NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Endometriosis

NICE quality standard

Draft for consultation

February 2018

This quality standard covers diagnosing and managing endometriosis in women, including young women aged 17 and under. It describes high-quality care in priority areas for improvement.

It is for commissioners, service providers, health, public health and social care practitioners, and the public.

This is the draft quality standard for consultation (from 16 February to 16 March 2018). The final quality standard is expected to publish in July 2018.

Quality statements

Statement 1 Women presenting with suspected endometriosis have an abdominal and pelvic examination.

Statement 2 Women receiving initial hormonal treatment for endometriosis are referred to a gynaecologist if it 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.

Statement 4 Community services are part of a managed clinical network providing coordinated care for women with suspected or confirmed endometriosis.

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) NICE quality standard 47

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

Questions for consultation

Questions about the quality standard

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

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

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

Questions about the individual quality statements

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

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

Local practice case studies

Question 6 Do you have an example from practice of implementing the NICE guideline that underpins this quality standard? If so, please submit your example to

NICE local practice case studies on the NICE website. Examples of using NICE quality standards can also be submitted.

Quality statement 1: Clinical examination for suspected endometriosis

Quality statement

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

Rationale

If healthcare professionals carry out an abdominal and pelvic examination when symptoms of endometriosis are present, delays in diagnosis and treatment can be reduced. Abdominal and pelvic examination can identify abdominal masses or pelvic signs of endometriosis such as reduced organ mobility or enlargement, points of tenderness, or visible vaginal endometriotic lesions. This enables the healthcare professional to reach a working diagnosis.

Quality measures

Structure

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

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

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

Denominator – the number of women presenting with symptoms suggesting endometriosis.

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

Outcome

Number of working diagnoses of endometriosis following initial presentation.

Data source: Local data collection, for example audits of GP 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 of endometriosis and that facilities are in place for women presenting with 1 or more symptoms of endometriosis to have an abdominal and pelvic 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 1 or more symptoms that suggest endometriosis. They carry out an abdominal and pelvic examination to exclude other possible causes of the symptom(s).

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 of endometriosis and the need for abdominal and pelvic examination when endometriosis is suspected.

Women with 1 or more symptoms that suggest endometriosis (such as chronic pelvic pain, severe period-related pain or deep pain during or after sexual intercourse) have an examination of their pelvis and abdomen the first time they visit a healthcare professional to discuss these symptoms. This examination can help to rule out other possible causes of their symptoms and means that treatment for endometriosis can be started quickly.

Source guidance

Endometriosis: diagnosis and management (2017) NICE Guideline NG73 recommendation 1.3.3.

Definitions of terms used in this quality statement

Suspected endometriosis

Endometriosis should be suspected 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.

[Adapted from NICE's guideline on Endometriosis: diagnosis and management, recommendation 1.3.1]

Equality and diversity considerations

Practitioners should be aware that some women may feel particularly anxious about having an abdominal and pelvic examination. This could be due to a number of reasons, for example their culture, age, or a learning disability. In these cases, suggesting they have a friend or relative as a chaperone and a female practitioner carrying out the examination may be helpful.

Transgender men should also have endometriosis considered as a possible diagnosis if they present with 1 or more symptom.

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

Quality statement

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

Rationale

Referral to a gynaecologist at a gynaecology service, specialist endometriosis service or paediatric and adolescent gynaecology service when initial hormonal treatment for endometriosis is not effective, not tolerated or contraindicated allows further investigation and treatment options to be explored. Making this referral promptly, at a time agreed between the woman and her healthcare professional, can reduce the possibility of women experiencing significant prolonged ill health and distress.

Quality measures

Structure

Evidence of local referral pathways to a gynaecology service, specialist endometriosis service or paediatric and adolescent 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

a) Proportion of women in whom initial hormonal treatment for endometriosis is contraindicated who are referred to a gynaecologist.

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

Denominator – the number of women in whom initial hormonal treatment for endometriosis is contraindicated.

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

b) Proportion of women in whom initial hormonal treatment for endometriosis is not effective 6 months after starting treatment who are referred to a gynaecologist.

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

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

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

c) Proportion of women in whom initial hormonal treatment for endometriosis is not tolerated who are referred to a gynaecologist.

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

Denominator – the number of women in whom initial hormonal treatment for endometriosis is not tolerated.

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

Outcome

a) Numbers of accident and emergency attendances for endometriosis symptoms.

Data source: Local data collection, such as accident and emergency department records.

b) 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 gynaecologist if initial hormonal

treatment for endometriosis is not effective, not tolerated or contraindicated. Referrals will be made to a gynaecologist at a 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 gynaecologist in a 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 NHS England and clinical commissioning groups) ensure 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 with signs and symptoms of endometriosis are referred to a gynaecologist 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. They are referred either to a 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

Gynaecology services for women with suspected or confirmed endometriosis

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, glossary]

Question for consultation

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

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 specialist treatment and, if surgery is needed, it can be carried out by specialists in deep endometriosis. Women also receive support from a clinical nurse specialist as part of this service.

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 and 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 and clinical commissioning groups) 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 specialist endometriosis 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.

[Adapted from NICE's full guideline on endometriosis]

Quality statement 4: Coordinated care through a managed clinical network

Quality statement

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

Rationale

Coordinating care through a managed clinical network that includes community services such as school nurses, GPs, practice nurses and sexual health services will ensure that healthcare professionals are aware of endometriosis, diagnosis is not delayed and women have support from healthcare professionals both before and after diagnosis. For example, young women of school age can receive advice and support from school nurses, who they may feel more comfortable approaching than the family GP. Care through a managed clinical network also ensures that women with suspected or confirmed endometriosis managed in the community have access to a multidisciplinary team that includes specialists in endometriosis.

Quality measures

Structure

a) Evidence that a managed clinical network for endometriosis that includes community services is in place.

Data source: Local data collection, for example local commissioning arrangements.

b) Evidence that local services within the managed clinical network have agreed clinical and referral protocols for women with suspected or confirmed endometriosis.

Data source: Local data collection, for example clinical and referral protocols and pathways.

c) Evidence that community services know how to refer women with endometriosis within the managed clinical network.

Data source: Local data collection, for example referral protocols and pathways.

Outcome

a) Number of days lost at school and work because of symptoms of endometriosis.

Data source: Local data collection, for example school attendance levels and employment sickness rates.

b) Satisfaction of women with endometriosis with the support they receive.

Data source: Local data collection, for example surveys of women with endometriosis.

c) Number of women who feel able to manage their symptoms of endometriosis.

Data source: Local data collection, for example surveys of women with endometriosis.

What the quality statement means for different audiences

Service providers (such as GP practices, school health services, sexual health services, gynaecology services and specialist endometriosis services) form part of a managed clinical network and ensure that they have clinical and referral protocols in place with other providers to ensure that women with suspected or confirmed endometriosis are cared for and supported through an agreed pathway.

Healthcare professionals (such as GPs, practice nurses, school nurses, sexual health nurses, gynaecologists, gynaecology nurses and specialist endometriosis practitioners) work with colleagues from other services, following agreed clinical and referral protocols, to ensure that women with suspected or confirmed endometriosis are cared for and supported through an agreed pathway.

Commissioners (such as NHS England, local authorities and clinical commissioning groups) ensure they commission managed clinical networks that care for and support women with suspected or confirmed endometriosis throughout the care pathway, including through community services.

Women who have, or might have, endometriosis are cared for and supported by healthcare professionals from different services who work together to arrange the woman's care.

Source guidance

Endometriosis: diagnosis and management (2017) NICE Guideline NG73 recommendations 1.1.1 and 1.1.2

Definitions of terms used in this quality statement

Community services

These are services which are provided in the community and include but are not limited to GPs, practice nurses, school nurses and sexual health services.

[Adapted from NICE's guideline on Endometriosis: diagnosis and management, recommendation 1.1.1]

Managed clinical network

Linked group of healthcare professionals from primary, secondary and tertiary care providing a coordinated patient pathway. This includes community services (including GPs, practice nurses, school nurses and sexual health services), gynaecology services and specialist endometriosis services.

Responsibility for setting up the network will depend on existing service provision and location.

[Adapted from NICE's guideline on endometriosis definitions and recommendation 1.1.1]

Suspected endometriosis

Endometriosis should be suspected in women, including young women aged under 17 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.

[Adapted from NICE's guideline on Endometriosis: diagnosis and management, recommendation 1.3.1]

Equality and diversity considerations

Some women, for example young women under 17 years or women from some cultural backgrounds, and transgender people may not feel comfortable discussing menstruation and associated problems. Healthcare professionals, particularly in schools, should keep this in mind and consider endometriosis as a possibility if young women are missing school on a regular basis.

Question for consultation

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

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 will be 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:

- 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's outcome frameworks:

- Adult social care outcomes framework 2016–17
- 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 products 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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