NICE National Institute for Health and Care Excellence

NICE quality standard

Endometriosis

Quality standard
Published: 6 August 2018

www.nice.org.uk/guidance/qs172

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

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

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

Quality statement 1: Presentation with suspected endometriosis

Quality statement

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

Rationale

By performing an abdominal and, if appropriate, a pelvic (internal vaginal) examination when a woman or person 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

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

Process

a) Proportion of women and people 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 and people 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 or emergency department records.

b) Proportion of women and people who present to healthcare professionals with symptoms or signs suggesting endometriosis for whom a pelvic examination is declined or is not suitable who have an abdominal examination.

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

Denominator – the number of women and people presenting with symptoms or signs suggesting endometriosis for whom a pelvic examination is declined or is not suitable.

Data source: Local data collection, for example audits of GP, practice nurse, sexual health clinic 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, 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 and people presenting with a symptom or sign of endometriosis to have a physical examination. They ensure that staff know that a pelvic (internal vaginal) and abdominal examination should be carried out if appropriate. They should ensure that staff are aware that a pelvic examination may not be appropriate for

some groups, for example women and people with learning disabilities, very young women and people, and women and people who have never been sexually active. These groups, and those who decline a pelvic examination, should have an abdominal examination.

Healthcare professionals (such as GPs, practice nurses, sexual health nurses and emergency department practitioners) consider endometriosis as a possible diagnosis when women and people present with a symptom or sign that suggests endometriosis. They carry out an abdominal and pelvic (internal vaginal) examination, if appropriate, to exclude other possible causes as soon as possible, either when the woman or person initially presents or a short time afterwards. They are aware that a pelvic examination may not be suitable for some groups, for example women and people with learning disabilities, very young women and people, and women and people who have never been sexually active. They carry out abdominal examination for these groups, and for those who decline a pelvic examination. They are aware that the possibility of endometriosis should not be ruled out if the examination findings are normal.

Commissioners 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 or person's circumstances, when endometriosis is suspected.

Women and people 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 (internal vaginal) 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. NICE guideline NG73 (2017, updated 2024), recommendations 1.3.5 and 1.3.6

Definitions of terms used in this quality statement

Suspected endometriosis

Suspect endometriosis in women and people (including young women and people 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 and people 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 their culture or age, or a learning disability. Consideration should therefore be given to carrying out an abdominal examination only, if this is clinically appropriate or the woman or person declines a pelvic examination, and ensuring that they can bring a friend or relative as a chaperone if they wish. Some women and people 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 treatment

Quality statement

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

Rationale

Initial treatment for endometriosis is usually given in primary care after a working diagnosis of endometriosis has been made. Referral to a gynaecology service if initial treatment is not effective, not tolerated or contraindicated allows further investigation and management options to be explored. This can reduce the possibility of women and people experiencing significant, prolonged ill health and distress, and improve their quality of life. Referral is made to a gynaecology service, or to a paediatric and adolescent gynaecology service or specialist endometriosis service, depending on the woman or person's age.

Quality measures

The following measure can be used to assess the quality of care or service provision specified in the statement. It is an example of how the statement can be measured, and can be adapted and used flexibly.

Process

Proportion of women and people in whom initial 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 and people in whom initial treatment for endometriosis is not effective after 6 months, not tolerated or contraindicated.

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

What the quality statement means for different audiences

Service providers (such as GP practices) ensure that systems are in place for women and people to be referred to a gynaecology service if initial treatment for endometriosis is not effective, not tolerated or contraindicated. Referrals will be made to a gynaecology service for women and people aged 18 and over. Young women and people aged 17 and under will be referred to a specialist endometriosis service or paediatric and adolescent gynaecology service.

Healthcare professionals (such as GPs and practitioners in emergency departments) are aware of the local referral pathways for women and people in whom initial treatment for endometriosis is not effective, not tolerated or contraindicated. They refer women and people aged 18 and over to a gynaecology service. They refer young women and people aged 17 and under to a specialist endometriosis service or paediatric and adolescent gynaecology service.

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

Women and people with signs and symptoms of endometriosis are referred for further investigation and management if the symptoms are not relieved by the initial treatment, or if they are not able to have treatment, for example if they are trying to conceive. Women and people aged 18 and over are referred to a gynaecology service. Young women and people aged 17 and under are referred to a specialist endometriosis service or paediatric and adolescent gynaecology service.

Source guidance

Endometriosis: diagnosis and management. NICE guideline NG73 (2017, updated 2024), recommendations 1.5.5 and 1.5.7

Definitions of terms used in this quality statement

Initial treatment that is not effective

For measurement purposes, a 6-month timescale can be used to decide whether initial 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 and people 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, recommendations 1.5.5 and 1.5.6]

Gynaecology services for women and people aged 18 and over with suspected or confirmed endometriosis

Gynaecology services for women and people 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, young women and people (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 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 and people with suspected or confirmed deep endometriosis involving the bowel, bladder or ureter are referred to a specialist endometriosis service.

Rationale

Management of deep endometriosis including that 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 and people 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 and people manage the condition.

Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

Process

Proportion of women and people 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 and people 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 and people with confirmed, or symptoms suggestive of, deep endometriosis including that 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 including that involving the bowel, bladder or ureter. They know how to refer women and people with confirmed, or symptoms suggestive of, deep endometriosis including that involving the bowel, bladder or ureter to a specialist endometriosis service.

Commissioners ensure that they commission services that have agreed referral pathways to specialist endometriosis services for women and people with suspected or confirmed deep endometriosis including that involving the bowel, bladder or ureter. They ensure that highly specialist urinary and gynaecological services are available in their local area for women and people with this condition.

Women and people 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. NICE guideline NG73 (2017, updated 2024), recommendation 1.5.6

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.

Update information

Minor changes since publication

November 2024: Changes have been made to align this quality standard with the updated NICE guideline on endometriosis. Gender language, statements and source guidance references have been updated throughout.

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 about our standing committees. Information about the topic experts invited to join the standing members is available from the webpage for this quality standard.

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 guidance and quality standards apply in England and Wales. Decisions on how they apply in Scotland and Northern Ireland are made by the Scottish government and Northern Ireland Executive. NICE quality standards may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

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 products for the NICE guideline on endometriosis to help estimate local costs.

Diversity, equality and language

Equality issues were considered during development and equality assessments for this quality standard 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.

ISBN: 978-1-4731-3049-4

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 (RCGP)

- Royal College of Nursing (RCN)