1.	What is the report looking at/what is the project measuring?	Endometriosis: A Long and Painful Road *A review of the quality of care provided to adult patients diagnosed with endometriosis*
2.	What countries are covered?	England, Wales and Northern Ireland
3.	The date the data is related to	1st February 2018 - 31st July 2020 inclusive

No.	Recommendation	Evidence in the report which underpins the recommendation	Guidance available
1	Raise awareness about endometriosis symptoms with the public and patients, highlighting that it is a chronic condition and how they can seek help. ***Primary audiences:*** *NHS England, Welsh Government, Northern Ireland Department of Health* ***Supported by:*** *Royal College of Obstetricians and Gynaecologists, Royal College of General Practitioners, Royal College of Surgeons, Royal College of Emergency Medicine, Royal College of Nursing, Royal College of Paediatrics and Child Health, Department for Education, Endometriosis UK, Endometriosis Cymru*	**CHAPTER 3** Figure 3.5 shows that in this study, the mean time from first appearance of symptoms to presentation to the GP was 4.1 years (range 0 to 40 years), with 588/840 (70%) survey respondents reporting it took them two years to present to the GP with symptoms.	Endometriosis UK: Dismissed, ignored and belittled NICE Clinical Guideline CG138: Patient experience in adult NHS services: improving the experience of care for people using adult NHS services APPG Report Oct 2020 Endometriosis care in Wales: Report of the Task and finish group NHSE- Women's health strategy for England
2	Raise awareness with all healthcare professionals that endometriosis is a chronic condition and should be treated as such. ***Primary audiences national:*** *Royal College of Obstetricians and Gynaecologists, Royal College of General Practitioners, Royal College of Surgeons, Royal College of Emergency Medicine, Royal*	**CHAPTER 3** 496/623 (79.6%) patients presented to their GP with symptoms of endometriosis prior to diagnosis and 80/623 (12.8%) patients were initially referred to specialties other than gynaecology. **CHAPTER 3** More than half (490/941; 52.1%) of the survey respondents felt 'not at all', or 'not very' listened to by their GP.	Endometriosis UK: Dismissed, ignored and belittled NICE Clinical Guideline CG138: Patient experience in adult NHS services: improving the experience of

	College of Nursing, Royal College of Paediatrics and Child Health, Society for Acute Medicine, British Society for Gynaecological Endoscopy ***Primary audiences local:*** *Medical Directors, Clinical Directors, and Clinical Audit/Quality Improvement departments* ***Supported by:*** *NHS England, Welsh Government, Northern Ireland Department of Health*	**CHAPTER 3** A similar number (452/941; 48.0%) felt that their GP had 'not been at all', or 'not very' compassionate about their symptoms of endometriosis. **CHAPTER 3** 546/941 (58.0%) respondents had multiple visits to the GP before any investigations were undertaken or treatment initiated. **CHAPTER 3** A total of 703/941 (74.7%) respondents felt that there was room for improvement in the care that they received from their GP.	care for people using adult NHS services APPG Report Oct 2020
3	Improve training on the recognition of symptoms of endometriosis, such as pelvic pain and heavy menstrual bleeding. a. In primary care - to support healthcare professionals in the initial assessment, and any ongoing care of patients b. In secondary care - enhanced training on endometriosis should be made available for all healthcare professionals who might care for patients with endometriosis. ***Primary audiences national:*** *Royal College of Obstetricians and Gynaecologists, Royal College of General Practitioners, Royal College of Emergency Medicine, Royal College of Nursing, Royal College of Paediatrics and Child Health, British Society for Gynaecological Endoscopy*	**CHAPTER 3** Presenting symptoms were variable in the patients in this study, but the majority presented with painful periods and/or heavy menstrual bleeding, irregular bleeding and/or painful intercourse (220/234; 94.0%) (unknown in 169). The location and type of pain (cyclical vs non-cyclical) were mixed. Some patients presented with bowel symptoms (18/234; 7.7%) and urinary/bladder symptoms (14/234; 6.0%). Inability to conceive (subfertility) was a presentation in 12/234 (5.1%) patients and was recorded as a comorbidity in a further 32 patients (Figure 3.1). **CHAPTER 3** According to the reviewers there was evidence in the case notes that 52/88 (59.1%) patients were examined by the GP (unknown in 45). Of the 36 patients who were not examined, the reviewers stated 19 should have been. **CHAPTER 3**	NICE Guideline NG73: Endometriosis: diagnosis and management NICE Endometriosis Quality Standard QS172 NHSE- Women's health strategy for England Endometriosis care in Wales: Report of the task and finish group

	Primary audiences local: *Medical Directors, Clinical Directors, and Clinical Audit/Quality Improvement departments* ***Supported by:*** *NHS England, Welsh Government, Northern Ireland Department of Health*	When GPs were asked about performing an internal pelvic examination, 48/87 said that they did undertake one and that the findings altered the management for 8/48 patients (unknown in 33). It was of note that in 21/48 patients examined, GPs stated that they did not feel confident in performing a pelvic examination, despite the examination going ahead. **CHAPTER 3** From the patient survey, 393/941 (41.8%) respondents said that they had a pelvic examination during a consultation with a GP and 566/941 (60.1%) said that they had an abdominal examination. The choice of examination may be a medical decision, but the low number of pelvic examinations carried out does demonstrate poor adherence to NICE guidance and could potentially lead to a less focused referral process. **CHAPTER 3** Reviewers stated that for 31/118 (26.3%) patients there was room for improvement in the referral letter to gynaecology services (unknown in 120) (Table 3.1). Commonly missing from the letter were details from the patient's history, findings from examination, whether hormonal medications had been used and the patient's fertility status. **CHAPTER 3** Reviewers believed that for 36/136 (26.5%) patients there was a delay in initial referral to gynaecology (unknown in 102) and in 25/36 the quality of the care they received was impacted by this (Table 3.1). **CHAPTER 3** Only 110/167 (65.9%) hospitals from which an organisational questionnaire was returned reported that patients were routinely	

		provided with all information about their condition. This was mostly in the form of a printed leaflet or verbally at the clinic appointment. Only 40/167 (24.0%) hospitals reported routinely directing patients to endometriosis patient support groups and other holistic services such as pain clinic and mental health assessment and support (Figure 3.4). **CHAPTER 3** There were 62/137 (45.3%) clinicians who completed the survey who said that they had attended additional training in the care of patients with endometriosis during the previous five years. This was provided by the workplace for only 11/62 clinicians. There were 50/137 (36.5%) clinicians who worked in a BSGE centre. **CHAPTER 3** The organisational questionnaire showed the availability of training in the care of patients with endometriosis in (76/167; 45.5%) hospitals, with 70/76 hospitals offering it to gynaecologists and 34/76 to endometriosis clinical nurse specialists (Table 3.4). Other specialists within a hospital would not be expected to undergo endometriosis training, but hospitals and professional bodies should raise awareness of endometriosis and how it might present within other specialties.	
4	Ask patients with endometriosis about the effects it has over and above physical symptoms, including its impact on their daily life and refer them as needed to support services (e.g. psychology/pain services), at all stages of the pathway. ***Primary audiences:*** *Healthcare professionals in primary care and secondary care*	**CHAPTER 4 PAGE 29** Data from the clinical questionnaire showed that onward referrals to mental health services (9/573; 1.6%) and pain clinics (46/573; 8.0%) were low. The most common referrals were to fertility services (80/573; 14.0%) and surgical specialties (65/573; 11.3%), while 319/573 (55.7%) patients had no onward referrals documented (unknown in 50) (Figure 4.1). **CHAPTER 4 PAGE 30**	N/A

	Supported by: *NHS England, Welsh Government, Northern Ireland Department of Health*	Pain and poor mental health are among the two most prevalent presenting comorbidities or symptoms. At an organisational level, only 15/167 (8.9%) hospitals reported routine psychology screening within the clinic appointment. Just 17/167 (10.2%) hospitals had a full-time psychologist within the service. If no psychology was available, 45/150 (30.0%) hospitals had a defined pathway to refer to psychology. **CHAPTER 4 PAGE 30** Only 18/623 (2.9%) patients in the study were referred to physiotherapy despite the high numbers reporting pain, much of which was musculoskeletal or pelvic pain and would benefit from physiotherapy. **CHAPTER 4 PAGE 30** Almost half (420/941; 44.6%) of survey respondents stated that they were not asked at any point of the pathway about the impact of symptoms on their quality of life. Where it was answered, a small number (22/667; 3.3%) said that they were referred to supportive psychology services, while 118/732 (16.1%) were referred to a pain clinic and 108/732 (14.8%) to fertility services. These are low numbers of referrals given the prevalence of these comorbidities among patients diagnosed with endometriosis. **CHAPTER 4 PAGE 31** Clinicians completing questionnaires reported that 202/623 (32.4%) patients did not have any form of quality of life assessment carried out as part of their care. For those who did, most commonly it was an assessment of pain 271/532 (50.9%) (unknown in 91) (Figure 4.2).	
5	Ensure multidisciplinary teams/clinical networks are set up and utilised across all healthcare settings to help agree treatment plans and support women	**CHAPTER 2** Data from the clinical questionnaire showed that 403/623 (64.7%) patients presented with comorbid conditions, 60/403 (14.8%)	[NICE Guideline NG73: Endometriosis: diagnosis and management]()

	with confirmed endometriosis. Input from specialties should be proportionate to the patient's needs. ***Primary audiences:*** *Integrated care boards, Commissioners, Clinical Directors and Executive Boards* ***Supported by:*** *Royal College of Obstetricians and Gynaecologists, Royal College of General Practitioners, Royal College of Emergency Medicine, Royal College of Nursing, Royal College of Paediatrics and Child Health, British Society for Gynaecological Endoscopy, and Commissioners*	patients had comorbidities that included pain not related to endometriosis and 35/403 (8.7%) had poor mental health. This was also reflected in the patient survey, where 224/941 (23.8%) respondents reported 'back pain' and 68/941 (7.2%) said they had 'chronic widespread pain'. **CHAPTER 4** The reviewers identified that failure to refer to supportive services resulted in less than best practice in 70/309 (22.7%) patients. They believed that 24/70 patients should have had their care within a specialist endometriosis centre to benefit from the MDT working. **CHAPTER 4** Reviewers found that only 27/242 (11.2%) (unknown in 67) patients were formally discussed in an MDT meeting and 28/215 (13.0%) patients who were not discussed should have been. **CHAPTER 4** Less than half (73/167; 43.7%) of hospitals held regular endometriosis MDT meetings.	NICE Endometriosis Quality Standard QS172 Requirements to be a BSGE Accredited Centre
6	Manage pain effectively for patients who have endometriosis: a. Set a low threshold for the prescription of analgesia b. Set a low threshold for hormonal treatment which may improve pain as well as other symptoms – while always considering fertility intentions c. Refer to pain management services as needed d. In parallel, refer patients for non-medical pain management e.g. physiotherapy	**CHAPTER 5** 25/167 (14.9%) hospitals had one whole-time pain specialist within the endometriosis team, while 6/167 (3.5%) did not have any pain specialist available. **CHAPTER 5** Pain medication was only prescribed to 231/425 (54.4%) patients (unknown in 198), most commonly by the GP (152/231; 65.8%) or gynaecologist (109/231; 47.2%) with NSAIDs being the most common class of drug prescribed (15/231; 79.9%). **CHAPTER 5**	NICE Guidance NG193: Chronic pain (primary and secondary) in over 16s: assessment of all chronic pain and management of chronic primary pain NICE Clinical Knowledge Summary: Analgesia for mild to moderate pain European Society of Human Reproduction and

	Primary audiences: *All healthcare professionals in primary, secondary, and specialist care who are in contact with people who have endometriosis* ***Supported by:*** *Royal College of General Practitioners*	Only 46/623 (7.4%) patients saw a pain medicine specialist, despite 185/238 (77.7%) presenting with pain and 60/403 (14.8%) having pain-related comorbidities.	Embryology: Endometriosis guidelines
7	Use interactions between patients with endometriosis and prescribing healthcare professionals to undertake a medication review. ***Primary audiences:*** *All healthcare professionals, including pharmacists, who care for patients with endometriosis* ***Supported by:*** *Medical Directors, Clinical Directors, and Clinical Audit/Quality Improvement departments*	**CHAPTER 5** Of the 733/941 (77.9%) survey respondents prescribed hormonal treatments, only 363/687 (52.8%) had any improvement in symptoms when first prescribed medications by their GP (Table 5.2), and only 209/733 (28.5%) had a follow-up appointment. **CHAPTER 5** A total of 294/687 (42.8%) respondents to the patient survey said they experienced no improvement with medication. Despite this, 200/244 (82.0%) had no further investigation by their GP (Table 5.3). **CHAPTER 5** There were 103/448 (23.0%) patients who did not have their medication reviewed by the treating gynaecologist (unknown in 175). **CHAPTER 5** The reviewers considered that 73/218 (33.5%) patients had inadequate medication reviews (unknown in 91), and of that group 32/73 had no review of medication plan documented at all.	NICE guideline NG5: Medicines optimisation: the safe and effective use of medicines to enable the best possible outcomes
8	Provide patients with clear, written information as part of the process that allows the patient to give informed consent for the laparoscopic diagnosis/treatment of endometriosis. This should form the basis of a documented discussion with the surgeon before the day of surgery. Include: a. What the procedure involves	**CHAPTER 6** The reviewers considered that 35/219 (16.0%) patients (unknown in 90) had not had the risks and benefits of the procedure adequately explained and that in 56/212 (26.4%) (unknown in 93) there was room for improvement in the consent process. **CHAPTER 6**	NICE Guideline NG73: Endometriosis: diagnosis and management NICE Endometriosis Quality Standard QS172

	b. The purpose of the procedure e.g. to diagnose, stage, treat the symptoms of endometriosis, or a combination of these c. What the patient's expectations are d. The possible effects on endometriosis symptoms e. Risks, benefits and limitations f. The need for further laparoscopic/open surgery for recurrent endometriosis or if complications arise *This is consistent with NICE guideline NG73* ***Primary audiences:*** *Consultant surgeons, including gynecology, urology, colorectal, and general surgeons* ***Supported by:*** *Medical Directors, Clinical Directors, and Clinical Audit/Quality Improvement departments*	The patient survey also confirmed a deficit in discussion prior to surgery, with 204/542 (37.6%) respondents stating that the limitations of the procedure were not discussed. **CHAPTER 6** Data from the clinician questionnaire showed that 161/459 (35.1%) patients had their consent taken on the day of the procedure, which is not in line with national guidance.	Royal College of Obstetricians and Gynaecologists. 2015. Clinical Governance Aid no. 6: obtaining valid consent Royal College of Surgeons. 2016. Consent: supported decision-making: a guide to good practice General Medical Council. 2020. Professional Standards - decision making and consent
9	Provide patients with clear, written information at discharge following laparoscopic diagnosis/treatment of endometriosis, including who to contact and how to initiate direct access back into the endometriosis care pathway. a. Who to contact if they have any concerns, e.g. GP, endometriosis clinical nurse specialists, consultant b. The follow-up plan and ongoing management of the endometriosis	**CHAPTER 6** Details of readmission plans, who to contact if symptoms return and onward referrals to supporting services were often omitted from the discharge summary (20/134; 14.9%). This was of particular note as 33/162 (20.4%) patients had residual endometriosis recorded at the end of the index operation. **CHAPTER 6** Most GPs (109/120; 90.8%) reported that they were sent a copy of the discharge summary. However, poor communication from the hospital to the GP was a theme arising from the patient survey.	NICE Guideline NG73: Endometriosis: diagnosis and management NICE Endometriosis Quality Standard QS172

	c. The option of patient-initiated follow-up d. Types and dosages of medication they are on at discharge, including analgesia and hormone therapy e. The consideration of bone health for people with endometriosis on long-term hormonal medication, including nutrition, weight-bearing exercise and alcohol intake ***Primary audiences:*** *All healthcare professionals who care for patients with endometriosis* ***Supported by:*** *Medical Directors, Clinical Directors, and Clinical Audit/Quality Improvement departments*	**CHAPTER 7** There were 143/308 (46.4%) patients with a management plan in place for the continued medical management of their condition with hormonal treatment. For 78/308 (25.3%) patients it included referrals to other specialties and for 23 patients the management plan was simply for the patient to contact their GP if they experienced recurrence of symptoms (unknown in 117). **CHAPTER 7** Not all patients were followed-up after having their laparoscopy (132/516; 25.6%) (unknown in 107). Of those who were followed-up, where data were available, 222/347 (64.0%) were with the operating surgeon, but the majority were with the gynaecologist (326/347; 94.0%). For 190/347 (54.8%) patients the follow-up appointment was with both. A total of 18 patients were followed-up by the GP only (Figure 7.1). **CHAPTER 7** According to the reviewers, 54/124 (43.5%) patients required readmission for a further laparoscopy (unknown in 114). Nine out of 54 patients required multiple laparoscopies, and 215/542 (39.7%) of the patients surveyed also had had subsequent laparoscopies or surgery relating to endometriosis. **CHAPTER 7** 32/124 (25.8%) patients experienced a delay in being investigated and/or treated for the recurrence of symptoms. Many (48/124; 38.7%) had to start the process over again and go back to the GP for referral back to the gynaecologist, endometriosis gynaecologist or another specialty. Only 12/124 (9.7%) were able to contact the gynaecology team or endometriosis clinical nurse specialist directly. **CHAPTER 7**	

		The organisational questionnaire showed that most patients were advised to see their GP if they experienced a recurrence of symptoms (125/167; 74.9%). Only 16/167 (9.6%) hospitals had a dedicated helpline for endometriosis patients. **CHAPTER 7** It was reported from 48/167 (28.7%) hospitals that contacting the endometriosis clinical nurse specialist or the named gynaecological consultant directly (68/167; 40.7%) (Table 7.2) was supported. In 73/167 (43.7%) hospitals it was possible to give patients contact details of a keyworker who they could access following discharge from hospital.	
10	Formalise a care pathway for patients with or suspected to have endometriosis. This pathway should include implementation of NICE guideline NG73, the European Society of Human Reproduction and Embryology (ESHRE) endometriosis guidelines, as well as the recommendations from this report. ***Primary audiences national:*** *Royal College of Obstetricians and Gynaecologists, Royal College of General Practitioners, Royal College of Surgeons, Royal College of Emergency Medicine, Royal College of Nursing, Royal College of Paediatrics and Child Health, Society for Acute Medicine, British Society for Gynaecological Endoscopy, British medical ultrasound society, Pelvic Obstetric and Gynaecological Physiotherapy*	**CHAPTER 3** NICE guidance on endometriosis recommends that the GP carries out a pelvic (internal) and abdominal examination on women presenting with symptoms suggestive of endometriosis as palpation of pelvic structures can aid in diagnosis.[7] According to the reviewers there was evidence in the case notes that 52/88 (59.1%) patients were examined by the GP (unknown in 45). Of the 36 patients who were not examined, the reviewers stated 19 should have been. **CHAPTER 3** From the patient survey, 393/941 (41.8%) respondents said that they had a pelvic examination during a consultation with a GP and 566/941 (60.1%) said that they had an abdominal examination. The choice of examination may be a medical decision, but the low number of pelvic examinations carried out does demonstrate poor adherence to NICE guidance and could potentially lead to a less focused referral process. **CHAPTER 3**	NICE Guideline NG73: Endometriosis: diagnosis and management NICE Endometriosis Quality Standard QS172 European Society of Human Reproduction and Embryology: Endometriosis guidelines

	Primary audiences local: *Medical Directors, Clinical Directors, and Clinical Audit/Quality Improvement departments* ***Supported by:*** *NHS England, Welsh Government, Northern Ireland Department of Health*	NICE guidance recommends that all patients are examined within secondary care gynaecological services.[7] In 442/623 (70.9%) patients, the clinicians had information about the first referral. From these data it could be seen that 250/442 (56.6%) patients had an abdominal examination and 268/442 (60.6%) had a pelvic examination (Table 3.2). **CHAPTER 3** A transvaginal ultrasound scan, as recommended by NICE,[7] was undertaken in 332/424 (78.3%) patients. However, only 32/332 (9.6%) of the ultrasound scans were performed by someone with specialist training in ultrasound use for diagnosing endometriosis. **CHAPTER 5** NICE recommends that patients should be offered initial management of pain, which is often the main symptom, with paracetamol or a non-steroidal anti-inflammatory drug (NSAID) either alone or in combination with hormonal treatment before considering referral to a gynaecology specialist.[7] In this study, 47/90 patients referred to a gynaecology specialist had medications prescribed by their GP before attending the gynaecology department (unknown in 43). The most common therapy prescribed by GPs was hormonal treatment 36/47 (Table 5.1). Ten patients were prescribed tranexamic acid to reduce heavy menstrual blood loss, although its efficacy to improve the pain associated with endometriosis has been questioned.[18] **CHAPTER 6** Clinicians completing questionnaires considered that the laparoscopy was delayed in 32/162 (19.8%) patients. The principal reasons for delay to surgery were organisational (16/32), GP referral to gynaecology (8/32) and clinical reasons (6/32).	

		CHAPTER 7 The case reviewers found that 124/238 (52.1%) patients experienced recurrence or persistence of endometriosis symptoms following admission for laparoscopy. Reviewers thought that 32/124 (25.8%) patients experienced a delay in being investigated and/or treated for the recurrence of symptoms. Many (48/124; 38.7%) had to start the process over again and go back to the GP for referral back to the gynaecologist, endometriosis gynaecologist or another specialty. Only 12/124 (9.7%) were able to contact the gynaecology team or endometriosis clinical nurse specialist directly. And only 6/124 (4.8%) patients needed to attend emergency or ambulatory services acutely.	
11	a. Collect surgical outcome data, including patient-reported outcomes, for benchmarking. b. Review local practice against NICE guideline NG73, the recommendations in this report. c. Undertake clinical trials to ascertain the efficacy of surgery for endometriosis-associated symptoms, especially for minimal or mild endometriosis. d. Assess the use of pain medication, and the medical treatment of endometriosis. e. Explore the use of imaging modalities in the diagnosis of endometriosis. ***Primary audiences:*** *Grant-making bodies such as the National Institute for Health and Care Research or Medical Research Council* ***Supported by:*** *Relevant Royal Colleges*	**CHAPTER 6** It is important that data are collected to inform the healthcare organisation and patients of outcomes. It was reported from 145/167 (86.8%) hospitals that data on acute surgical complications were recorded, meaning that 22/167 (13.2%) did not. Furthermore 53/167 (31.7%) reported that data were not collected on how many of each procedure were performed by individual surgeons (Table 6.3). **CHAPTER 6** From the patient's perspective, only 127/732 (17.3%) of those who completed the patient survey were satisfied with the results of surgery and 215/542 (39.7%) were referred for repeat laparoscopies or other surgery relating to their endometriosis.	European Society of Human Reproduction and Embryology: Endometriosis guidelines Requirements to be a BSGE Accredited Centre