ENDOMETRIOSIS: Clinical Questionnaire

A. Introduction

What is this study about:

This study will look at the care provided to patients aged 18 and over, with a diagnosis of endometriosis. It will look at the whole pathway of care from the events leading to the initial diagnosis and treatment, to discharge, follow-up and subsequent attendances and admissions for the investigation and treatment of endometriosis, reviewing any remediable factors in the quality of care provided.

Inclusions:

Patients, aged 18 and older, who were admitted to hospital with a diagnosis of endometriosis during the study period: 1st February 2018 - 31st July 2020 (this is the "index admission") and have undergone a laparoscopic (or other surgical) procedure to treat their symptoms. Exclusions:

Patients who have been miscoded and are found not to have endometriosis

Who should complete the questionnaire?

The questionnaire should be completed by the gynaecologist responsible for the patient at the time of the index admission (or by another consultant gynaecologist nominated by the Local Reporter).

Please do not include any patient identifiers in the free text boxes.

Questions or help:

Further information regarding this study can be found here: https://www.ncepod.org.uk/endometriosis.html If you have any queries about this study or this questionnaire, please contact: endometriosis@ncepod.org.uk or telephone 020 7251 9060.

Definitions

A list of definitions can be found at www.ncepod.org.uk/Endo definitions

CPD accreditation

Consultants who complete NCEPOD questionnaires make a valuable contribution to the investigation of patient care. Completion of questionnaires also provides an opportunity for consultants to review their clinical management and undertake a period of personal reflection. These activities have a continuing medical and professional development value for individual

consultants. Consequently, NCEPOD recommends that consultants who complete NCEPOD questionnaires keep a record of this activity which can be included as evidence of internal/self directed Continuous Professional Development in their appraisal portfolio.

About NCEPOD

The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) reviews healthcare practice by undertaking confidential studies, and makes recommendations to improve the quality of the delivery of care, for healthcare professionals and policymakers to implement. Data to inform the studies are collected from NHS hospitals and Independent sector hospitals across England, Wales, Northern Ireland and the Offshore Islands. NCEPOD are supported by a wide range of bodies and the Steering Group consists of members from the Medical Royal Colleges and Specialist Associations, as well as observers from The Coroners Society of England and Wales, and the Healthcare Quality Improvement Partnership (HQIP).

Impact of NCEPOD

Recommendations from NCEPOD reports have had an impact on many areas of healthcare including: Development of the NICE 'Acutely ill patients in hospital guideline' (CG50) - following publication of the 2005 'An Acute Problem' report. Appointment of a National Clinical Director for Trauma Care - following publication of 'Trauma: Who Cares?' 2007. Development of NICE Clinical Guidelines for Acute Kidney Injury, published in 2013 - 'Adding Insult to

Injury' 2009. Development of ICS Standards for the care of adult patients with a temporary Tracheostomy, published

2014 - 'On the right trach?' 2014. Development of guidelines from the British Society of Gastroenterology: diagnosis and management of

acute lower gastrointestinal bleeding, published 2019 - 'Time to Get Control' 2015. Development of the British Thoracic Society's Quality Standards for NIV, published 2018 - 'Inspiring Change' 2017.

This study was commissioned by The Healthcare Quality Improvement Partnership (HQIP) as part of the Clinical Outcome Review Programme into Medical & Surgical care.

B. Patient details

The index admission for this study refers to the first recorded admission to hospital for a laparoscopy* during the study period (01/02/2018-31/07/2020) for endometriosis (dates of admission / discharge for the index admission are indicated on the previous "assignments" screen of the questionnaire portal

| | | de of care which identified the patient for the study part of the patient details on the previous "assignments" |
|--------------------|--|--|
| <i>Screeny</i> | | years Unknown |
| Value should be no | more than 120 | |
| 2. Ethnicity: | | |
| O White British | n/White other | |
| O Black/Africa | n/Caribbean/Black British | |
| • | • | Bangladeshi, Chinese, other Asian) |
| • | ole ethnic groups | |
| Unknown | | |
| If not listed abo | ve, please specify here | |
| | | |
| a. Was there a d | ocumented learning di | sability? |
| O Yes | O No | O Unknown |
| | es" to [3a] then: documented learning (| disability? |
| | | |
| a. Did the patien | t have any co-morbidit | ties related to endometriosis? |
| | | |

| Answers may be m | o-morbidities relate nultiple, please select a | d to endometriosis: all that apply | |
|--|---|---------------------------------------|-------------|
| Answers may be m | syndrome itis thritis cis inful bowel movement) syndrome iread pain isease e syndrome / myalgic e | all that apply | |
| ☐ Early natural m☐ Ovarian cysts | • | | |
| _ | additional options her | re | |
| | | ties that were not related to end | ometriosis? |
| Yes 5b. If answered "Yes | O No | O Unknown | |
| | | ated to endometriosis: | |

C. Pre-diagnosis of endometriosis

| diagnosis of end *please see defini | | |
|--|--|--|
| General pract | itioner | |
| ☐ Emergency de | epartment | |
| _ | logy department (non-speciali | |
| _ | logy department (BSGE centre | |
| _ | nospital gynaecology departm | ent |
| ☐ Other specialt ☐ Unknown | y department | |
| | | |
| Please specify any | y additional options here | |
| esentation to the | e GP | |
| In the case note | neral practitioner" to [1a] record, do you have acces prior to diagnosis? | then: ss to any information regarding the patient's |
| O Yes | O No | ○ Unknown |
| | tes in DD/MM/YYYY format. If o | exact date is unknown, if possible, please just include |
| month and year If answered "Ge | neral practitioner" to [1a] | and "Yes" to [1b] then: |
| If answered "Ge Please indicate their first reference or the second control of the secon | neral practitioner" to [1a] | and "Yes" to [1b] then: tient first presented with to the GP, prior to |
| If answered "Ge Please indicate their first referr Answers may be in | eneral practitioner" to [1a] the symptoms that the par ral to gynaecology: multiple, please select all that | and "Yes" to [1b] then: tient first presented with to the GP, prior to |
| If answered "Ge Please indicate their first reference or month and year | eneral practitioner" to [1a] the symptoms that the particle and the particle pain | and "Yes" to [1b] then: tient first presented with to the GP, prior to |
| If answered "Ge Please indicate their first reference Answers may be in the control of the contr | eneral practitioner" to [1a] the symptoms that the particle and the particle pain | and "Yes" to [1b] then: tient first presented with to the GP, prior to tapply Constipation |
| If answered "Ge Please indicate their first reference Answers may be in the control of the contr | eneral practitioner" to [1a] the symptoms that the partial to gynaecology: multiple, please select all that it pain ain the control of the co | and "Yes" to [1b] then: tient first presented with to the GP, prior to tapply Constipation Painful periods (dysmenorrhea) |
| If answered "Ge Please indicate their first referr Answers may be in a cyclical pelving Extra-pelvic pure Heavy menstreside Multi-site pain Diarrhoea | eneral practitioner" to [1a] the symptoms that the partial to gynaecology: multiple, please select all that ic pain ain rual bleeding (menorrhagia) | and "Yes" to [1b] then: tient first presented with to the GP, prior to tapply Constipation Painful periods (dysmenorrhea) Irregular bleeding Dyschezia Abdominal bloating |
| If answered "Ge Please indicate their first referr Answers may be in Acyclical pelvic Extra-pelvic p Heavy menstr Multi-site pain Diarrhoea Bladder symp | eneral practitioner" to [1a] the symptoms that the partical to gynaecology: multiple, please select all that ic pain ain rual bleeding (menorrhagia) | and "Yes" to [1b] then: tient first presented with to the GP, prior to tapply Constipation Painful periods (dysmenorrhea) Irregular bleeding Dyschezia Abdominal bloating Painful urination (dysuria) |
| If answered "Ge Please indicate their first referr Answers may be I Extra-pelvic p Heavy menstr Multi-site pain Diarrhoea Bladder symp Painful interce | eneral practitioner" to [1a] the symptoms that the partial to gynaecology: multiple, please select all that ic pain ain rual bleeding (menorrhagia) | and "Yes" to [1b] then: tient first presented with to the GP, prior to tapply Constipation Painful periods (dysmenorrhea) Irregular bleeding Dyschezia Abdominal bloating |
| If answered "Ge Please indicate their first referr Answers may be in Acyclical pelvic Extra-pelvic p Heavy menstr Multi-site pain Diarrhoea Bladder symp | eneral practitioner" to [1a] the symptoms that the particle to gynaecology: multiple, please select all that ic pain ain rual bleeding (menorrhagia) | and "Yes" to [1b] then: tient first presented with to the GP, prior to tapply Constipation Painful periods (dysmenorrhea) Irregular bleeding Dyschezia Abdominal bloating Painful urination (dysuria) |
| If answered "Ge Please indicate their first referr Answers may be in a continuous may be in | eneral practitioner" to [1a] the symptoms that the particle to gynaecology: multiple, please select all that ic pain ain rual bleeding (menorrhagia) | and "Yes" to [1b] then: tient first presented with to the GP, prior to tapply Constipation Painful periods (dysmenorrhea) Irregular bleeding Dyschezia Abdominal bloating Painful urination (dysuria) |
| If answered "Ge Please indicate their first referr Answers may be in Acyclical pelving Extra-pelvic powers the Heavy menstrom Multi-site pain Diarrhoea Bladder sympom Painful intercom Unknown | eneral practitioner" to [1a] the symptoms that the partial to gynaecology: multiple, please select all that ic pain ain rual bleeding (menorrhagia) toms burse (dyspareunia) | and "Yes" to [1b] then: tient first presented with to the GP, prior to tapply Constipation Painful periods (dysmenorrhea) Irregular bleeding Dyschezia Abdominal bloating Painful urination (dysuria) |
| If answered "Ge Please indicate their first referr Answers may be in Acyclical pelving Extra-pelvic powers the Heavy menstrom Multi-site pain Diarrhoea Bladder sympom Painful intercom Unknown | eneral practitioner" to [1a] the symptoms that the partial to gynaecology: multiple, please select all that ic pain ain rual bleeding (menorrhagia) toms burse (dyspareunia) | and "Yes" to [1b] then: tient first presented with to the GP, prior to tapply Constipation Painful periods (dysmenorrhea) Irregular bleeding Dyschezia Abdominal bloating Painful urination (dysuria) |
| If answered "Ge Please indicate their first reference Answers may be in Acyclical pelvic per Heavy menstre Multi-site pain Diarrhoea Bladder sympe Painful interce Unknown Please specify any If answered "Ge Is there any evice their series of the series | eneral practitioner" to [1a] the symptoms that the partial to gynaecology: multiple, please select all that ic pain ain rual bleeding (menorrhagia) toms burse (dyspareunia) y additional options here | and "Yes" to [1b] then: tient first presented with to the GP, prior to apply Constipation Painful periods (dysmenorrhea) Irregular bleeding Dyschezia Abdominal bloating Painful urination (dysuria) None of these |
| If answered "Ge Please indicate their first referr Answers may be in a cyclical pelvic per Extra-pelvic per Heavy menstre multi-site pain point per Bladder sympers per Painful intercord Unknown Please specify any lift answered "Ge Is there any evice per Painful intercord per Painful i | eneral practitioner" to [1a] the symptoms that the partial to gynaecology: multiple, please select all that ic pain ain rual bleeding (menorrhagia) ttoms burse (dyspareunia) y additional options here | and "Yes" to [1b] then: tient first presented with to the GP, prior to tapply Constipation Painful periods (dysmenorrhea) Irregular bleeding Dyschezia Abdominal bloating Painful urination (dysuria) None of these and "Yes" to [1b] then: |

| - 1 | | es in DD/MM/YYYY form | |
|---|---|--|---|
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| 1 | Was there any ev | | [1a] and "Yes" to [1b] then: that the GP provided the patient with informationed endometriosis? |
| (| O Yes | O No | Unknown |
| | lf answered "Yes Please provide fu | | |
| | • | | |
| | | | |
| [| | | |
| ef | ferral to gynaeco | alogy and attendance | at gynaecology clinic |
| | | | at gynaecology clinic |
| 5. I | In the case note | record, is there any | at gynaecology clinic information regarding the first referral to the gynaecology clinic, prior to diagnosis of |
| 5. l | In the case note gynaecology and | record, is there any | information regarding the first referral to |
| 5. ((| In the case note gynaecology and endometriosis? Yes If answered "Yes | record, is there any large in the large in t | information regarding the first referral to the gynaecology clinic, prior to diagnosis of |
| 5. ((| In the case note gynaecology and endometriosis? Yes If answered "Yes | record, is there any idea of the second is the second in t | information regarding the first referral to the gynaecology clinic, prior to diagnosis of |
| 5. | In the case note gynaecology and endometriosis? Yes If answered "Yes Date of first refe | record, is there any idea of the idea of t | information regarding the first referral to the gynaecology clinic, prior to diagnosis of Unknown Unknown |
| 5. | In the case note gynaecology and endometriosis? Yes If answered "Yes Date of first refe | record, is there any idea of the idea of t | information regarding the first referral to the gynaecology clinic, prior to diagnosis of Unknown |
| a. | In the case note gynaecology and endometriosis? Yes If answered "Yes Date of first refe If answered "Yes If answered "Yes If exact date unk | record, is there any idea of the idea of t | information regarding the first referral to the gynaecology clinic, prior to diagnosis of Unknown Unknown |
| 6. 9 9 9 9 9 9 9 9 9 | In the case note gynaecology and endometriosis? Yes If answered "Yes Date of first refe If answered "Yes If exact date unk gynaecology? | record, is there any identify or attendances at the No No No Street to [6] then: strain to gynaecology street to [6] then: known, could you est | information regarding the first referral to the gynaecology clinic, prior to diagnosis of Unknown Unknown Unknown imate the month and year of the first referral to |
| 5. ! 9. ! [] 0. ! 9. ! | In the case note gynaecology and endometriosis? Yes If answered "Yes Date of first refe If answered "Yes If exact date unk gynaecology? If answered "Yes In your opinion, o | record, is there any idea of the idea of t | information regarding the first referral to the gynaecology clinic, prior to diagnosis of Unknown Unknown imate the month and year of the first referral to the diagnosis of the diagnosis of the gynaecology sooner? |
| 5. 9. 1. 1. 1. 1. 1. 1. 1 | In the case note gynaecology and endometriosis? Yes If answered "Yes Date of first refe If answered "Yes If exact date unk gynaecology? | record, is there any identify or attendances at the No No State of them: The record is them: The record is the state of them: The record is the state of the state of them: The record is the state of the state | information regarding the first referral to the gynaecology clinic, prior to diagnosis of Unknown Unknown Unknown imate the month and year of the first referral to |

| O Yes | ○ No | Unknow | า |
|--|---|---|---|
| If answered "Ye What term was | es" to [6] and "Yes" | to [9a] then: | of endometriosis in the referral to |
| gynaecology? | domotriosis | rababla andamatriacia | Ouery and emotrics is |
| ☐ Suspected en | domethosis | robable endometriosis | Query endometriosis |
| Please specify an | y additional options h | nere | |
| If answered "Ye | os" to [6] then: | | |
| Please give the | | ent was first seen in t | ne gynaecology clinic regarding |
| | | П | Unknown |
| | n, please could you | estimate the month a | and year the patient was first s of endometriosis: |
| | | | |
| | | | |
| If answered "Ye Please indicate endometriosis: | | undertaken by the gyı | naecologist, for the symptoms of |
| ☐ Abdominal ex | amination 🔲 P | Pelvic examination | Unknown |
| | | | |
| Please specify an | v additional options h | nere | |
| Please specify an | y additional options h | nere | |
| | | | ation" to [11a] and "Yes" to [6] |
| If answered "Ak then: Did the examina | | ion" or "Pelvic examin | ation" to [11a] and "Yes" to [6] |
| If answered "Ak then: Did the examina | odominal examinat ation/s identify: multiple, please selec | ion" or "Pelvic examin | ation" to [11a] and "Yes" to [6] |
| If answered "Akthen: Did the examina Answers may be Any abdomina Adnexal mass | odominal examination/s identify: multiple, please select al masses | ion" or "Pelvic examin | ation" to [11a] and "Yes" to [6] |
| If answered "Abthen: Did the examinate Answers may be a second Answers may be a second Answer and Adnexal mass Lower abdom | ation/s identify: multiple, please select al masses s inal tenderness | ion" or "Pelvic examin ct all that apply | ation" to [11a] and "Yes" to [6] |
| If answered "Akthen: Did the examination Answers may be a second Answers may be a second Answer abdomination and the second Adnexal mass and Lower abdom Fixed and ten | odominal examination/s identify: multiple, please select al masses inal tenderness ider retroverted uteru | ion" or "Pelvic examin ct all that apply | ation" to [11a] and "Yes" to [6] |
| If answered "Akthen: Did the examinate Answers may be Any abdominate Adnexal mass Lower abdom Fixed and tental Adnexal tender | odominal examination/s identify: multiple, please select al masses inal tenderness ider retroverted uteruerness | ion" or "Pelvic examin ct all that apply | |
| If answered "Akthen: Did the examinate Answers may be Any abdominate Adnexal mass Lower abdom Fixed and tental Adnexal tender | ation/s identify: multiple, please select al masses inal tenderness der retroverted uteru erness inderness and tension | ion" or "Pelvic examin ct all that apply | |
| If answered "Ab then: Did the examina Answers may be a Any abdomina Adnexal mass Lower abdom Fixed and tend Adnexal tender Pelvic floor te Unable to ans | ation/s identify: multiple, please select al masses inal tenderness der retroverted uteru erness inderness and tension | ion" or "Pelvic examin ct all that apply us n (If pelvic floor assessed | |
| If answered "Abthen: Did the examina Answers may be a Answers may be a Adnexal mass Lower abdom Fixed and tend Adnexal tender Pelvic floor tell Unable to answered Table 1. | ation/s identify: multiple, please select al masses inal tenderness der retroverted uteru erness inderness and tension swer | ion" or "Pelvic examin ct all that apply us n (If pelvic floor assessed | |
| If answered "About then: Did the examina Answers may be a larger and tender a | ation/s identify: multiple, please select al masses inal tenderness ider retroverted uteru erness inderness and tension swer y additional options h | ion" or "Pelvic examin ct all that apply IS In (If pelvic floor assessed | |
| If answered "Akthen: Did the examina Answers may be a language of the examina Answers may be a language of the examina Adnexal mass language of the language o | ation/s identify: multiple, please select al masses inal tenderness ider retroverted uteru erness inderness and tension swer y additional options h | ion" or "Pelvic examin ct all that apply IS In (If pelvic floor assessed |) e specialist, prior to diagnosis? |
| If answered "Abthen: Did the examina Answers may be a large and tender and te | ation/s identify: multiple, please select al masses inal tenderness ider retroverted uteru erness inderness and tension wer y additional options h es" to [6] then: have contact with | ion" or "Pelvic examin ct all that apply IS IS In (If pelvic floor assessed mere a endometriosis nurse |) e specialist, prior to diagnosis? |
| If answered "Ak then: Did the examina Answers may be Any abdomina Adnexal mass Lower abdom Fixed and tend Adnexal tend Pelvic floor te Unable to ans Please specify an If answered "Ye Did the patient Yes On-gynaecologica At any time price | ation/s identify: multiple, please select al masses inal tenderness der retroverted uteru erness inderness and tension swer y additional options h es" to [6] then: have contact with | ion" or "Pelvic examin ct all that apply Is Is It (If pelvic floor assessed mere a endometriosis nurse Unknown Indometriosis, was thi |) e specialist, prior to diagnosis? |

| | | any non-gynaecological, endometriosis related, |
|---|---|---|
| Yes | O No | Unknown |
| Please give de | es" to [14a] then: stails and relevant date/s | |
| | , , , | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| nging | | |
| | | |
| Prior to diagno | osis of endometriosis, wa | ns the patient referred for an ultrasound scan ometriosis? |
| Prior to diagno (USS) relating | | |
| Prior to diagno (USS) relating | to the symptoms of ende | ometriosis? |
| Prior to diagno (USS) relating Yes If answered "Y | to the symptoms of endo No [Section 1985] No [16] then: | ometriosis? O Unknown |
| Prior to diagno (USS) relating Yes If answered "Y | to the symptoms of endo No [Section 1985] No [16] then: | ometriosis? |
| Prior to diagno (USS) relating Yes If answered "Y Who first referont's | To the symptoms of endo No No Yes" to [16] then: Tred the patient for an Use general practitioner | Ometriosis? O Unknown SS, prior to diagnosis of endometriosis? |
| Prior to diagno (USS) relating Yes If answered "Y Who first reference of the patient's of the physic of the phys | Tes" to [16] then: rred the patient for an Us s general practitioner | Ometriosis? Unknown SS, prior to diagnosis of endometriosis? The patient's gynaecologist |
| Prior to diagno (USS) relating Yes If answered "Y Who first reference of the patient's of the physic of the phys | To the symptoms of endo No No Yes" to [16] then: Tred the patient for an Use general practitioner | Ometriosis? Unknown SS, prior to diagnosis of endometriosis? The patient's gynaecologist |
| Prior to diagno (USS) relating Yes If answered "Y Who first reference of the patient's of the physic of the phys | Tes" to [16] then: rred the patient for an Us s general practitioner | Ometriosis? Unknown SS, prior to diagnosis of endometriosis? The patient's gynaecologist |
| Prior to diagno (USS) relating Yes If answered "Yes The patient's Acute physic Unknown If not listed above If answered "Yes | Tes" to [16] then: rred the patient for an Us s general practitioner cian ve, please specify here | O Unknown SS, prior to diagnosis of endometriosis? O The patient's gynaecologist O Other specialty doctor |
| (USS) relating Yes If answered "Y Who first refer The patient's Acute physic Unknown If not listed above If answered "Y | No No No No Nes" to [16] then: rred the patient for an Uses general practitioner cian ve, please specify here | O Unknown SS, prior to diagnosis of endometriosis? O The patient's gynaecologist O Other specialty doctor |

| 1 | | nown, if possible please es | • |
|---|---|--|-------------------------|
| 9. If answered " | Yes" to [16] then: | | |
| What type of | USS did the patient has a multiple, please select | | |
| ☐ Trans-abdo | | | ☐ No ultrasound scan |
| Please specify a | any additional options he | re | |
| | Yes" to [16] then: ent scanned by someor | ne specially trained in endo | metriosis scanning? |
| O Yes | O No | O Unknown | _ |
| | Yes" to [16] then: ults of the USS shared | with the patient's GP? | |
| O Yes | O No | O Unknown | |
| 22. Prior to diagn scans? | osis, was the patient ı | referred for any Magnetic R | esonance Imaging (MRI) |
| O Yes | O No | O Unknown | |
| | Yes" to [22] then: date of the MRI scan? |) | |
| | Yes" to [22] then: ate of the MRI is not k | nown, if possible please es | imate the month and yea |
| | | | |
| | Yes" to [22] then: ent scanned by someor | ne specially trained in endo | metriosis scanning? |
| | | ne specially trained in endo O Unknown | metriosis scanning? |
| Was the patie | ent scanned by someor | O Unknown | metriosis scanning? |
| Was the patie O Yes If not listed about | No No News, please specify here Yes" to [22] then: | O Unknown | metriosis scanning? |

D. First diagnosis of endometriosis 1a. Date of diagnosis Please include dates in DD/MM/YYYY format ☐ Unknown 1b. If the exact date is not known, please estimate the month and year. 2. What was the diagnosis? Answers may be multiple, please select all that apply ☐ Endometriosis on the uterine surface Endometriosis of ovary ☐ Endometriosis of fallopian tube ☐ Endometriosis of pelvic peritoneum ☐ Endometriosis of rectovaginal septum and vagina ☐ Endometriosis of intestine ☐ Endometriosis in cutaneous scar ☐ Endometriosis of thorax ☐ Endometriosis in the bladder ☐ Endometriosis of the urinary tract ☐ Endometriosis, unspecified ☐ Unknown Please specify any additional options here... 3. Has the patient been diagnosed with deep endometriosis? involving the bowel, bladder or ureter Yes O No Unknown 4. Has the patient been diagnosed with endometriosis outside of the pelvic cavity? O Yes O No Unknown 5. In the case note record, is there any information from the hospital admission when endometriosis was first diagnosed? The diagnosis may have been during the index admission* or may have happened prior to this (*see definitions). O No Yes Unknown 6a. If answered "Yes" to [5] then: How was the diagnosis of endometriosis confirmed? Answers may be multiple, please select all that apply ☐ Other surgical procedure ☐ Laparoscopy ☐ Biopsy ☐ Imaging Unknown Please specify any additional options here... 6b. If answered "Imaging" to [6a] then: Please provide details of imaging 6c. If answered "Other surgical procedure" to [6a] then: Please provide details of other surgical procedure

| wnat procedure wa | s performed when endo | ometriosis was first diagnosed? |
|--|--|---|
| ☐ Laparoscopic abla☐ Laparoscopic abla☐ Hysterectomy | tion | Laparoscopic excision Other laparoscopy Unknown |
| Please specify any add | ditional options here | |
| [6a] then: When was consent | taken for the laparosco | ", "Biopsy" or "Other surgical procedure" to py (or other surgical procedure) that was lometriosis was first diagnosed? |
| | | Unknown |
| 9. If answered "Yes" to Were the risks and | | cussed with the patient? |
| O Yes | ○ No | O Unknown |
| .0. If answered "Yes" to What was the speci | o [5] then: alty of the operating su | ırgeon? |
| GynaecologyUnknown | General surgery | O Colorectal surgery O Urology |
| If not listed above, ple | ease specify here | |
| [6a] then: | nplications of the proce | |
| | () NO | () Unknown |
| 1b.If answered "Yes" to | ○ No o [11a] then: ails of any complications | Unknown s of the procedure: |
| 1b.If answered "Yes" to | o [11a] then: | |
| 1b.If answered "Yes" to Please provide deta | o [11a] then: ails of any complications o [5] then: nt's stage of endometri | osis at the time of diagnosis? |
| 1b.If answered "Yes" to Please provide deta | o [11a] then: ails of any complications o [5] then: nt's stage of endometri Mild (Stage | osis at the time of diagnosis? |

| O Yes | O No | Unknown |
|--|--|--|
| | s" to [13a] then: | |
| Please give furt | ther details: | |
| | | |
| In your oninion | was there a delay in t | the initial diagnosis of endometriosis? |
| Yes | No | () Unknown |
| • | es" to [14a] then: | 9 |
| Please provide | further details | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | s" to [14a] then: . did the delay lead to | a worsening of symptoms? |
| | ala tile aciay lead to | |
| | | |
| Yes If answered "Yes | O No | ○ Unknown |
| Yes If answered "Yes | No s" to [5] then: dmission when endom | |
| Yes If answered "Ye Following the a | No s" to [5] then: dmission when endom | ○ Unknown |
| Yes If answered "Ye Following the acappointments a Yes If answered "Yes | No No S" to [5] then: dmission when endom rranged? No No S" to [15a] then: | Unknownetriosis was first diagnosed, were any follow-uUnknown |
| Yes If answered "Ye Following the acappointments a Yes If answered "Yes Who were the fo | No s" to [5] then: dmission when endom rranged? No ss" to [15a] then: ollow-up appointment/ | Unknown etriosis was first diagnosed, were any follow-u Unknown /s with? |
| Yes If answered "Ye Following the acappointments a Yes If answered "Ye Who were the for Answers may be a | No Ses" to [5] then: dmission when endom erranged? No Ses" to [15a] then: collow-up appointment/ multiple, please select all | Unknown etriosis was first diagnosed, were any follow-u Unknown /s with? / that apply |
| Yes If answered "Yes Following the adappointments a Yes If answered "Yes Who were the form of the second of the | No ss" to [5] then: dmission when endom rranged? No ss" to [15a] then: ollow-up appointment/ multiple, please select all t | Unknown etriosis was first diagnosed, were any follow-u Unknown /s with? I that apply Operating surgeon |
| Yes If answered "Ye Following the acappointments a Yes If answered "Ye Who were the form th | No es" to [5] then: dmission when endom erranged? No es" to [15a] then: collow-up appointment/ multiple, please select all t itioner | Unknown etriosis was first diagnosed, were any follow-u Unknown /s with? / that apply Operating surgeon Endometriosis nurse specialist |
| Yes If answered "Ye Following the acappointments a Yes If answered "Ye Who were the for Answers may be a Yes Gynaecologist General pract Physiotherapi | No Ps" to [5] then: dmission when endom erranged? No Ps" to [15a] then: collow-up appointment/ multiple, please select all t itioner st | <pre>Unknown etriosis was first diagnosed, were any follow-u Unknown /s with? / that apply</pre> |
| Yes If answered "Ye Following the acappointments a Yes If answered "Ye Who were the form th | No ss" to [5] then: dmission when endom rranged? No ss" to [15a] then: ollow-up appointment/ multiple, please select all t itioner st lalist | Unknown etriosis was first diagnosed, were any follow-u Unknown /s with? / that apply Operating surgeon Endometriosis nurse specialist |
| Yes If answered "Ye Following the acappointments a Yes If answered "Ye Who were the for Answers may be a Yes Gynaecologist General pract Physiotherapi | No ss" to [5] then: dmission when endom rranged? No ss" to [15a] then: ollow-up appointment/ multiple, please select all t itioner st lalist | <pre>Unknown etriosis was first diagnosed, were any follow-u Unknown /s with? / that apply</pre> |
| Yes If answered "Ye Following the arappointments a Yes If answered "Ye Who were the form the arappointments a Gynaecologist General pract Physiotherapi Fertility special Mental health | No ss" to [5] then: dmission when endom rranged? No ss" to [15a] then: ollow-up appointment/ multiple, please select all t itioner st lalist specialist | <pre>Unknown etriosis was first diagnosed, were any follow-u Unknown /s with? / that apply</pre> |
| Yes If answered "Ye Following the arappointments a Yes If answered "Ye Who were the form the arappointments a Gynaecologist General pract Physiotherapi Fertility special Mental health | No ss" to [5] then: dmission when endom rranged? No ss" to [15a] then: ollow-up appointment/ multiple, please select all t itioner st lalist | <pre>Unknown etriosis was first diagnosed, were any follow-u Unknown /s with? / that apply</pre> |
| Yes If answered "Ye Following the arappointments a Yes If answered "Ye Who were the form the arappointments a Gynaecologist General pract Physiotherapi Fertility special Mental health | No ss" to [5] then: dmission when endom rranged? No ss" to [15a] then: ollow-up appointment/ multiple, please select all t itioner st lalist specialist | <pre>Unknown etriosis was first diagnosed, were any follow-u Unknown /s with? / that apply</pre> |
| Yes If answered "Ye Following the arappointments a Yes If answered "Ye Who were the form the arappointments a Gynaecologist General pract Physiotherapi Fertility special Mental health | No ss" to [5] then: dmission when endom rranged? No ss" to [15a] then: ollow-up appointment/ multiple, please select all t itioner st lalist specialist | <pre>Unknown etriosis was first diagnosed, were any follow-u Unknown /s with? / that apply</pre> |
| Yes If answered "Ye Following the arappointments a Yes If answered "Ye Who were the form the arappointments a Gynaecologist General pract Physiotherapi Fertility special Mental health | No ss" to [5] then: dmission when endom rranged? No ss" to [15a] then: ollow-up appointment/ multiple, please select all t itioner st lalist specialist y additional options here. | <pre>Unknown etriosis was first diagnosed, were any follow-u Unknown /s with? / that apply</pre> |
| If answered "Ye Following the arappointments a Yes If answered "Ye Who were the for Answers may be a Yes Gynaecologist General pract Physiotherapi Fertility specif Mental health Please specify any If answered "Ye Was the dischar | S" to [5] then: dmission when endom rranged? No ss" to [15a] then: collow-up appointment/ multiple, please select all t itioner st lalist specialist y additional options here. ss" to [5] then: rge summary shared w | etriosis was first diagnosed, were any follow-u Unknown Unknown Operating surgeon Endometriosis nurse specialist Gastroenterologist Pain specialist |
| If answered "Ye Following the arappointments a Yes If answered "Ye Who were the for Answers may be a Yes Gynaecologist General pract Physiotherapi Fertility specif Mental health Please specify any If answered "Ye Was the dischar | No ss" to [5] then: dmission when endom rranged? No ss" to [15a] then: ollow-up appointment/ multiple, please select all t itioner st lalist specialist y additional options here. | etriosis was first diagnosed, were any follow-u Unknown Unknown Operating surgeon Endometriosis nurse specialist Gastroenterologist Pain specialist |
| If answered "Ye Following the arappointments a Yes If answered "Ye Who were the for Answers may be a Yes Gynaecologist General pract Physiotherapi Fertility specif Mental health Please specify any If answered "Ye Was the dischar | No ss" to [5] then: dmission when endom irranged? No ss" to [15a] then: collow-up appointment/ multiple, please select all it itioner st lalist specialist y additional options here. ss" to [5] then: rge summary shared w multiple, please select all irrge summary shared w multiple, please select all | etriosis was first diagnosed, were any follow-u Unknown Unknown Operating surgeon Endometriosis nurse specialist Gastroenterologist Pain specialist |
| If answered "Ye Following the arappointments a Yes If answered "Ye Who were the form Answers may be a Mental health Please specify any If answered "Ye Was the dischard Answers may be a Mental health Answers may be a | No ss" to [5] then: dmission when endom irranged? No ss" to [15a] then: collow-up appointment/ multiple, please select all it itioner st lalist specialist y additional options here. ss" to [5] then: rge summary shared w multiple, please select all irrge summary shared w multiple, please select all | etriosis was first diagnosed, were any follow-u Unknown Unknown Operating surgeon Endometriosis nurse specialist Gastroenterologist Pain specialist |
| If answered "Ye Following the acappointments a Yes If answered "Ye Who were the for Answers may be a Yes Gynaecologist General pract Physiotherapi Fertility specif Mental health Please specify any Hease specify any Hease specify and The General Fertility Specification of the Hease Specify and The General Fertility Specification of the Hease Specify and The General Fertility Another province The Patient Another province Another Province The Specification of the Hease Specif | No ss" to [5] then: dmission when endom irranged? No ss" to [15a] then: collow-up appointment/ multiple, please select all it itioner st lalist specialist y additional options here. ss" to [5] then: rge summary shared w multiple, please select all irrge summary shared w multiple, please select all | Unknown Unknown Unknown So with? That apply Derating surgeon Endometriosis nurse specialist Gastroenterologist Pain specialist That apply |
| If answered "Ye Following the acappointments acappointment answers may be acappointment answered "Ye Was the discharate Answers may be acappointment acappointmen | No es" to [5] then: dmission when endom erranged? No es" to [15a] then: collow-up appointment/ multiple, please select all t itioner est lalist specialist y additional options here. es" to [5] then: rge summary shared w multiple, please select all Practitioner | Unknown Unknown Unknown So with? That apply Derating surgeon Endometriosis nurse specialist Gastroenterologist Pain specialist That apply |
| If answered "Ye Following the arappointments a Yes If answered "Ye Who were the form Answers may be a Yes Gynaecologist General pract Physiotherapi Fertility specil Mental health Please specify any If answered "Ye Was the dischara Answers may be a Yes Was the General Form The Patient Another provi Unknown | No es" to [5] then: dmission when endom erranged? No es" to [15a] then: collow-up appointment/ multiple, please select all t itioner est lalist specialist y additional options here. es" to [5] then: rge summary shared w multiple, please select all Practitioner | Unknown Unk |

| Following the admisted oatient re-admitted Yes fanswered "Yes" to | o [5] then: | nent care plan hen endometriosis was 1 30 days of discharge? | ïrst diagnosed, was t |
|--|---------------------------------------|---|-----------------------|
| ollowing the admis atient re-admitted) Yes answered "Yes" to | ssion to hospital wl | | ïrst diagnosed, was t |
| Following the admisted oatient re-admitted Yes fanswered "Yes" to | ssion to hospital wl | | ïrst diagnosed, was t |
| Following the admis patient re-admitted Yes If answered "Yes" to | ssion to hospital wl | | ïrst diagnosed, was t |
| patient re-admitted Yes If answered "Yes" to | ssion to hospital wl | | ïrst diagnosed, was t |
| Following the admis patient re-admitted Yes If answered "Yes" to | ssion to hospital wl | | ïrst diagnosed, was t |
| Yes O.If answered "Yes" to | • | | |
| o.lf answered "Yes" to Please provide deta | O No | Unknown | O Not applicable |
| - | o [18a] then: ails of the readmiss | ion to hospital: | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |

E. Medications

| 1a. | At any time, were endometriosis? | e any hormonal trea | tments prescribed to manage the symptoms of |
|-----|--|--|---|
| | O Yes | O No | O Unknown |
| 1b. | Answers may be me Combined horm Contraceptive p Oral progestoge Levonorgestrel Nexplanon Depo-Provera in Gonadotrophin | hormonal treatment ultiple, please select a sonal contraception eatch en releasing intrauterine spection | system onist (+/- add-back hormone replacement therapy (HRT)) |
| 2. | Answers may be mu The general pra Endometriosis n | ormonal treatment ultiple, please select a ctitioner | all that apply The gynaecologist Unknown |
| | If answered "Yes" | e hormone treatme to [1a] then: | ent first prescribed? Unknown Ot known, if possible please estimate the month and |
| | If answered "Yes" | e prescription of th | ue hormone treatment first reviewed? Unknown Dwn, if possible please estimate the month and year: |

| | atment was not prescribed, please indicate the reasons why: multiple, please select all that apply | |
|--|---|----|
| _ | already on an alternative successful treatment | |
| Patient choice | | |
| _ | sks of hormonal treatments were too great for this patient as not previously effective | |
| | esolved without treatment | |
| Unknown | rying to conceive | |
| Please specify an | ny additional options here | |
| ricuse specify an | y additional options here | |
| 5. If answered "Ye | | |
| | nal treatment stopped at any time? | |
| O Yes | O No O Unknown | |
| 7. If answered "Ye | es" to [6] then: prescription of hormonal treatment stopped? | |
| | ate in DD/MM/YYYY format. If full date not known, please estimate month and yea | or |
| | | |
| | | |
| | | |
| | es" to [6] then: reason for stopping the prescribing of hormonal treatment? multiple, please select all that apply | |
| What was the re | reason for stopping the prescribing of hormonal treatment? multiple, please select all that apply | |
| What was the re Answers may be | reason for stopping the prescribing of hormonal treatment? multiple, please select all that apply cy Side effects of treatment Potential risks of treatment | |
| What was the real Answers may be Lack of efficact Patient trying | reason for stopping the prescribing of hormonal treatment? multiple, please select all that apply cy Side effects of treatment Potential risks of treatment | |
| What was the real Answers may be Lack of efficact Patient trying | reason for stopping the prescribing of hormonal treatment? multiple, please select all that apply acy Side effects of treatment Potential risks of treatment g to conceive Patient's wishes Unknown | |
| What was the real Answers may be a Lack of efficated Patient trying Please specify an | reason for stopping the prescribing of hormonal treatment? multiple, please select all that apply acy Side effects of treatment Potential risks of treatment g to conceive Patient's wishes Unknown any additional options here | |
| What was the real Answers may be Lack of effication Patient trying Please specify an D. Was pain medication | reason for stopping the prescribing of hormonal treatment? multiple, please select all that apply acy Side effects of treatment Potential risks of treatment action to conceive Patient's wishes Unknown any additional options here cation prescribed at any time to alleviate the symptoms of endometriosi | |
| What was the real Answers may be a Lack of efficated Patient trying Please specify an | reason for stopping the prescribing of hormonal treatment? multiple, please select all that apply acy Side effects of treatment Potential risks of treatment g to conceive Patient's wishes Unknown any additional options here | |
| What was the real Answers may be a lack of efficated Patient trying Please specify an lack of efficient Patient Trying Please specify an lack of efficient Patient Patie | reason for stopping the prescribing of hormonal treatment? multiple, please select all that apply acy Side effects of treatment Potential risks of treatment by to conceive Patient's wishes Unknown any additional options here cation prescribed at any time to alleviate the symptoms of endometriosi No Unknown | |
| What was the real Answers may be a lack of efficated Patient trying Please specify an lack of efficient Patient Trying Please specify an lack of efficient Patient Patie | reason for stopping the prescribing of hormonal treatment? multiple, please select all that apply acy Side effects of treatment Dotential risks of treatment by to conceive Patient's wishes Unknown any additional options here cation prescribed at any time to alleviate the symptoms of endometriosi No Unknown es" to [9] then: d the pain medication? | |
| What was the real Answers may be a lack of efficated Patient trying Please specify an Please specify and | reason for stopping the prescribing of hormonal treatment? multiple, please select all that apply acy Side effects of treatment Dotential risks of treatment by to conceive Patient's wishes Unknown any additional options here cation prescribed at any time to alleviate the symptoms of endometriosi No Unknown es" to [9] then: d the pain medication? | |
| What was the real Answers may be a lack of efficated Patient trying Please specify an Please specify and | reason for stopping the prescribing of hormonal treatment? multiple, please select all that apply acy | |
| What was the real Answers may be a lack of efficated Patient trying Please specify an Please specify and | reason for stopping the prescribing of hormonal treatment? multiple, please select all that apply acy | |
| What was the real Answers may be a lack of effication of Patient trying. Please specify an efficient answered "Yes who prescribed General praction." Please specify an efficient answered "Yes answe | reason for stopping the prescribing of hormonal treatment? multiple, please select all that apply acy | |
| What was the real Answers may be a lack of effication of Patient trying. Please specify an efficient answered "Yes who prescribed General praction." Please specify an efficient answered "Yes answe | reason for stopping the prescribing of hormonal treatment? multiple, please select all that apply acy | |
| What was the real Answers may be a lack of effication Patient trying Please specify an Please indicate Answers may be a lack and a lack answers may be a lack and a lack answers may be a lack and a lack and a lack and a lack answers may be a lack and a lack and a lack and a lack and a lack answers may be a lack and a lack and a lack and a lack answers may be a lack and a la | reason for stopping the prescribing of hormonal treatment? multiple, please select all that apply acy | |
| What was the real Answers may be a lack of effication Patient trying Please specify an Please indicate Answers may be a lack and a lack answers may be a lack and a lack answers may be a lack and a lack and a lack answers may be a lack and a la | reason for stopping the prescribing of hormonal treatment? multiple, please select all that apply acy | |

| O Yes | O No | O Unknown |
|--------------------------------------|--|--|
| 3. Was 'add-back | c HRT' also prescribed? | |
| O Yes | ○ No | ○ Unknown |
| 1. Was the patie | nt offered GnRH agonis | ts to reduce endometriosis-associated pain? |
| O Yes | ○ No | O Unknown |
| | | in medication, was the patient prescribed any other symptoms of endometriosis? |
| O Yes | O No | ○ Unknown |
| b.If answered "Y Please give fu | es" to [15a] then: rther details: | |
| | | |
| | | |
| | y side effects recorded endometriosis? | from any of the medication prescribed for the |
| | | from any of the medication prescribed for the Unknown |
| symptoms of e Yes b.If answered "Y | endometriosis? | ○ Unknown |
| symptoms of e Yes b.If answered "Y | endometriosis? No Yes" to [16a] then: | ○ Unknown |
| symptoms of e Yes b.If answered "Y | endometriosis? No Yes" to [16a] then: | ○ Unknown |
| symptoms of o | endometriosis? No Yes" to [16a] then: | ○ Unknown |
| symptoms of o | endometriosis? No Yes" to [16a] then: | ○ Unknown |
| symptoms of e Yes b.If answered "Y | endometriosis? No Yes" to [16a] then: | ○ Unknown |
| symptoms of e Yes b.If answered "Y | endometriosis? No Yes" to [16a] then: | ○ Unknown |
| symptoms of e | endometriosis? O No Yes" to [16a] then: e details of the side effe | ○ Unknown |

F. Index admission: Laparoscopy for endometriosis

This section is about the events leading up to, during and following the "index admission". This is the first recorded admission to hospital for a laparoscopy (or other surgery for endometriosis) during the study period (01/02/2018- 31/07/2020) for endometriosis (dates of admission / discharge are indicated on the previous "assignments" screen of the questionnaire portal)

If the index admission was for the laparoscopy* when the patient was first formally diagnosed with endometriosis and you have already fully completed sections C and D in relation to this admission, then you do not need to complete this section

| | Please confirm whether endometriosis was first diagnosed during the index admission* and if so, that sections C & D of this questionnaire have been fully completed in relation to this admission? see definitions |
|-----|--|
| | YES: Endometriosis was diagnosed during the index admission and sections C and D have been completed.NO: Endometriosis was diagnosed at a different admission to the index admission.Unknown |
| Pre | e-admission |
| | If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then: Please indicate the referral route for the index admission for laparoscopy |
| | □ GP referral to gynaecologist □ Referral from gynaecologist following clinic attendance □ Emergency department attendance □ Referral to gynaecology from other specialty □ Unknown |
| | Please specify any additional options here |
| | that the patient was first referred to the gynaecologist (e.g. from primary care or another specialty)? *or other surgery for endometriosis Unknown |
| | If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then: If exact date unknown, if possible please estimate the month and year the patient was first referred to the gynaecologist (e.g. from primary care or another specialty)? in relation to the laparoscopy* that occurred during the index admission |
| | If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then: Please give the date that the patient was first seen in the gynaecology clinic regarding their symptoms of endometriosis: In relation to the laparoscopy (or other surgery for endometriosis) that occurred during the index admission. |
| | ☐ Unknown |
| 3b. | If answered "NO: Endometriosis was diagnosed at a different admission to the index |
| | admission" or "Unknown" to [1a] then: If exact date unknown, if possible could you estimate the month and year the patient was |

| Abdominal examinations ase specify any a answered "Abdo I the examinations abdominal mass Lower abdominal Pelvic floor tender ase specify any a answered "NO: I mission" or "Un or to the laparo | minal examination" ons identify: Itiple, please select all I tenderness erness dditional options here Endometriosis was dknown" to [1a] then scopy* that occurred | or "Pelvic that apply | examination" to [4a] then: Adnexal mass Fixed tender retroverted uterus Unknown at a different admission to the index the index admission, was any imaging | |
|--|--|------------------------|--|--|
| Abdominal examinations assessment "Abdominal mass Lower abdominal Pelvic floor tenders specify any a session" or "Un or to the laparomination or to the laparomination of the la | ination were carried out dditional options here minal examination" ons identify: ltiple, please select all tenderness erness dditional options here Endometriosis was d known" to [1a] then scopy* that occurred | or "Pelvic that apply | examination" to [4a] then: Adnexal mass Fixed tender retroverted uterus Unknown at a different admission to the index | |
| Inswered "Abdo I the examinations Abdominal mass Lower abdominal Pelvic floor tende ase specify any a Inswered "NO: I Inswered Instead surg | minal examination" ons identify: Itiple, please select all I tenderness erness dditional options here Endometriosis was dknown" to [1a] then scopy* that occurred | or "Pelvic that apply | examination" to [4a] then: Adnexal mass Fixed tender retroverted uterus Unknown at a different admission to the index | |
| Inswered "Abdo I the examination wers may be much abdominal mass." Lower abdomination Pelvic floor tenders specify any and the lapard of the listed surgestimates and the lapard of the listed surgestimates. | minal examination" ons identify: Itiple, please select all I tenderness erness dditional options here Endometriosis was d known" to [1a] then scopy* that occurre | or "Pelvic" that apply | Adnexal mass Fixed tender retroverted uterus Unknown at a different admission to the index | |
| A the examination were may be much abdominal mass. Lower abdominal Pelvic floor tenders as especify any and assessment of the lapard or to the lapard or other listed surgestimes. | ens identify: Itiple, please select all Itenderness erness dditional options here Endometriosis was denown" to [1a] then scopy* that occurred | that apply | Adnexal mass Fixed tender retroverted uterus Unknown at a different admission to the index | |
| Lower abdominated Pelvic floor tender asses specify any a see see specify any a see see see see see see see see see s | Endometriosis was d known" to [1a] then scopy* that occurred | iagnosed | Fixed tender retroverted uterus Unknown at a different admission to the index | |
| ng nswered "NO: I mission" or "Un or to the lapard | Endometriosis was d known" to [1a] then scopy* that occurred | liagnosed | Unknown at a different admission to the index | |
| ng nswered "NO: I mission" or "Un or to the laparo | Endometriosis was d known" to [1a] then scopy* that occurred | liagnosed | at a different admission to the index | |
| ng inswered "NO: I mission" or "Un or to the lapard ried out? other listed surg | Endometriosis was d known" to [1a] then scopy* that occurre | liagnosed | | |
| inswered "NO: I mission" or "Un or to the lapard ried out? | known" to [1a] thense scopy* that occurred ery for endometriosis | : | | |
| mission" or "Un or to the lapard ried out? rother listed surg | known" to [1a] thense scopy* that occurred ery for endometriosis | : | | |
| _ | _ | | | |
| | O No | O | Unknown | |
| nswered "Yes" at imaging was swers may be mu | | that apply | | |
| Ultrasound scan Unknown | (USS) | | Magnetic resonance imaging (MRI) scan | |
| ase specify any a | dditional options here | | | |
| | | | s carried out prior to the laparoscopy | |
| | | | Unknown | |
| If answered "Yes" to [5a] then: If the exact date of the most recent imaging is not known, if possible please estimate the month and year: | | | | |
| nth and year: | | | | |
| nth and year: | | | | |
| nth and year: ase include dates inswered "Yes" | erpreted by healtho | care profe | ssional/s with specialist expertise in | |
| • | | | nth and year: se include dates in DD/MM/YYYY format | |

| 8a. | If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then: What was the date of referral for the laparoscopy that occurred during the index admission? | | | | |
|-----|--|---|---|--|--|
| | | | Unknown | | |
| 8b. | admission" or "U | nknown" to [1a] th of the referral for | s diagnosed at a different admission to the index nen: the laparoscopy is not known, if possible please | | |
| | | | | | |
| | admission" or "U Is there evidence | nknown" to [1a] th | vas formally discussed at a complex endometriosis | | |
| | O Yes | O No | Unknown | | |
| 9b. | If answered "No" If the patient was been? | | s part of an MDT, in your opinion, should they have | | |
| | O Yes | O No | O Unknown | | |
| 9c. | If answered "Yes Did the MDT resu | | reatment plan for the patient? | | |
| | O Yes | O No | O Unknown | | |
| 9d. | | " to [9a] then: s were present at t nultiple, please select | | | |
| | ☐ Urologist☐ Other surgeon☐ Other nurse☐ Physiotherapy☐ Reproductive n☐ Radiology | | ☐ Colorectal surgeon ☐ Endometriosis nurse specialist ☐ Anaesthesia ☐ Unable to answer ☐ Pharmacy | | |
| | Please specify any | additional options he | ere | | |
| 10. | admission" or "U When was conse admission? | nknown" to [1a] th | paroscopy* that was carried out during the index | | |
| 11. | admission" or "U | nknown" to [1a] th | s diagnosed at a different admission to the index ien: discussed with the patient? | | |
| | O Yes | O No | Unknown | | |
| Ad | mission for lapar | oscopy | | | |

| | | Unknown |
|--|--|--|
| If answered "NO: admission" or "Ur What procedure v | nknown" to [1a] then: | agnosed at a different admission to the index |
| C Laparascopic ab | - | Laparascopic excisionHysterectomy |
| If not listed above, p | please specify here | |
| admission" or "Ur | Endometriosis was dia nknown" to [1a] then: was performed during | agnosed at a different admission to the index the index admission? |
| ☐ Laparascopic ab☐ Laparascopic ab☐ Unknown | plation plation and excision | Laparascopic excisionHysterectomy |
| Please specify any a | additional options here | |
| | | |
| What was the spe | nknown" to [1a] then: ecialty of the clinician gynaecology () Genera | performing the procedure? al surgery |
| If not listed above, ¡ | please specify here | |
| If not listed above, I | please specify here | |
| a.lf answered "NO: admission" or "Ur | | agnosed at a different admission to the index |
| a.lf answered "NO: admission" or "Ur | Endometriosis was dia | |
| a.If answered "NO: admission" or "Ur Were any other p O Yes O.If answered "Yes" | Endometriosis was dianknown" to [1a] then: rocedures undertaken | n? O Unknown |
| a.If answered "NO: admission" or "Ur Were any other p O Yes O.If answered "Yes" | Endometriosis was dianknown" to [1a] then: rocedures undertaken No ' to [15a] then: | n? O Unknown |
| a.If answered "NO: admission" or "Ur Were any other p O Yes O.If answered "Yes" | Endometriosis was dianknown" to [1a] then: rocedures undertaken No ' to [15a] then: | n? O Unknown |
| a.If answered "NO: admission" or "Ur Were any other p O Yes O.If answered "Yes" | Endometriosis was dianknown" to [1a] then: rocedures undertaken No ' to [15a] then: | n? O Unknown |
| a.If answered "NO: admission" or "Ur Were any other p O Yes D.If answered "Yes" Please give detail 6. If answered "NO: admission" or "Ur | Endometriosis was dianknown" to [1a] then: rocedures undertaken No to [15a] then: Is of any other proced | Unknown dures performed: agnosed at a different admission to the index |
| a.If answered "NO: admission" or "Ur Were any other p O Yes D.If answered "Yes" Please give detail 6. If answered "NO: admission" or "Ur | Endometriosis was dianknown" to [1a] then: rocedures undertaken No to [15a] then: Is of any other proced | Unknown |

| 17a. | admission" or "U In your opinion, | Endometriosis was d nknown" to [1a] then was the laparoscopy* to treat endometriosis) | ı: | at a different admission to the index |
|------|--|--|---|--|
| | O Yes | O No | O | Unknown |
| | | " to [17a] then: ason/s for this delay? aultiple, please select all | | |
| | Patient decisio Organisational GP referral to g Delay in imagii Surgeon availa Unknown | factors gynaecology ng/ investigations | | Clinical reasons COVID-19 pandemic Delay in decision of gynaecologist Theatre availability Availability of other staff |
| | Please specify any | additional options here. | | |
| 17c. | If answered "Yes | | | |
| | _ | did the patient's sym | ptoms wor | sen during this time? |
| | O Yes | O No | O | Unknown |
| | O Yes | to treat endometriosis) No | 0 | Unknown |
| | If answered "Yes Please give furth | | | |
| | | | | |
| | • | p from index admissi | | |
| 19. | | nknown" to [1a] then | _ | at a different admission to the index |
| | | | | Unknown |
| 20. | admission" or "U Is there a discha This is the first rec (01/02/2018- 31/0 | nknown" to [1a] then rge summary available orded admission to hosp | i: le in the n pital for a la is (dates of | at a different admission to the index otes for the index admission? paroscopy during the study period admission / discharge are indicated on the ortal |
| | O Yes | O No | | Unknown |
| | | | | |

| | | ny of the following information: all that apply |
|--|---|---|
| Details of the Follow-up ap No discharge Reason for properties of me Details of on Details of postalls of tre Details of reason postalls of reason Details of the Details of reason Details of reason Details of reason Details of the Details of t | summary available rocedure edications ward referrals to support ssible complications atment plan | ing services contact if symptoms return |
| 22. If answered "You was information any concerns? | | charge summary of who to contact if the patient has |
| O Yes | O No | O Unknown |
| 23a.If answered "Yo Was a copy of | | ry sent to the patients GP practice? |
| O Yes | O No | O Unknown |
| 23b.If answered "You was a copy of the cop | | ry shared with the patient? |
| O Yes | O No | O Unknown |
| admission" or ' | O: Endometriosis was 'Unknown" to [1a] the ment/ care plan put in | |
| O Yes | O No | O Unknown |
| 24b.If answered "Ye Please provide | es" to [24a] then: details of the care pla | an: |
| | | |
| | | |
| admission" or ' Following disch | 'Unknown" to [1a] the | scopy performed during the index admission, was the |
| O Yes | O No | O Unknown |
| | | |

| admission" or "Unknown" to [1a] then: Was the patient readmitted to hospital within 30 days of discharge? O Yes O No O Unknown | General surgeon Urologist General Practitioner Endometriosis nurse specialist Pain specialist Physiotherapist Please specify any additional options here Ga.If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then: Was the patient readmitted to hospital within 30 days of discharge? Yes No Unknown Gb.If answered "Yes" to [26a] then: | Please indicate | • | |
|--|--|--|------------------------------------|--|
| a.If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then: Was the patient readmitted to hospital within 30 days of discharge? O Yes O No O Unknown b.If answered "Yes" to [26a] then: | Sa. If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then: Was the patient readmitted to hospital within 30 days of discharge? Yes O NO Unknown Sb. If answered "Yes" to [26a] then: | General surg Urologist Endometrios Pain speciali | geon sis nurse specialist st | Colorectal surgeonGeneral PractitionerReproductive medicine consultant |
| admission" or "Unknown" to [1a] then: Was the patient readmitted to hospital within 30 days of discharge? O Yes O No O Unknown b.If answered "Yes" to [26a] then: | admission" or "Unknown" to [1a] then: Was the patient readmitted to hospital within 30 days of discharge? O Yes O No O Unknown b.If answered "Yes" to [26a] then: | Please specify a | ny additional options here | 2 |
| | | admission" or | "Unknown" to [1a] ther | n: |
| | | Was the patier | _ | al within 30 days of discharge? |
| | | Was the patien O Yes Sb.If answered "Y | ○ No 'es" to [26a] then: | cal within 30 days of discharge? O Unknown |
| | | Was the patien O Yes Sb.If answered "Y | ○ No 'es" to [26a] then: | cal within 30 days of discharge? O Unknown |
| | | Was the patien O Yes Sb.If answered "Y | ○ No 'es" to [26a] then: | cal within 30 days of discharge? Unknown |

G. Referral to supporting services

| In relation to the | e care or endornerrosis. Answer. | s may be martiple, prease sereet an that apply |
|--|--|---|
| _ | sis nurse-led clinic py specialist in endometriosis urgery ology | ☐ Clinical psychologist ☐ Physiotherapist ☐ Urology ☐ Other surgery ☐ Fertility services ☐ Pain clinic ☐ None of these |
| | ny additional options here | |
| | | |
| a. At any time, w | No | h a mental health assessment? () Unknown |
| b. If answered "Y | es" to [2a] then: e details of who undertook th | ne mental health assessment/ screening? |
| _ | sis nurse specialist | General Practitioner |
| Gynaecology | | Clinical psychologistRegistered Mental Health nurse |
| | Matrist | I I Registered Mental Health hurse |
| Liaison psyc | | |
| _ | ny additional options here | |
| Please specify a c. If answered "Y Was the patien | ny additional options here Yes" to [2a] then: | nologist at any time in relation to their |
| Please specify a c. If answered "Y Was the patien | ny additional options here Yes" to [2a] then: nt referred to a clinical psycl | |
| Please specify a c. If answered "Y Was the patient symptoms of existing of the symptoms of existing of the symptoms of the sy | res" to [2a] then: Intreferred to a clinical psyclendometriosis? No No Vidence that the patient was e.g. information from Endor | nologist at any time in relation to their Unknown sign-posted to information about |
| Please specify a c. If answered "Y Was the patient symptoms of existing of the symptoms of existing of the symptoms of the sy | res" to [2a] then: Intreferred to a clinical psyclendometriosis? No No No No No No No No No N | nologist at any time in relation to their Unknown sign-posted to information about netriosis UK |
| Please specify a c. If answered "Y Was the paties symptoms of e O Yes 3. Is there any evendometriosis This could be in O Yes | res" to [2a] then: Intreferred to a clinical psychendometriosis? No No No No No No No No No N | ologist at any time in relation to their Unknown sign-posted to information about metriosis UK et or verbal, but documented in the case notes. Unknown |
| Please specify a C. If answered "Y Was the paties symptoms of e O Yes 3. Is there any evendometriosis This could be in O Yes | res" to [2a] then: Intreferred to a clinical psychendometriosis? No No No No No No No No No N | ologist at any time in relation to their Unknown sign-posted to information about metriosis UK et or verbal, but documented in the case notes. Unknown |
| Please specify a Co. If answered "Y Was the paties symptoms of e Yes 3. Is there any evendometriosis This could be in Yes At any time, w Yes | res" to [2a] then: Intreferred to a clinical psychendometriosis? No No No No No No No No No N | nologist at any time in relation to their Unknown sign-posted to information about metriosis UK et or verbal, but documented in the case notes. Unknown Specialist pelvic pain clinic? |
| Please specify a C. If answered "Y Was the paties symptoms of e Yes 3. Is there any evendometriosis This could be in Yes a. At any time, w Yes b. If answered "Y Please provide a. Was this patie | res" to [2a] then: Intreferred to a clinical psychendometriosis? No No No No No No No No No N | nologist at any time in relation to their Unknown sign-posted to information about metriosis UK et or verbal, but documented in the case notes. Unknown specialist pelvic pain clinic? Unknown |
| Please specify a C. If answered "Y Was the paties symptoms of e O Yes 3. Is there any evendometriosis This could be in O Yes a. At any time, w O Yes b. If answered "Y Please provide a. Was this patie O Yes | res" to [2a] then: Intreferred to a clinical psychendometriosis? No No No No No No No No No N | nologist at any time in relation to their Unknown sign-posted to information about metriosis UK et or verbal, but documented in the case notes. Unknown specialist pelvic pain clinic? Unknown |
| Please specify a Co. If answered "Y Was the paties symptoms of e O Yes 3. Is there any evendometriosis This could be in O Yes a. At any time, w O Yes b. If answered "Y Please provide a. Was this patie O Yes b. If answered "Yes | res" to [2a] then: Intreferred to a clinical psychendometriosis? No No No No No No No No No N | sign-posted to information about metriosis UK et or verbal, but documented in the case notes. Unknown Specialist pelvic pain clinic? Unknown Unknown Unknown |

| nswered "Yes" to ase provide detail nswered "Yes" to rour opinion, did feiving less than b Yes nswered "Yes" to ase provide further | [6a] then: ailure to refer to any spect practice care? | O Unknown Decific specialty/service result in this patient O Unknown |
|--|---|--|
| nswered "Yes" to rour opinion, did feiving less than b | [6a] then: ailure to refer to any spect practice care? | |
| our opinion, did feiving less than b Yes nswered "Yes" to | ailure to refer to any spest practice care? No | |
| our opinion, did feiving less than b Yes nswered "Yes" to | ailure to refer to any spest practice care? No | |
| nswered "Yes" to | • | O Unknown |
| | [Ca] +ham. | |
| | | |
| | | cient being assessed/ treated by any of the triosis care? |
| Yes | O No | O Unknown |
| ase provide detail | s on how the delay in a | ppointment/s with supporting services |
| | | |
| | porting services r Yes nswered "Yes" to ase provide detail | porting services regarding their endome |

| 1a. | | dex admission did the endometriosis symp | he patient have a subsequent recurrence (or toms? |
|-----|--|--|--|
| | O Yes | O No | ○ Unknown |
| 1b. | endometriosis s Please use DD/MM year. If there have | e date(s) when the p ymptoms following t M/YYY format. If exact of the been multiple episod | atient first presented with recurrence of the index admission: date(s) not known, if possible, please include month and es, please include each recorded date when the patient first with recurrent symptoms of endometriosis |
| | | | |
| 2. | | atient first present | with the onset of recurrent endometriosis symptoms? refer to the first recurrence following the index admission |
| | O General practi O Emergency de | | Out-patient /follow-up gynaecology clinic |
| | If not listed above | , please specify here | |
| 3a. | If answered "Yes | s" to [1a] then: | |
| Ju. | Has the patient | | t re-admissions to hospital for laparoscopy, (or other netriosis? |
| | O Yes | O No | Unknown |
| 36. | Please provide da | details (including da | tes and procedures performed): lischarge and the route of admission, procedure/s performed ital |
| 4a. | | | ays in the patient being investigated and treated for appropriate in the patient being investigated and treated for appropriate in the patient being investigated and treated for appropriate in the patient being investigated and treated for appropriate in the patient being investigated and treated for appropriate in the patient being investigated and treated for appropriate in the patient being investigated and treated for appropriate in the patient being investigated and treated for appropriate in the patient being investigated and treated for approximate in the patient being investigated and treated for approximate in the patient being investigated and treated for approximate in the patient being investigated and treated for approximate in the patient being investigated and treated for approximate in the patient being investigated and treated for approximate in the patient being investigated and the patient bein |
| | O Yes | O No | Unknown |
| 4b. | If answered "Yes Please provide f | | |
| 5a. | | been re-admitted to | hospital for treatment of recurrent endometriosis since the index admission? |
| | O Yes | O No | O Unknown |

H. Ongoing care and subsequent re-admissions

| Name coloct and of | the fellowing cuteoms w | | anded for this maticut |
|---|---|-------------------------|-------------------------|
| t any time following | the following outcome n y the index admission? ole, please select all that ap | | corded for this patient |
| ☐ Functional outcome | e 🔲 Return to work | Pain/ discomfort | Usual activities |
| Quality of life | Sexual function | Digestive function | Fatigue |
| Urinary function | ■ Depression/ Anxiety | ☐ Unknown | ☐ None of the above |
| lease specify any add | tional options here | | |
| | | | |
| | · | | |
| Please use this box to | o highlight any other ar as where you feel with h | | |
| Please use this box t | o highlight any other ar | | |
| Please use this box to | o highlight any other ar | | |
| Please use this box to | o highlight any other ar | | |
| Please use this box to | o highlight any other ar | | |
| Please use this box to | o highlight any other ar | | |
| Please use this box to | o highlight any other ar | | |
| Please use this box to | o highlight any other ar | | |
| Please use this box to | o highlight any other ar | | |
| Please use this box to | o highlight any other ar | | |
| Please use this box to actice and any are mproved: | o highlight any other ar as where you feel with h | nindsight that the care | could have been |
| Please use this box to ractice and any are improved: | o highlight any other ar | TE THIS QUESTIONNAIR | could have been |
| Please use this box to ractice and any are improved: NK YOU FOR TAKING answers will contributed. | co highlight any other ar as where you feel with h | TE THIS QUESTIONNAIR | could have been |
| Please use this box to ractice and any are improved: NK YOU FOR TAKING answers will contributed. | co highlight any other ar as where you feel with h | TE THIS QUESTIONNAIR | could have been |
| Please use this box to ractice and any are improved: NK YOU FOR TAKING answers will contributed. | co highlight any other ar as where you feel with h | TE THIS QUESTIONNAIR | could have been |
| Please use this box to ractice and any are improved: NK YOU FOR TAKING answers will contributed. | co highlight any other ar as where you feel with h | TE THIS QUESTIONNAIR | could have been |
| Please use this box to ractice and any are improved: | co highlight any other ar as where you feel with h | TE THIS QUESTIONNAIR | could have been |
| Please use this box to ractice and any are improved: NK YOU FOR TAKING answers will contributed. | co highlight any other ar as where you feel with h | TE THIS QUESTIONNAIR | could have been |
| Please use this box to practice and any are improved: | co highlight any other ar as where you feel with h | TE THIS QUESTIONNAIR | could have been |