NICE National Institute for Health and Care Excellence

NICE quality standard

Endometriosis

Quality standard

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This standard is based on NG73.

This standard should be read in conjunction with QS143, QS73 and QS47.

Quality statements

Statement 1 Women presenting with suspected endometriosis have an abdominal and, if appropriate, a pelvic examination.

Statement 2 Women are referred to a gynaecology service if initial hormonal treatment for endometriosis is not effective, not tolerated or contraindicated.

Statement 3 Women with suspected or confirmed deep endometriosis involving the bowel, bladder or ureter are referred to a specialist endometriosis service.

NICE has developed guidance and a quality standard on patient experience in adult NHS services (see the NICE Pathway on patient experience in adult NHS services), which should be considered alongside these quality statements.

Other quality standards that should be considered when commissioning or providing endometriosis services include:

- Menopause (2017) NICE quality standard 143
- Fertility problems (2014) NICE quality standard 73
- Heavy menstrual bleeding (2013 updated 2018) NICE quality standard 47

A full list of NICE quality standards is available from the quality standards topic library.

Quality statement 1: Presentation with suspected endometriosis

Quality statement

Women presenting with suspected endometriosis have an abdominal and, if appropriate, a pelvic examination.

Rationale

By performing an abdominal and, if appropriate, a pelvic examination when a woman first presents with symptoms of endometriosis, delays in diagnosis and treatment can be reduced. A physical examination of the abdomen, and the pelvis if appropriate, can identify signs of endometriosis such as abdominal or pelvic masses, reduced organ mobility or enlargement, points of tenderness, or visible vaginal endometriotic lesions. This enables the healthcare professional to consider a working diagnosis of endometriosis and begin a treatment plan.

Quality measures

Structure

a) Evidence of local arrangements to identify women with signs and symptoms of endometriosis.

Data source: Local data collection, for example training records on endometriosis for healthcare professionals and audits of healthcare records.

b) Evidence of protocols detailing symptoms of endometriosis and the need for abdominal and pelvic examination when this is suspected.

Data source: Local data collection, for example local clinical protocols.

Process

a) Proportion of women who present to healthcare professionals with symptoms or signs suggesting endometriosis who have an abdominal and pelvic examination.

Numerator – the number in the denominator who have an abdominal and a pelvic examination.

Denominator – number of women presenting with symptoms or signs suggesting endometriosis for whom a pelvic examination is appropriate.

Data source: Local data collection, for example audits of GP, practice nurse, sexual health clinic, school health service or emergency department records.

b) Proportion of women who present to healthcare professionals with symptoms or signs suggesting endometriosis for whom a pelvic examination would not be appropriate who have an abdominal examination.

Numerator – the number in the denominator who have an abdominal examination.

Denominator – the number of women presenting with symptoms or signs suggesting endometriosis for whom a pelvic examination would not be appropriate.

Data source: Local data collection, for example audits of GP, practice nurse, sexual health clinic, school health service or emergency department records.

Outcome

a) Number of working diagnoses of endometriosis following initial presentation.

Data source:Local data collection, for example audits of GP records.

b) Time from initial presentation with symptoms or signs of endometriosis to diagnosis.

Data source:Local data collection, for example audits of GP and gynaecology services records.

What the quality statement means for different audiences

Service providers (such as GP practices, school health services, sexual health clinics, and emergency departments) ensure that staff are aware of the symptoms and signs of endometriosis and that facilities are in place for women presenting with a symptom or sign of endometriosis to have a physical examination. They ensure that staff know that a pelvic and abdominal examination should be carried out if appropriate. They should ensure that staff are aware that a pelvic examination may not be suitable or appropriate for some groups, for example women with learning disabilities, very young women and women who have never been sexually active, and that these groups should have an abdominal examination.

Healthcare professionals (such as GPs, practice nurses, school nurses, sexual health nurses and emergency department practitioners) consider endometriosis as a possible diagnosis when women

present with a symptom or sign that suggests endometriosis. They carry out an abdominal and pelvic examination, if appropriate, to exclude other possible causes as soon as possible, either when the woman initially presents or a short time afterwards. They are aware that a pelvic examination may not be suitable or appropriate for some groups, for example women with learning disabilities, very young women and women who have never been sexually active, and they carry out abdominal examination for these groups. They are aware that the possibility of endometriosis should not be ruled out if the examination findings are normal.

Commissioners (such as NHS England, clinical commissioning groups and local authorities) ensure that they commission services that raise awareness of endometriosis among staff and have clinical protocols in place for detailing symptoms and signs of endometriosis and the need for different types of examination, depending on the woman's circumstances, when endometriosis is suspected.

Women with symptoms or signs of endometriosis (such as chronic pelvic pain, severe period-related pain or deep pain during or after sexual intercourse) have an examination of their abdomen, and of their pelvis if this is appropriate, the first time they visit a healthcare professional to discuss these symptoms or signs, or shortly afterwards if they prefer. This examination can help to rule out other possible conditions and means that treatment for endometriosis can be started quickly.

Source guidance

Endometriosis: diagnosis and management (2017) NICE guideline NG73, recommendations 1.3.3 and 1.3.4

Definitions of terms used in this quality statement

Suspected endometriosis

Suspect endometriosis in women (including young women aged under 17 years) 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.

[NICE's guideline on endometriosis, recommendation 1.3.1]

Equality and diversity considerations

Practitioners should be aware that some women may feel particularly anxious or have extreme difficulties undergoing some procedures such as abdominal and pelvic examinations. There could be a number of reasons for this, for example the woman's culture or age, or a learning disability. Consideration should therefore be given to carrying out an abdominal examination only, if this is clinically appropriate, and ensuring that the woman can bring a friend or relative as a chaperone if she wishes. Some women may also prefer to have a female practitioner carry out the examination.

Transgender men should have endometriosis considered as a possible diagnosis if they present with suspected endometriosis.

Quality statement 2: Referral after initial hormonal treatment

Quality statement

Women are referred to a gynaecology service if initial hormonal treatment for endometriosis is not effective, not tolerated or contraindicated.

Rationale

Initial hormonal treatment for endometriosis is usually given in primary care after a working diagnosis of endometriosis has been made. Referral to a gynaecology service if this initial hormonal treatment is not effective, not tolerated or contraindicated allows further investigation and treatment options to be explored. This can reduce the possibility of women experiencing significant, prolonged ill health and distress, and improve their quality of life.

Quality measures

Structure

Evidence of local referral pathways to a gynaecology service for women in whom initial hormonal treatment for endometriosis is not effective, not tolerated or contraindicated.

Data source: Local data collection, for example local commissioning agreements and service specifications.

Process

Proportion of women in whom initial hormonal treatment for endometriosis is not effective after 6 months, not tolerated or contraindicated who are referred to a gynaecology service.

Numerator – the number in the denominator who are referred to a gynaecology service.

Denominator – the number of women in whom initial hormonal treatment for endometriosis is not effective after 6 months, not tolerated or contraindicated.

Data source: Local data collection, for example primary care referral records.

Outcome

Satisfaction of women with suspected or confirmed endometriosis with their treatment plan.

*Data source:*Local data collection, such as patient experience surveys.

What the quality statement means for different audiences

Service providers (such as GP practices and emergency departments) ensure that systems are in place for women to be referred to a gynaecology service if initial hormonal treatment for endometriosis is not effective, not tolerated or contraindicated. Referrals will be made to a general gynaecology service, specialist endometriosis service or paediatric and adolescent gynaecology service depending on the nature of the woman's symptoms, her age and local service provision.

Healthcare professionals (such as GPs and practitioners in emergency departments) are aware of the local referral pathways for women in whom initial hormonal treatment for endometriosis is not effective, not tolerated or contraindicated. They will make referrals to a general gynaecology service, specialist endometriosis service or paediatric and adolescent gynaecology service, depending on the nature of the woman's symptoms, her age and local service provision.

Commissioners (such as clinical commissioning groups and clinical networks) ensure that they commission secondary and tertiary services that include the necessary healthcare professionals to diagnose and treat endometriosis (general gynaecology service, specialist endometriosis service or paediatric and adolescent gynaecology service).

Women with signs and symptoms of endometriosis are referred to a gynaecology service if the symptoms are not relieved by their first hormonal treatment (such as the combined oral contraceptive pill or a progestogen), or if they are not able to have hormonal treatment, for example if they are trying to conceive. They are referred to a general gynaecology service, a specialist endometriosis service, or a paediatric and adolescent gynaecology service, depending on their symptoms, their age and the services that are available in their area.

Source guidance

Endometriosis: diagnosis and management (2017) NICE Guideline NG73, recommendation 1.8.7

Definitions of terms used in this quality statement

Initial hormonal treatment that is not effective

For measurement purposes, a 6-month timescale can be used to decide whether initial hormonal treatment is effective. However, a referral should be made before 6 months if it becomes clear that treatment is not effective.

[Expert opinion]

Gynaecology service

Women can be referred to one of the following services:

- general gynaecology service
- specialist endometriosis service (endometriosis centre)
- paediatric and adolescent gynaecology service.

[Adapted from NICE's guideline on endometriosis, recommendation 1.8.7]

General gynaecology services for women with suspected or confirmed endometriosis

General gynaecology services for women with suspected or confirmed endometriosis 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.

[Adapted from NICE's guideline on endometriosis, recommendation 1.1.3]

Specialist endometriosis service (endometriosis centre)

Specialist endometriosis services (endometriosis centres) 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.

[Adapted from NICE's guideline on endometriosis, recommendation 1.1.4]

Paediatric and adolescent gynaecology service

Paediatric and adolescent gynaecology services are hospital-based, multidisciplinary specialist services for girls and young women (usually aged under 18).

[NICE's guideline on endometriosis, terms used in this guideline]

Equality and diversity considerations

Transgender men should be referred to gynaecology services if endometriosis is suspected because initial hormonal treatment for endometriosis may be contraindicated. Some transgender men may find it distressing to attend appointments in a women's hospital or dedicated women's unit and may need to be seen in another clinic or setting.

Some services, such as paediatric and adolescent gynaecology services and specialist endometriosis services, may not be available in all local areas. This should not prevent access to appropriate care.

Quality statement 3: Referral for deep endometriosis

Quality statement

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

Rationale

Management of deep endometriosis involving the bowel, bladder or ureter needs the expertise of healthcare professionals working in a specialist endometriosis service. This will help to ensure that women with deep endometriosis receive the appropriate treatment and, if surgery is needed, it can be carried out by specialists in deep endometriosis. A specialist endometriosis service can also provide support from a clinical nurse specialist to help women manage the condition.

Quality measures

Structure

a) Evidence of local referral protocols for women with suspected or confirmed deep endometriosis involving the bowel, bladder or ureter.

Data source: Local data collection, for example referral pathways and protocols for women with suspected or confirmed deep endometriosis.

b) Evidence of services working toward accreditation as specialist endometriosis services.

Data source: Local data collection, for example service plans and accreditation applications.

Process

Proportion of women with suspected or confirmed deep endometriosis involving the bowel, bladder or ureter who are referred to a specialist endometriosis service.

Numerator – the number in the denominator who are referred to a specialist endometriosis service.

Denominator – the number of women with suspected or confirmed deep endometriosis involving the bowel, bladder or ureter.

Data source: Local data collection, for example GP, gynaecology service or paediatric and adolescent gynaecology service records.

Outcome

a) Diagnosis rates of deep endometriosis involving the bowel, bladder or ureter.

*Data source:*Local data collection, for example specialist endometriosis services records.

b) Rates of surgical treatment for deep endometriosis involving the bowel, bladder or ureter by specialist endometriosis services.

*Data source:*Local data collection, for example specialist endometriosis services records.

What the quality statement means for different audiences

Service providers (such as GP practices, sexual health clinics, emergency departments, gynaecology services, and paediatric and adolescent gynaecology services) ensure that systems are in place for women with confirmed, or symptoms suggestive of, deep endometriosis involving the bowel, bladder or ureter to be referred to a specialist endometriosis service.

Healthcare professionals (such as GPs, practice nurses, sexual health nurses, practitioners in emergency departments, gynaecologists and gynaecology nurses) are aware of the symptoms of deep endometriosis involving the bowel, bladder or ureter. They know how to refer women with confirmed, or symptoms suggestive of, deep endometriosis involving the bowel, bladder or ureter to a specialist endometriosis service.

Commissioners (such as NHS England, clinical commissioning groups and clinical networks) ensure that they commission services that have agreed referral pathways to specialist endometriosis services for women with suspected or confirmed deep endometriosis involving the bowel, bladder or ureter. They ensure that highly specialist adult urinary and gynaecological services are available in their local area for women with this condition.

Women who have, or might have, endometriosis that has spread to the bowel, bladder or ureter (deep endometriosis) are referred to a specialist endometriosis service. This service has healthcare professionals, including specialist nurses, who are trained and experienced in treating this type of endometriosis.

Source guidance

Endometriosis: diagnosis and management (2017) NICE Guideline NG73, recommendation 1.4.2

Definitions of terms used in this quality statement

Specialist endometriosis service (endometriosis centre)

Specialist endometriosis services (endometriosis centres) 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.

[Adapted from NICE's guideline on endometriosis, recommendation 1.1.4]

Deep endometriosis

This is endometriosis in which the nodules infiltrate at least 5 mm below the peritoneum (the lining of the pelvis). Structures that can be penetrated include the bowel, bladder, ureter and the ligaments supporting the womb.

The symptoms of deep endometriosis can include:

- 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.

[Adapted from NICE's full guideline on endometriosis, NICE's guideline on endometriosis, recommendation 1.3.1 and expert opinion.]

Equality and diversity considerations

The needs of transgender men should be considered when deep endometriosis is suspected. Some transgender men may find it distressing to attend appointments in a women's hospital or dedicated women's unit and may need to be seen in another clinic or setting. When transgender men have an inpatient stay for endometriosis, they may need to stay in a male, non-gynaecology ward, in line with their preference.

Some services, such as paediatric and adolescent gynaecology services and specialist endometriosis services, may not be available in all local areas. This should not prevent access to appropriate care.

About this quality standard

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so achievement levels of 100% should be aspired to (or 0% if the quality statement states that something should not be done). However, this may not always be appropriate in practice. Taking account of safety, shared decision-making, choice and professional judgement, desired levels of achievement should be defined locally.

Information about how NICE quality standards are developed is available from the NICE website.

See quality standard advisory committees on the website for details of standing committee 2 members who advised on this quality standard. Information about the topic experts invited to join the standing members is available on the quality standard's webpage.

This quality standard has been included in the NICE Pathway on endometriosis, which brings together everything we have said on endometriosis in an interactive flowchart.

NICE has produced a quality standard service improvement template to help providers make an initial assessment of their service compared with a selection of quality statements. This tool is updated monthly to include new quality standards.

NICE produces guidance, standards and information on commissioning and providing high-quality healthcare, social care, and public health services. We have agreements to provide certain NICE services to Wales, Scotland and Northern Ireland. Decisions on how NICE guidance and other products apply in those countries are made by ministers in the Welsh government, Scottish government, and Northern Ireland Executive. NICE guidance or other products may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

Improving outcomes

This quality standard is expected to contribute to improvements in the following outcomes:

- awareness of endometriosis
- rates of early diagnosis of endometriosis
- quality of life of women with endometriosis
- access to specialist services for management of deep endometriosis
- pain management for women with endometriosis.

It is also expected to support delivery of the Department of Health and Social Care outcome frameworks:

- NHS outcomes framework 2016–17
- Public health outcomes framework for England, 2016–19.

Resource impact

NICE quality standards should be achievable by local services. The potential resource impact is considered by the quality standards advisory committee, drawing on resource impact work for the source guidance. Organisations are encouraged to use the resource impact statement for the source guidance to help estimate local costs.

Diversity, equality and language

During the development of this quality standard, equality issues were considered and equality assessments are available. Any specific issues identified during development of the quality statements are highlighted in each statement.

Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

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Endorsing organisation

This quality standard has been endorsed by NHS England, as required by the Health and Social Care Act (2012)

Supporting organisations

Many organisations share NICE's commitment to quality improvement using evidence-based guidance. The following supporting organisations have recognised the benefit of the quality standard in improving care for patients, carers, service users and members of the public. They have agreed to work with NICE to ensure that those commissioning or providing services are made aware of and encouraged to use the quality standard.

- Faculty of Sexual and Reproductive Healthcare
- Royal College of Obstetricians and Gynaecologists
- Royal College of Pathologists
- Primary Care Women's Health Forum
- Pelvic Pain Support Network
- Endometriosis UK
- Royal College of General Practitioners
- Royal College of Nursing