.1) | approach to diagnosing endometriosis. Their level of awareness and knowledge of the disease varies and so women will experience disparities in diagnosis, treatment and referrals. | recognising the symptoms of endometriosis.<br>The NICE guidance recommends informing women that keeping a pain and symptom diary can aid discussion with a health care professional. Aids can be used to prevent unnecessary delays in diagnosis and ongoing distress to women. |
| 11 | SCM | Key area for quality improvement 4<br>Specialist Endometriosis Services to provide specialist expertise in the gynaecological imaging of endometriosis. | The NICE guidance recommends considering ultrasound to identify endometriomas and deep endometriosis involving the bowel, bladder and ureter. Also that MRI should be considered to assess the extent of deep endometriosis.<br>To aid achieving a timely positive diagnosis of deep endometriosis involving the bowel, bladder or ureter to ensure the planning of effective treatment. | For women not having a diagnosis can be deeply distressing and symptoms can be normalised. This can have a psychological impact, as women may believe they have an inability to cope with their symptoms. Providing a positive diagnosis of endometriosis without an invasive laparoscopy can offer relief to women and reassurance about their symptoms.<br>Imaging is a useful follow up tool in women with suspected deep disease who choose not to have surgery (NICE guideline). | The RCOG highlight that TVS is an appropriate investigation to assess adenexal masses and structural abnormalities.<br>The NHS standard contract for severe endometriosis lists transvaginal ultrasound should be used in the management of endometriosis. Also that is service that have a suitable radiology a radiologist should form part of the multi disciplinary team discussion on case management. |
| 12 | SCM | Key area for quality improvement 2<br>Timely referrals for Ultrasound Scan or gynaecological opinion if women meet specific criteria. | The Endometriosis UK diagnosis survey identified that GPs took on average 4 years to refer women to a specialist.<br>The NICE guidance recommends considering a referral to a gynaecological service for a ultrasound or opinion if they meet specific criteria (1.4) | Prior to the NICE guidance primary care health care professionals did not have a set criteria for making a referrals to secondary care services.<br>Delays in referrals can cause women significant prolonged ill health, distress and poor self-management of symptoms. | The endometriosis nurse specialist is in a position to offer advice to primary care practitioners on making referrals to gynaecologist and specialist centres. The NICE guidance highlight the use of managed clinical networks providing coordinated patient pathway.<br>The RCOG recommend that GP's might consider referral when the pain is not explained to the women's satisfaction or when pain is inadequately controlled.<br>The NHS standard contract for complex gynaecology also supports that women with proven severe |

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| | | | | | disease should be referred into gynaecological services.<br>The RCN endometriosis fact sheet states also women with fertility issue should also be referred to a gynaecologist or specialist centre. |
| 13 | SCM | Referral to Gynaecology Service | Endometriosis is a common Gynaecological condition, which can cause severe debilitating symptoms and may also impact on fertility.<br>NICE guidelines suggest that Gynaecological referral should be considered if initial therapy has been ineffective, if recurrent symptoms occur or if there are pelvic signs of endometriosis.<br>The main objective of the guideline is to advise what action to take when women first present with symptoms and signs. | There are persistent on-going delays in diagnosis and treatment for patients suffering from Endometriosis. This is highlighted in the Endometriosis Diagnosis Survey of 2011, which found that women waited on average 4 years to be referred to a specialist and that it took an average of 7.5 years to achieve a diagnosis of endometriosis. This was a moderate improvement on the previous 2005 survey, however the results of this survey indicated delays were still significant. | Please see the Endometriosis Diagnosis Survey 2011. Endometriosis UK (2011) |
| **Management** | | | | | |
| 14 | British Pain Society | Multidisciplinary assessment and management of pain associated with endometriosis | Consistency with other chronic pain conditions | Aim is to prevent avoidable distress and disability associated with chronic pain. | |
| 15 | Centre for Reproduction Research | Endometriosis and fertility care to be more joined up:<br>- When women are receiving endometriosis and fertility related care, this to be better integrated;<br>A new guideline addressing both endometriosis and infertility, and how to treat women when these two issues co-exist, to be developed which would help patients and healthcare providers make informed decisions about their care | It is suggested that up to 47% of infertile women have endometriosis (Meuleman et al., 2009). Amongst studies of women with endometriosis, Sepulcri and do Amaral (2009) and Christian (1993) reported that 50% of couples had experienced problems conceiving. Infertility may be more common however as Fourquet et al. (2010) found that 71% of women had attempted to conceive and 90% of these had experienced difficulties. Fourquet et al. (2010) also found that only 47% of women who had difficulties conceiving sought infertility treatment and Mathias et al. (1996) found that | Infertility, or concerns about possible infertility, is reported to result in worry, depression and feelings of inadequacy among women, and to contribute to relationship breakdown (Jones et al., 2004, Culley et al 2013).<br>Women experience uncertainty regarding fertility in the future (Denny, 2009) and report wanting more information about potential infertility (Cox et al., 2003a).<br>The NICE guideline states that desire for fertility needs to be taken into account when assessing the individual information and support needs of women. | Christian A. (1993) The relationship between women's symptoms of endometriosis and self-esteem. J Obstet Gynecol Neonatal Nurs 4:370–376.<br>• Culley L, Hudson N, Mitchell H, Law C, Denny E, Raine-Fenning N (2013) Endometriosis: improving the wellbeing of couples: Summary Report and Recommendations (www.dmu.ac.uk/endopartreport)<br>Fagervold B, Jenssen M, Hummelshoj L, Moen M. (2009) Life after a diagnosis with endometriosis: a 15 years follow-up |

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| | | | only 4% of women were undergoing infertility treatment. Fagervold et al. (2009) reported that of 45 women with endo and infertility, 76% went on to deliver a biological child and 44% of these were conceived via IVF.<br>• Either actual or anticipated infertility is a significant issue and couples report a range of impacts including effects on decision-making about whether or when to have children and how many, and distress at not having children (Culley et al 2013).<br>In another study, women recalled being given varied, often conflicting, information about the consequences for their fertility of an endometriosis diagnosis. While some recounted positive experiences with the way their doctor communicated with them about endometriosis and fertility, all women reported adverse experiences such as receiving insufficient or inappropriate information or having their doctor prioritize their fertility over other aspects of their care, including quality of life and symptom relief, without first consulting them. (Young et al., 2016). | | study. Acta Obstet Gyn Scan, 8:914–919.<br>Fourquet J, Gao X, Zavala D, Orengo JC, Abac S, Ruiz A, Laboy J, Flores I. (2010) Patients' report on how endometriosis affects health, work, and daily life. Fertil Steril, 7:2424–2428.<br>Mathias SD, Kuppermann M, Liberman RF, Lipschutz RC, Steege JF. (1996) Chronic pelvic pain: prevalence, health-related quality of life, and economic correlates. Obstet Gynecol, 3:321–327.<br>Meuleman C, Vandenabeele B, Fieuws S, Spiessens C, Timmerman D, D'Hooghe T. (2009) High prevalence of endometriosis in infertile women with normal ovulation and normospermic partners. Fertil Steril, 1:68–74.<br>Sepulcri RD, do Amaral VF. (2009) Depressive symptoms, anxiety, and quality of life in women with pelvic endometriosis. Eur J Obstet Gyn R B, 1:53–56.<br>Young K, Fisher J, Kirkman M (2016) Endometriosis and fertility: women's accounts of healthcare, *Hum Reprod*, 31, 3, 554–562. |
| 16 | RCOG | | Initial management with hormonal treatments (e.g. long acting reversible contraception or the oral contraceptive pill)<br>Surgical treatment at laparoscopy if peritoneal endometriosis does not involve bowel bladder or ureter<br>Full discussion of risks and benefits of laparoscopy, including plan if negative<br>Where fertility is a priority for the woman who have an endometrioma, | | |

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| | | | laparoscopic ovarian cystectomy with excision of the cyst wall should be undertaken<br>Full risks and benefits of hysterectomy discussed | | |
| 17 | SCM | Documentation of findings on laparoscopy of extent of disease in a standardised format with image storage and transfer facility | It is recommended that During a diagnostic laparoscopy, a gynaecologist with training and skills in laparoscopic surgery for endometriosis should perform a systematic inspection of the pelvis.<br>This should be supported with standardised template for correct documentation to help prevent multiple laparoscopies when referred from one care provider to another.<br>Further supported by image storage facilities eg video recording of laparoscopy should be standard | | |
| 18 | SCM | Initial pharmacological management of Endometriosis in the primary care setting | Depending on the degree of symptom and disease severity it would be beneficial to the patient to consider a short trial of analgesia, anti-inflammatory drugs and/or hormonal treatment, as stated in NICE guidelines for the initial management of Endometriosis. This can offer effective symptom and disease control at a primary care level, thus delaying or preventing the need for further gynaecological referral. | This is highlighted in the Royal College of Obstetricians and Gynaecologists Guidelines for The Initial Management of Chronic Pelvic Pain, which states that many women could be managed within primary care. Therefore only referring women into secondary care if symptoms are not adequately explained or controlled with initial therapy.<br>The National Heavy Menstrual Bleeding Audit found that nearly one third of their responders had received no treatment in primary care prior to referral. Whilst immediate referral can be appropriate, this highlights potential discrepancy in the initial management of potentially controllable symptoms. | Please see the Royal College of Obstetricians and Gynaecologists Green-top Guideline No.4. May 2012.<br>The Initial Management of Chronic Pelvic Pain.<br>Please see RCOG National Heavy Menstrual Bleeding Audit July 2014. Summary of findings from the Second Annual Report. |
| **Organisation of care** | | | | | |
| 19 | Centre for Reproduction Research | All women diagnosed with endometriosis to have access to an endometriosis Clinical Nurse Specialist (CNS), and the role of the | Commissioning specification identified that accredited BSGE centres, managing complex endometriosis cases, must have an endometriosis | Despite this guidance a recent study at De Montfort University, “The role of Endometriosis Clinical Nurse Specialists in British Society for Gynaecological Endoscopy registered centres: a UK survey of practice”, has found that 87% | NHS England. (2013) NHS Standard Contract for Complex Gynaecology – severe endometriosis. NHS Commissioning Board. Available at: |

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| | | CNS in British Society for Gynaecological Endoscopy (BSGE) centres to be recognised as a primary role (rather than an 'add on' to a different role) to ensure more time for patient contact and support | CNS in place to meet the accreditation criteria.<br>It also makes specific reference to the role of the CNS in providing an interface between patients and the specialist team, liaising directly with women using the service to support them in the management of the condition, and improving their quality of care.<br>The Royal College of Nursing (RCN) Women's Health Forum, in collaboration with Endometriosis UK and the BSGE, devised a skills and knowledge framework to establish a baseline standard for this CNS role to inform and enhance practice across the UK.<br>Whilst women with complex endometriosis have access to an endometriosis CNS via the BSGE accredited specialist centres, women with minor and moderate cases of endometriosis are managed in gynaecology departments, which lie outside of the service commissioning. | of the CNS respondents have another nursing role alongside their endo CNS role: 26 CNSs (81%) had one other role; 4 CNSs had 2 other roles; and 2 CNSs had 3 other roles).<br>The average weekly hours working in this endometriosis CNS role was only 13.5hrs, with this ranging from 5 hours per week to the maximum 37.5 hours, indicating a variation in practice across accredited centres. This results in a lack of direct patient contact time and difficulty for patients trying to access the CNS for on-going support, as well as an inequitable provision for patients.<br>In addition, the majority of women who need support with their symptoms are those who do not fit into the severe category for surgery and those who have endometriosis outside of the pelvis. These women also need support in managing the condition, and improving their quality of care, however these women are not guaranteed access to a nurse specialist.<br>Equally, those women with severe endometriosis that choose not to have surgery for whatever reason, will not be cared for within BSGE specialist centres, and therefore do not access to an endometriosis CNS, despite the severity of their condition. | https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2014/04/e10-comp-gynae-endom-0414.pdf<br>• Norton, W; Holloway, D; Mitchell, H. "A Survey of the Endometrioses CNS Role in BSGE Centres" British Society for Gynaecological Endoscopy Annual Scientific Meeting, Hull, UK. 17 - 19 May 2017.<br>Royal College of Nursing. (2015) Clinical nurse specialist in endometriosis. RCN: London.<br>Norton et al. (2017) The role of Endometriosis Clinical Nurse Specialists in British Society for Gynaecological Endoscopy registered centres: a UK survey of practice (forthcoming) |
| 20 | Endometriosis UK | Gynaecologists with a Special Interest in endometriosis are appointed in all general gynaecological services | The NICE guidelines state that all general gynaecological services should have at least one gynaecologist with a Special Interest in Endometriosis.<br>Without this, women with endometriosis risk being mistreated and misdiagnosed due to lack of knowledge and experience. | The competences, experience and education for this role should be developed, and all general gynaecological services have recruited this position.<br>It is vital to have someone trained appropriately to undertake diagnostic laparoscopies and, where appropriate, surgery. It is also vital that severe cases that need referral to a specialist centre are done so, and not treated in a general setting. | NICE guidelines on endometriosis |
| 21 | Endometriosis UK | Documented care pathways for endometriosis in every locality, funded by the CCG, and supported by a | Endometriosis is a serious and potentially life changing disease, affecting 10% of women of reproductive age – and many others no longer able | The provision of and access to treatment, management and support varies significantly across the country. With no pathway, different women experience very different journeys to | • All Party Parliamentary Group on Women's Health https://static1.squarespace.com/static/5757c9a92eeb8124fc5b9077/ |

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| | | multidisciplinary team, and providing women with a seamless journey between primary and secondary care | to reproduce still have longer term effects of the condition or due to the treatments and/or surgery they have had. It is vital that each CCG in England, and their equivalent in the rest of the UK, plan and commission care pathways to diagnose, treat, manage and support these women throughout their life.<br>This should include (but is not limited to) provision of and access to pain management support, and access to fertility support for those women who wish to have children. | diagnosis, treatment and management, often with 'dead ends' as sent to the wrong specialists, or with no effective hand over between secondary and primary care. As well as the significant detrimental impact this can have on a woman's health and wellbeing, it is also be wasteful to the NHS with unnecessary appointments and treatments in primary and secondary care (including A&E).<br>Care pathways should include management of pain and fertility, as recommended in the NICE guidelines. | t/58d8c98b1b10e366b431ba06/1490602405791/APPG+Womens+Health+March+2017+web+title.pdf<br>• Endometriosis costs the UK approximately £8.2bn per annum in lost working time and healthcare costs. Source: Simoens S, Dunselman G, Dirksen C, et al. The burden of endometriosis: costs and quality of life of women with endometriosis and treated in referral centres. Hum Reprod 2012; 27(5):1292-9.<br>• NICE guidelines on endometriosis |
| 22 | RCGP | Clear access to diagnostics e.g. ultra sound, MRI | | | |
| 23 | RCGP | Clear relevant referral pathways from Primary to Secondary Care | | | |
| 24 | RCGP | Psychologist involvement in the MDT | | | |
| 25 | Royal College of Nursing | Standardisation of treatment pathways | There is great variation in care planning and pathways depending on the consultant and the organisation. | Women should be confident that they know their care pathway, wherever they may be, and that they will not receive any less / more care than a patient with the same condition in another part of the country. | Endometriosis Fact sheet – Royal College of Nursing (2017) |
| 26 | Royal College of Nursing | Increasing numbers of Endometriosis specialist centre and access to clinical nurses specialists | Many gynaecology units do not have healthcare professionals with the specialist knowledge or skills to manage complex cases of endometriosis.<br>Recent commissioning consultations identified that complex endometriosis cases should be managed by dedicated specialist centres that are accredited by the British Society for Gynaecological Endoscopy (BSGE). The review also considered that women attending these | This leads to variation in practice specifically around access to clinical nurse specialists. Access needs to be expanded to all women with endometriosis<br>Women should be cared for by healthcare professionals who have specialist knowledge and are competent to manage their cases. | Endometriosis Fact sheet – Royal College of Nursing (2017)<br>RCN Guidance: Clinical nurse specialist in endometriosis (2015) |

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| | | | centres would benefit from improved quality of care by having direct access to an endometriosis clinical nurse specialist (CNS) and accreditation of these specialist centres are now dependent on having an endometriosis nurse specialist in place.<br>Further, the current set up of CNS input for women with severe endometriosis is defined by a surgical definition. | | |
| 27 | RCOG | | The use of a true multidisciplinary team and information provision for women who will be made medically or surgically menopausal (crosses over with QS 143 number 5 from Menopause guideline).<br>Organisation of services involving a managed clinical network | | |
| 28 | SCM | Gynaecology Services | Improve patient care and outcome | Access to a gynaecologist in conjunction with endometriosis nurse, pain management service and fertility services if applicable would coordinate and improve patient care | |
| 29 | SCM | Pain Management Services | Endometriosis can cause severe pain restricting daily activities and affecting quality of life | Current provision for management and treatment of pelvic pain associated with endometriosis is very varied and not available to all patients who require this level of expertise and support. | |
| 30 | SCM | Access to Specialist Endometriosis Services | Improve patient care and outcome | Current provision is limited and is not available to all patients who require this level of expertise and support | |
| 31 | SCM | | There are a limited number of specialist centres in the UK and as a result there is variation in the level of care that women experience in different geographical areas. | | |
| 32 | SCM | Timely diagnosis of endometriosis: referral pathways | Because delay in diagnosis and initiation of treatment can affect | | NICE guidance: see below<br>ESHRE guidance |

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| | | | quality of life and result in disease progression | | |
| 33 | SCM | Provision of coordinated care: managed clinical network consisting of community services (including GPs, practice nurses, school nurses and sexual health services), gynaecology services and specialist endometriosis services (endometriosis centres) for women with suspected or confirmed endometriosis | To help attain prompt diagnosis and offer timely treatment | | Studies suggest that there may be a delay of 4–10 years between first presentation and diagnosis. Many women think that the delay in diagnosis leads to increased personal suffering, prolonged ill health and a disease state that is more difficult to treat. Many women with endometriosis also believe that delays in diagnosis occur because healthcare professionals fail to recognise the significance of symptoms and think that women are ‘overreacting’. Endometriosis is associated with lower quality of life. A study reported that the diagnosis of endometriosis was associated with more sick days, tiredness, frequent pain, a higher daily pain level, and feeling depressed. Endometriosis is also an important cause of subfertility and this can also have a significant effect on QOL. |

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| 34 | SCM | Access to appropriate Gynaecology services in secondary care for women with suspected or confirmed endometriosis<br>Eg. gynaecologist with training and skills in laparoscopic surgery or HCP with interest in gynae imaging. | As recommended by NICE:<br>For appropriate management of these women, they should have access to:<br>• a gynaecologist with expertise in diagnosing and managing endometriosis, including training and skills in laparoscopic surgery<br>• a gynaecology specialist nurse with expertise in endometriosis<br>• a multidisciplinary pain management service<br>• a healthcare professional with an interest in gynaecological imaging<br>• fertility services.<br>However, this is lacking in many hospitals across the UK | | Earlier diagnosis and cost-effective treatment of endometriosis may improve quality of life and productivity in the workplace, reduce healthcare cost, and consequently reduce total cost to patients and society (NICE guidance) |
| **Information and support** | | | | | |
| 35 | Centre for Reproduction Research | Support services to be inclusive of relationships, sex and intimacy:<br>- when women's history and quality of life data are taken, ask women if endometriosis impacts on their relationships with spouses/partners, including specifically on sex and intimacy, and offer them the opportunity to bring their partner to consultations if they wish to;<br>- for those women/couples who report an impact on sex and intimacy, facilitate access to psychosexual support | Endometriosis can affect relationships, sex and intimacy in a range of ways for women and couples, including strain on relationship and relationship breakdown, as well as partners being an important source of support. Women and partners report a range of emotions including frustration, inadequacy, loss, guilt, powerlessness, worry, helplessness and anger. Impacts on sex and intimacy result from not only dyspareunia, but also issues such as bleeding during and/or after sex, general fatigue and feeling unwell, reduced sexual desire as a result of medication, having a low mood, the stress of trying to get pregnant and feeling generally unattractive and unfeminine. Without adequate support, the impacts of the condition on sex and intimacy may result in further relationship strain/ relationship breakdown, impaired quality of life and | The impact of endometriosis on relationships, sex and intimacy, and the lack of adequate support, was documented in the ENDOPART study (Culley et al, 2013; Hudson et al, 2016; Culley et al., 2017) and in other academic articles (Bernuit et al., 2011, Butt and Chesla, 2007, Chene et al. 2012, Christian, 1993, Cox et al.,2003, Denny 2004a, Denny 2004b, Denny and Mann, 2007, Fagervold et al., 2009, Ferrero et al., 2005, Fernandez et al 2006, Fourquet et al., 2010, Fourquet et al., 2011, Huntington and Gilmour, 2005, Jones et al., 2004, Tripoli et al., 2011, Waller and Shaw, 1995). In addition, Denny (2004 a, b) found that women were reluctant to discuss dyspareunia with healthcare professionals and that women reported that healthcare professionals did not ask about this. Research also suggests that interventions to enable couples to address the impact of endometriosis on sexual relations are limited and those that are available are reported by | Bernuit D, Ebert AD, Halis G, Strothmann A, Gerlinger C, Geppert K, Faustmann T. (2011) Female perspectives on endometriosis: findings from the uterine bleeding and pain women's research study. J Endometriosis, 2:73–85.<br>Butt F, Chesla C. Relational patterns of couples living with chronic pelvic pain from endometriosis (2007) Qual Health Res, 5:571–585.<br>Chene G, Jaffeux P, Lasnier C, Cuvelier BA, Tamburro S, Matsuzaki S, Jardon K, Mage G, Pouly J, Canis M (2012) Quality of life of women with endometriosis: comparison between epiphenomenon and severe disease. J Endometriosis, 2:77–84.<br>Christian A. (1993) The relationship between women's symptoms of endometriosis and self-esteem. J |

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| | | | emotional wellbeing, and stress and distress for both partners. | couples to be unhelpful (Butt and Chesla, 2007; Culley et al, 2013).<br>The NICE guideline recognises that endometriosis ‘may also have a significant impact on the emotional, psychosocial and psychosexual wellbeing of women and their partners and families’ and includes recommendations that assessments should take into account ‘psychosexual and emotional needs.’ | Obstet Gynecol Neonatal Nurs 4:370–376.<br>Cox H, Henderson L, Wood R, Cagliarini G. (2003) Learning to take charge: women’s experiences of living with endometriosis. Complement Ther Nurs Midwifery, 2:62–68.<br>• Culley L, Hudson N, Mitchell H, Law C, Denny E, Raine-Fenning N (2013) Endometriosis: improving the wellbeing of couples: Summary Report and Recommendations (www.dmu.ac.uk/endopartreport)<br>Culley L, Hudson N, Law C, Mitchell H, Denny E. Raine-Fenning (2016) A qualitative study of the impact of endometriosis on male partners, Hum Reprod, 32, 8, 1667–1673.<br>Denny E. Women’s experience of endometriosis (2204a) J Adv Nurs, 6:641–648.<br>Denny E. ‘You are one of the unlucky ones’: delay in the diagnosis of endometriosis (2004b) Divers Health Social Care 2004b;1:39–44.<br>Denny E, Mann CH. Endometriosis-associated dyspareunia: the impact on women’s lives (2007) J Fam Plan Reprod H, 3:189–193.<br>Fagervold B, Jenssen M, Hummelshoj L, Moen M. (2009) Life after a diagnosis with endometriosis: a 15 years follow-up study. Acta Obstet Gyn Scan, 8:914–919.<br>Fernandez I, Reid C, Dziurawiec S. (2006) Living with endometriosis: the perspective of male partners. J Psychosom Res, 4:433–438. |

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| | | | | | Fourquet J, Gao X, Zavala D, Orengo JC, Abac S, Ruiz A, Laboy J, Flores I. (2010) Patients’ report on how endometriosis affects health, work, and daily life. Fertil Steril, 7:2424–2428.<br>Fourquet J, Ba´ez L, Figueroa M, Iriarte RI, Flores I. (2011) Quantification of the impact of endometriosis symptoms on health-related quality of life and work productivity. Fertil Steril, 1:107–112.<br>Hudson N, Culley L, Law C, Mitchell H, Denny E. Raine-Fenning (2016) ‘We needed to change the mission statement of the marriage’: biographical disruptions, appraisals and revisions amongst couples living with endometriosis. Sociol Health Ill, 5:721–735<br>Huntington A, Gilmour J. (2005) A life shaped by pain: women and endometriosis. J Clin Nurs, 9:1124–1132.<br>Jones G, Jenkinson C, Kennedy S. (2004) The impact of endometriosis upon quality of life: a qualitative analysis. J Psychosom Obst Gyn, 2:123–133.<br>Tripoli TM, Sato H, Sartori MG, de Araujo FF, Gira˜o M, Schor E. (2011) Evaluation of quality of life and sexual satisfaction in women suffering from chronic pelvic pain with or without endometriosis. J Sex Med, 2:497–503.<br>Waller KG, Shaw RW. (1995)Endometriosis, pelvic pain, and psychological functioning. Fertil Steril, 4:796–800. |

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| 36 | Centre for Reproduction Research | Endometriosis and fertility care to be more joined up:<br>• upon diagnosis, healthcare practitioners to raise the topic of planning for and having children, and open up a discussion that allows women and couples to explore this important issue and to receive evidence-based information, advice and support from appropriately trained individuals; | It is suggested that up to 47% of infertile women have endometriosis (Meuleman et al., 2009). Amongst studies of women with endometriosis, Sepulcri and do Amaral (2009) and Christian (1993) reported that 50% of couples had experienced problems conceiving. Infertility may be more common however as Fourquet et al. (2010) found that 71% of women had attempted to conceive and 90% of these had experienced difficulties. Fourquet et al. (2010) also found that only 47% of women who had difficulties conceiving sought infertility treatment and Mathias et al. (1996) found that only 4% of women were undergoing infertility treatment. Fagervold et al. (2009) reported that of 45 women with endo and infertility, 76% went on to deliver a biological child and 44% of these were conceived via IVF.<br><br>Either actual or anticipated infertility is a significant issue and couples report a range of impacts including effects on decision-making about whether or when to have children and how many, and distress at not having children (Culley et al 2013).<br>In another study, women recalled being given varied, often conflicting, information about the consequences for their fertility of an endometriosis diagnosis. While some recounted positive experiences with the way their doctor communicated with them about endometriosis and fertility, all women reported adverse experiences such as receiving insufficient or inappropriate information or having their doctor | Infertility, or concerns about possible infertility, is reported to result in worry, depression and feelings of inadequacy among women, and to contribute to relationship breakdown (Jones et al., 2004, Culley et al 2013).<br>Women experience uncertainty regarding fertility in the future (Denny, 2009) and report wanting more information about potential infertility (Cox et al., 2003a).<br>The NICE guideline states that desire for fertility needs to be taken into account when assessing the individual information and support needs of women. | Christian A. (1993) The relationship between women's symptoms of endometriosis and self-esteem. J Obstet Gynecol Neonatal Nurs 4:370–376.<br>• Culley L, Hudson N, Mitchell H, Law C, Denny E, Raine-Fenning N (2013) Endometriosis: improving the wellbeing of couples: Summary Report and Recommendations (www.dmu.ac.uk/endopartreport)<br>Fagervold B, Jenssen M, Hummelshoj L, Moen M. (2009) Life after a diagnosis with endometriosis: a 15 years follow-up study. Acta Obstet Gyn Scan, 8:914–919.<br>Fourquet J, Gao X, Zavala D, Orengo JC, Abac S, Ruiz A, Laboy J, Flores I. (2010) Patients' report on how endometriosis affects health, work, and daily life. Fertil Steril, 7:2424–2428.<br>Mathias SD, Kuppermann M, Liberman RF, Lipschutz RC, Steege JF. (1996) Chronic pelvic pain: prevalence, health-related quality of life, and economic correlates. Obstet Gynecol, 3:321–327.<br>Meuleman C, Vandenabeele B, Fieuws S, Spiessens C, Timmerman D, D'Hooghe T. (2009) High prevalence of endometriosis in infertile women with normal ovulation and normospermic partners. Fertil Steril, 1:68–74.<br>Sepulcri RD, do Amaral VF. (2009) Depressive symptoms, anxiety, and quality of life in women with pelvic endometriosis. Eur J Obstet Gyn R B, 1:53–56. |

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| | | | prioritize their fertility over other aspects of their care, including quality of life and symptom relief, without first consulting them. (Young et al., 2016). | | Young K, Fisher J, Kirkman M (2016) Endometriosis and fertility: women's accounts of healthcare, *Hum Reprod*, 31, 3, 554–562. |
| 37 | PrimeHealth London | Access to culturally sensitive information on endometriosis | | | |
| 38 | PrimeHealth London | Access to culturally sensitive support in primary care for women and family members | | | |
| 39 | PrimeHealth London | Access to culturally sensitive support in secondary care for BAME women diagnosed with endometriosis | | | |
| 40 | PrimeHealth London | Appropriate education on endometriosis at community level | | | |
| 41 | PrimeHealth London | Appropriate education on endometriosis at secondary level | | | |
| 42 | RCOG | The provision of information and support to women with suspected or confirmed endometriosis | | | |
| 43 | SCM | Key area for quality improvement 3<br>Provide information and support to women with suspected or confirmed endometriosis. | The NICE guidance raises awareness that endometriosis is potentially a chronic condition and therefore requires long-term support. It is recommended that services should provide information and support for women on specified key areas (1.2.3) | Providing the right support and information is crucial to help women understand their disease and therefore utilise appropriate self-management strategies.<br>The RCOG suggest that women need to feel they have been able to tell their story, listened to and believed.<br>Women may access information presented in different formats and varying quality of information. This may impact on their decision-making and management of the disease.<br>The Endopart Survey (2013) looked at the wellbeing of couples and identified common | NHS England specialist contract for severe endometriosis states that services will provide appropriate counselling and psychological support and provide a nurse specialist.<br>They also state an initial outpatient assessment in specialist centres should be with a specialist nurse with information giving, counselling and explanations.<br>The RCN endometriosis CNS guidance also supports that the CNS should be the first point of contact on the women's initial visit to the centre and they should offer a clinical assessment along with the |

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| | | | | themes with endometriosis management of delayed diagnosis, differing quality of health care provision and insufficient information from healthcare professionals. | appropriate information, counselling and support, so offering a holistic package of care.<br>The British Society for Gynaecological Endoscopy (BSGE) has set criteria that all specialist centre should have an endometriosis CNS and this has been recognised in the NICE guideline. |
| 44 | SCM | Psycho-social support to meet long term needs of women with complex needs | This is a chronic disease affecting women in reproductive age group and some of these women will have complex needs which needs appropriate psychological and social support network which is currently lacking in the NHS. | | |
| 45 | SCM | Provide Patient Information Literature For Endometriosis | Providing information and support for women with suspected or confirmed Endometriosis is recommended within NICE guidance. This includes information about what Endometriosis is, what the symptoms and signs are, how it is diagnosed and treated and guidance on further support resources etc.<br>Endometriosis is a complex condition with variable presentations, degrees of severity and outcomes, which will also have a variable impact on Women's quality of life in terms of physical and psychological impact.<br>Treatment/management options are also varied and may depend upon a wide range of factors including; the severity of the condition, symptoms, fertility wishes, lifestyle, cultural and emotional needs.<br>Therefore it is necessary for women to have a good understanding of their condition and to understand what | Due to the varied nature of presentation for Endometriosis and the range of management options, it is difficult to map an exact patient treatment pathway. However providing patients with information about their condition will assist them in making informed choices about their treatment and also assist in the effective planning of treatment regimes in the clinic setting.<br><br>Whilst there is limited information regarding the national availability of patient information leaflets specifically for Endometriosis, there is variability in the quality of available literature and the distribution of literature throughout secondary care.<br>The National Heavy Menstrual Bleeding Audit encompasses a proportion of patients who suffer from endometriosis (although not exclusively endometriosis patients) and highlights the improvement in secondary care providers offering patient information leaflets between 2010 and 2013. However there is still scope for improvement. | Please see NHS England (2013) NHS Standard Contract For Complex Gynaecology-Severe Endometriosis. This document highlights patient information as a service aim/objective to be delivered at primary outpatient assessment.<br><br>RCOG National Heavy Menstrual Bleeding Audit July 2014 – Illustrates improvement in the delivery of patient information leaflets, but also highlights variation in treatment uptakes according to social deprivation, white and non-white ethnic backgrounds. |

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| | | | options are available to effectively balance their treatment against their individual needs. | Information should also be tailored to the patients' cultural and needs and made more readily available according to the patient demographic of the clinical institution. | |
| **Additional areas** | | | | | |
| 46 | RCOG | | In terms of topic engagement, need to take account of religious or minority ethnic groups, where talking about periods is even more of a taboo than it is in the general population so that there are ways to reach women from such groups who may not be presenting themselves to a GP with these problems.<br>A strategy needs to be developed which enables younger patients to be listened to.<br>Female bias: although this would account for a very small minority of actual or potential endometriosis patients, transgender people with endometriosis have to be considered so that they are able to access services in an appropriate and sensitively handled way. | | |
| 47 | Royal College of Nursing | Highlight the symptoms in primary care and with teenagers | Increase awareness in endometriosis. | Women are not often aware of the symptoms and leads to women not seeking help. Increasing knowledge of what is an acceptable period and talking about menstruation will increase the number of women seeking help. Often young women are told its normal and not offered help | Getting diagnosed with Endometriosis: Endometriosis UK |
| 48 | SCM | Awareness of endometriosis amongst the general population | Endometriosis is a common disease but there is poor public awareness | If women were aware of symptoms of endometriosis this could reduce delays in diagnosis | |
| 49 | Centre for Reproduction Research | That endometriosis in adolescents and young women, and the psychosocial impact of the | Few studies have explored the experiences of younger women, despite the significance of this time frame for life transitions and evidence that | There is a lack of research in this area, and relatedly a lack of support and information aimed at younger women, despite research on other conditions and research with adult | Cox H, Ski C,Wood R, Sheahan M. (2003) Endometriosis, an unknown entity: the consumer's perspective. Int J Consum Stud, 3:200–209 |

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| | | condition, is seen as a priority area for future research | symptoms might be worse in younger women. Studies of other chronic conditions demonstrate specific problems for young people, including feelings of isolation and dependency that can be detrimental to self-esteem, forming relationships, and the development of adult identities (Taylor et al., 2008; Burles & Thomas, 2013). Experiences in the transition to adulthood can also have significant consequences for adult life in relation to educational achievement and employment. Adult women retrospectively report the negative impact of endometriosis during young adulthood, including a lack of understanding from families, missing time at school, and relationship difficulties (Cox et al., 2003; Manderson et al., 2008). However, few studies allow young women to express the impact of endometriosis on their lives. | women with endometriosis suggesting the needs of young women may be different from those of older-adult women. | Manderson L,Warren N, Markovic M. (2008) Circuit breaking: pathway of treatment seeking for women with endometriosis in Australia. Qual Health Res, 4:522–534.<br>Taylor RM, Gibson F, Franck LS. (2008) The experience of living with a chronic illness during adolescence: a critical review of the literature. J Clin Nurs, 23;3083–3091.<br>Burles M, Thomas R (2013) 'But they're happening to you at the wrong time': Exploring young adult women's reflections on serious illness through photovoice. Qualitative Social Work, 12, 5, 671–688. |
| 50 | Centre for Reproduction Research | Endometriosis and fertility care to be more joined up: A new guideline addressing both endometriosis and infertility, and how to treat women when these two issues co-exist, to be developed which would help patients and healthcare providers make informed decisions about their care | It is suggested that up to 47% of infertile women have endometriosis (Meuleman et al., 2009). Amongst studies of women with endometriosis, Sepulcri and do Amaral (2009) and Christian (1993) reported that 50% of couples had experienced problems conceiving. Infertility may be more common however as Fourquet et al. (2010) found that 71% of women had attempted to conceive and 90% of these had experienced difficulties. Fourquet et al. (2010) also found that only 47% of women who had difficulties conceiving sought infertility treatment and Mathias et al. (1996) found that only 4% of women were undergoing infertility treatment. Fagervold et al. | Infertility, or concerns about possible infertility, is reported to result in worry, depression and feelings of inadequacy among women, and to contribute to relationship breakdown (Jones et al., 2004, Culley et al 2013).<br>Women experience uncertainty regarding fertility in the future (Denny, 2009) and report wanting more information about potential infertility (Cox et al., 2003a).<br>The NICE guideline states that desire for fertility needs to be taken into account when assessing the individual information and support needs of women. | Christian A. (1993) The relationship between women's symptoms of endometriosis and self-esteem. J Obstet Gynecol Neonatal Nurs 4:370–376.<br>• Culley L, Hudson N, Mitchell H, Law C, Denny E, Raine-Fenning N (2013) Endometriosis: improving the wellbeing of couples: Summary Report and Recommendations (www.dmu.ac.uk/endopartreport)<br>Fagervold B, Jenssen M, Hummelshoj L, Moen M. (2009) Life after a diagnosis with endometriosis: a 15 years follow-up study. Acta Obstet Gyn Scan, 8:914–919. |

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| | | | (2009) reported that of 45 women with endo and infertility, 76% went on to deliver a biological child and 44% of these were conceived via IVF.<br>• Either actual or anticipated infertility is a significant issue and couples report a range of impacts including effects on decision-making about whether or when to have children and how many, and distress at not having children (Culley et al 2013).<br>In another study, women recalled being given varied, often conflicting, information about the consequences for their fertility of an endometriosis diagnosis. While some recounted positive experiences with the way their doctor communicated with them about endometriosis and fertility, all women reported adverse experiences such as receiving insufficient or inappropriate information or having their doctor prioritize their fertility over other aspects of their care, including quality of life and symptom relief, without first consulting them. (Young et al., 2016). | | Fourquet J, Gao X, Zavala D, Orengo JC, Abac S, Ruiz A, Laboy J, Flores I. (2010) Patients' report on how endometriosis affects health, work, and daily life. Fertil Steril, 7:2424–2428.<br>Mathias SD, Kuppermann M, Liberman RF, Lipschutz RC, Steege JF. (1996) Chronic pelvic pain: prevalence, health-related quality of life, and economic correlates. Obstet Gynecol, 3:321–327.<br>Meuleman C, Vandenabeele B, Fieuws S, Spiessens C, Timmerman D, D'Hooghe T. (2009) High prevalence of endometriosis in infertile women with normal ovulation and normospermic partners. Fertil Steril, 1:68–74.<br>Sepulcri RD, do Amaral VF. (2009) Depressive symptoms, anxiety, and quality of life in women with pelvic endometriosis. Eur J Obstet Gyn R B, 1:53–56.<br>Young K, Fisher J, Kirkman M (2016) Endometriosis and fertility: women's accounts of healthcare, *Hum Reprod*, 31, 3, 554–562. |
| 51 | RCGP | Clear guidance on Primary Care Management | | | |
| 52 | Royal College of Pathologists | As there is a risk of neoplasia arising in endometrioisis, I would suggest that there should be guidelines on when conservative management should not be pursued. | | | |