

# Analysis of Endometriosis Service Provision in Scotland

Endometriosis UK report for the  
Scottish Government

January 2022

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**Rocket Science** were commissioned by Endometriosis UK to work on this research.

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# Executive Summary

Endometriosis UK is pleased to have conducted this research for the Scottish Government to understand the provision of, and barriers to, care for endometriosis in Scotland.

Through consultation with primary, secondary and specialist NHS practitioners, we have identified a number of barriers practitioners face in diagnosing and caring for patients with endometriosis. Analysis of data on patient experiences and hospital waiting times have shown the impact of these barriers, and we found that the base level of care for endometriosis as outlined in the NICE Guideline is not currently being met.

Ensuring the consistent implementation of the NICE Guideline for and Quality Standards on Endometriosis across Scotland will be key in improving the standard of care for those living with and awaiting diagnosis for the disease. This includes ensuring that all areas have a managed clinical network to coordinate endometriosis care, and that all patients with confirmed or suspected endometriosis have access to a gynaecologist with expertise in diagnosing and managing endometriosis. Having a Gynaecologist with a Special Interest in Endometriosis in all general gynaecology departments will be vital to supporting those who are seen outside of tertiary care. Consistent access to an endometriosis clinical nurse specialist, multidisciplinary pain management services and, for those who need them, fertility services will also be needed to ensure consistent care.

To deliver this consistently for Scotland, appropriate planning and funding is needed to ensure nation-wide provision of specialist endometriosis services. Without this, access to and quality of care will continue to vary across different regions.

Improved and increased education on endometriosis is necessary for all healthcare professionals at a primary and secondary care level, with many primary care practitioners having identified a need for further training and resources. This could include increasing awareness of existing resources already available to support practitioners, such as the RCGP Menstrual Wellbeing toolkit, as well as the development of new resources for different practitioner groups.

We encourage the strengthening of relationships between healthcare services in Scotland. Creating an environment where services can easily liaise with one another on the referral and management of patients will be an important part of improving patient care. Implementing managed clinical networks for endometriosis will support this.

Increasing public awareness and ensuring that more patients know about endometriosis and its signs and symptoms will help ensure that they seek help and the right care. This should be available from puberty onwards, to enable anyone experiencing symptoms to seek help. We recommend investing in a public health campaign and menstrual wellbeing materials for schools.

# 1. Introduction

As part of the Scottish Government led Women's Health Plan 'Menopause and Menstrual Health including Endometriosis' sub-group, Endometriosis UK were funded to complete an analysis of the existing provision of endometriosis diagnosis and care in Scotland. To support the project, Rocket Science were commissioned by Endometriosis UK to work with them on this research. The main aims of this research were to:

- Understand the gaps between current service provision of endometriosis diagnosis and management and the NICE guideline on this
- Identify the barriers to implementing and delivering the care set out in the guideline.

To meet these research aims, it was important to:

- Gain an understanding of what current service provision of diagnosis and management looked like both prior and during the Covid-19 pandemic
- Understand to what extent the NICE guideline and quality standards were being implemented across the healthcare system
- Identify the challenges faced by healthcare professionals in providing endometriosis diagnosis and management, and in implementing the guideline.

## 2. Methodology

To conduct this project, a six-stage methodology was delivered:

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### Stage 1: Inception and planning

An inception meeting was held to discuss the project in detail and agree on the methodology. Discussion also covered the background, context and priorities for this piece of work; identifying data available for analysis and key stakeholders to speak to; and agree fieldwork.

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### Stage 2: Scoping and designing fieldwork

To develop a plan for fieldwork, a scoping meeting was held with six attendees from Endometriosis UK, the Scottish Government and the University of Edinburgh. The purpose of the meeting was to answer the following questions:

- Who should participate in field research?
- What field research methods should be used with each stakeholder group?
- When field research should be conducted?
- What questions should stakeholders be asked during the field research?

Following this meeting a fieldwork plan was developed, detailing who would be consulted, when and how, alongside fieldwork materials including surveys and interview topic guides for each of the different participant types.

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### Stage 3: Desk based analysis of existing data and information

Analysis on a range of existing data was conducted. Where data was available by location, analysis was done to look at endometriosis diagnosis and care in Scotland, as opposed to the UK. Data sources included:

- APPG survey of those with endometriosis
  - BBC survey of those with endometriosis
  - The NICE Guideline (NG73) on endometriosis
  - The NICE Quality Standard (QS172) on endometriosis
  - Public Health Scotland data on endometriosis
  - 2015 Scottish research conducted when the three specialist centres were agreed.
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<b>Stage 4: Conducting and analysing field work:</b>	<p>20 minute-1 hour interviews were conducted with healthcare professionals from across a range of health boards to ensure appropriate representation from across Scotland. This was done to enable a nation-wide picture and to identify any regional differences in relation to endometriosis diagnosis and care. Due to time limitations, in some cases interviews were conducted with people who were available despite already having representation from their health board. A total of 29 Interviews were held with:</p> <ul style="list-style-type: none"><li>• 8 healthcare professionals from endometriosis specialist centres</li><li>• 9 non-specialist gynaecologists</li><li>• 3 pain management healthcare professionals</li><li>• 3 sexual health healthcare professionals</li><li>• 6 primary care healthcare professionals (GPs).</li></ul> <p>Surveys were undertaken, of non-specialist gynaecology and primary care, along with polling data at a primary care webinar.</p>
<b>Stage 5: Gap and barrier analysis and development of recommendations:</b>	<p>Findings from the desk review, interviews and survey were analysed to understand:</p> <ul style="list-style-type: none"><li>• Where existing care provision in Scotland differs from the care standard outlined in the NICE guideline</li><li>• The likely barriers faced by services and staff in reaching the standards outlined in the NICE guideline</li></ul> <p>Once all fieldwork was complete and analysed, a set of practical and realistic recommendations were developed to help address the barriers and improve endometriosis care in Scotland.</p>
<b>Stage 6: Reporting:</b>	<p>Work from across the stages was drawn together to produce this report for the Scottish Government.</p>

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## Research log

This report includes findings of our research. It was agreed that, in light of constraints on primary care due to the Covid-19 vaccination programme, initial fieldwork January – March focused on secondary and tertiary care, and engagement with GPs and primary care practitioners in April-May. The following table explains desk research and fieldwork that has been conducted.

	<b>Completed</b>
Data analysis	APPG survey (2020) analysis at Scotland level BBC survey (2019) analysis at Scotland level Analysis of Public Health Scotland (PHS) data
Endometriosis specialist centre interviews	8 complete: 3 in Edinburgh 3 in Aberdeen 2 in Glasgow
Non-specialist gynaecology interviews	9 complete
Non-specialist gynaecology survey	36 complete responses
Pain management services interviews	3 complete
Sexual health services interviews	3 complete
Primary care interviews	6 complete
Primary care survey	58 complete responses
Primary care event	142 attendees polling data

## 3. Context

This chapter provides a brief summary of the impact of endometriosis on people in Scotland, a summary of endometriosis admissions across Scotland, and describes the NICE guideline and quality standards for endometriosis diagnosis and care in the UK.

### 3.1 Impact of endometriosis

The impact endometriosis and its symptoms have on the lives of patients can be substantial and far reaching. The **majority of patients (96%) find that their endometriosis and/or the symptoms of endometriosis negatively impacts their wellbeing**, over 60% said it had a ‘very negative’ impact on their wellbeing. Only around 2% of Scottish patients believe it has a ‘neutral’ impact and an even smaller proportion (1%) feel it has a positive impact. Similarly, Scottish patients find that endometriosis and its symptoms impacted their ability to live life as they would want, 90% felt it had had a negative impact (46% ‘very negative’ and 44% ‘negative’).<sup>1</sup>

When looking at the specific symptoms associated with endometriosis, **many symptoms negatively impact the ability of patients to live life as they want**. The two symptoms where the highest proportion of patients felt it ‘negatively’ or ‘very negatively’ impacted their ability to live their lives as they would like were pelvic pain (93%) and fatigue (92%). More detail on the impacts of the various symptoms can be found in the table below:<sup>2</sup>

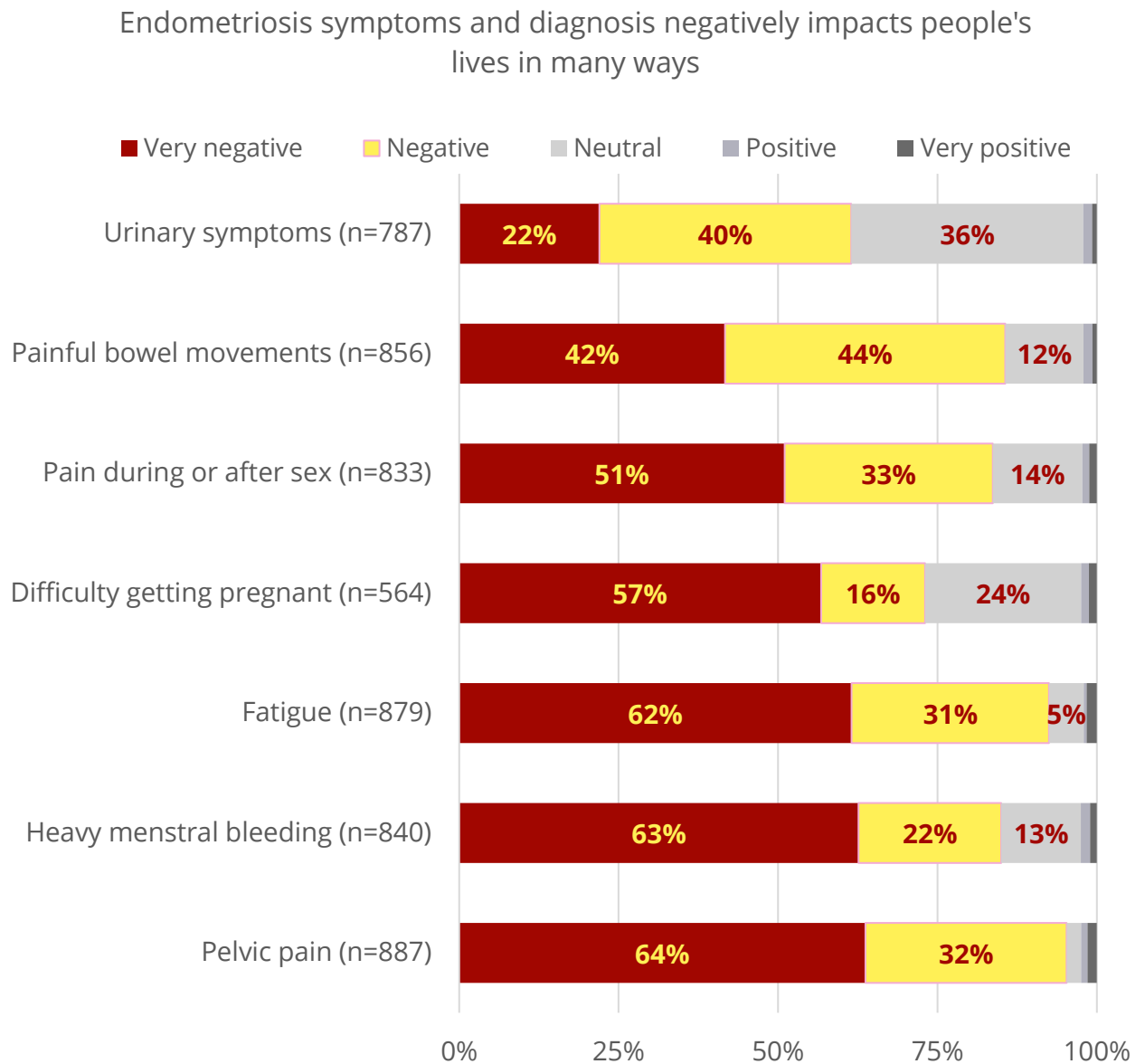
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<sup>1</sup> Data throughout this paragraph is from the APPG survey - Endometriosis APPG report, Endometriosis in the UK: Time For Change, 2020, <https://www.endometriosis-uk.org/sites/endometriosis-uk.org/files/files/Endometriosis%20APPG%20Report%20Oct%202020.pdf>

<sup>2</sup> Ibid.



**Figure 1: Considering this in more detail, to what extent have the different symptoms of endometriosis that you have experienced affected your ability to live your life as you want?**

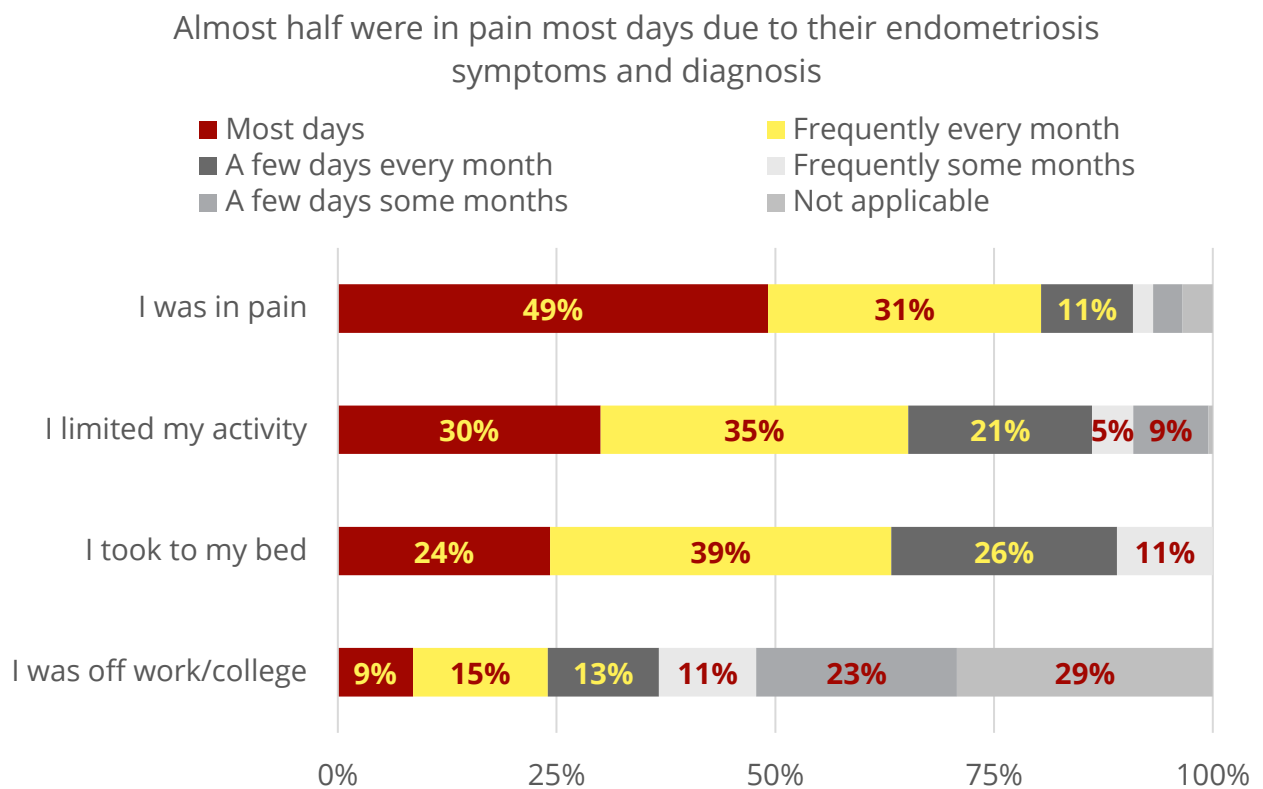


*The table above uses Scotland specific data from the APPG survey*

Endometriosis symptoms affect patients in many ways. **In the prior year, almost half (49%) were in pain most days** due to the impact of endometriosis and/or its symptoms, a further third (31%) were in pain frequently every month and 10% a few days every month. Only 9% were in pain less frequently throughout the year or answered not applicable. Many found their activities limited. The majority limited their activities frequently every month (35%), but a further 30% limited their activities most days, and 21% limited their activities a few days every month. In total 39% found they had to take to their bed frequently every month, while a further quarter each had found this happened most days every month (24%) or a few days

every month (26%). Only 11% found they took to bed less frequently, however this was still frequently some months. The endometriosis diagnosis and symptoms also impacts work and/or college attendance quite variably. Almost one third answered not applicable (29%), however almost one quarter (23%) take days off work or college a few some months. Half of respondents (48%) take time off work or college more frequently, 11% frequently some months, 13% a few days every month, 15% frequently every month, and 9% most days.<sup>3</sup>

**Figure 2: In the last year, what impact did endometriosis/symptoms have on your life?**



*The table above uses Scotland specific data from the BBC survey*

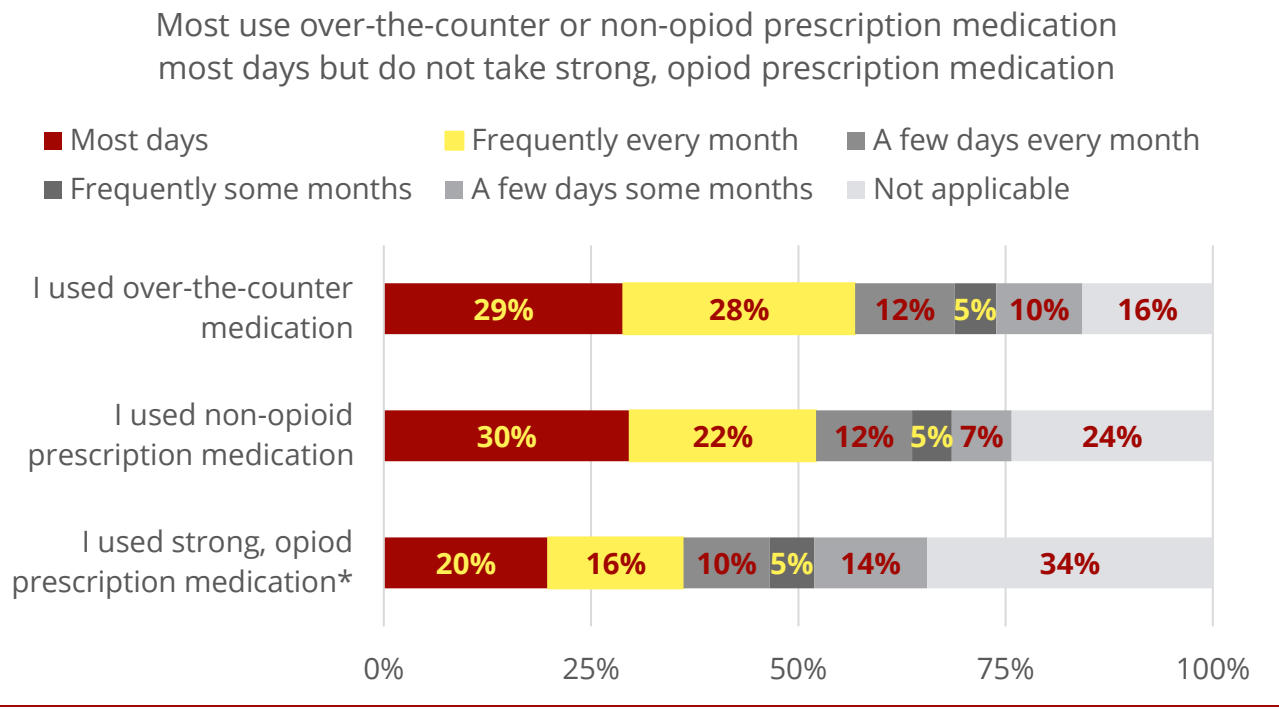
**The majority use painkillers**, either most of the time (51%) or use them most months (29%). A smaller proportion use them only some months (15%) and only 5% do not use painkillers at all. Generally, people do not struggle to access the painkillers they need, 44% have never struggled, 37% have sometimes struggled and 17% have often struggled. 3% do not know.<sup>4</sup>

<sup>3</sup> Data throughout paragraph is from the BBC survey - BBC Endometriosis Survey, 2019, <https://www.endometriosis-uk.org/news/bbc-research-announced-today-wake-call-provide-better-care-15-million-endometriosis-37606>

<sup>4</sup> Data throughout paragraph is from the BBC survey - BBC Endometriosis Survey, 2019, <https://www.endometriosis-uk.org/news/bbc-research-announced-today-wake-call-provide-better-care-15-million-endometriosis-37606>

Similar proportions most days use either over-the-counter medications (29%) or non-opioid prescription medication (30%). A further 28% use over-the-counter medications frequently every month and 23% use non-opioid prescription medication frequently every month. Most do not use strong opioid prescription medication, with 35% choosing not applicable. Of those who do, the majority do so most days (20%) or frequently every month (16%).<sup>5</sup>

**Figure 3: If you use painkillers, what have you taken in the last year and how often?**



*The table above uses Scotland specific data from the BBC survey*

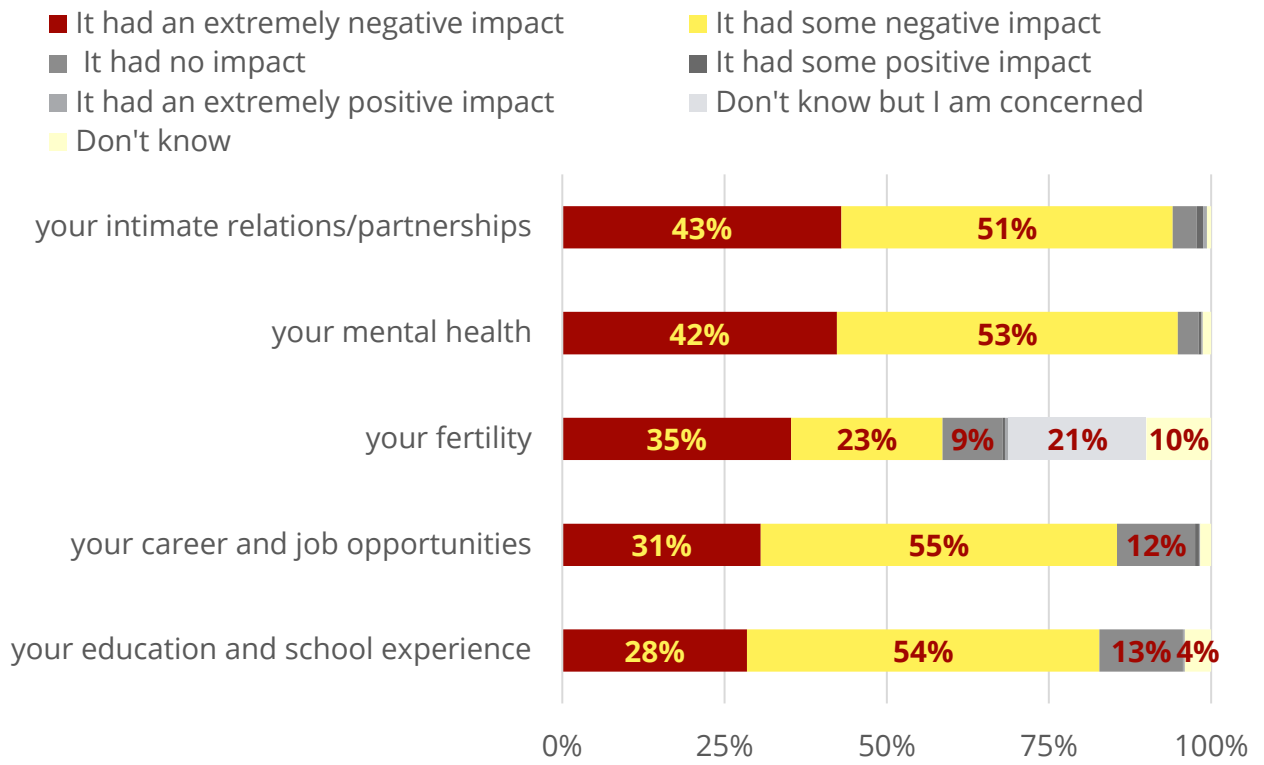
In terms of **intimate relationships and partnerships** 94% feel endometriosis and its symptoms has a negative impact; 43% feel it has an extremely negative impacts and 51% feel it has some negative impacts. Just 4% feel it had no impact while just 2% felt it had positive impact and 1% do not know. Similarly, the majority feel that endometriosis and its symptoms had a negative impact on their mental health (95%); 43% extremely negative and 53% some negative impact. Even fewer felt it had no impact (3%) or had a positive impact (1%) and 1% do not know. In terms of fertility, 21% are concerned about their fertility in the future. 10% state that endometriosis symptoms and diagnosis had no impact on their fertility, but the majority (59%) still feel it had a negative impact; 35% extremely and 23% some negative impact. While some feel that their endometriosis diagnosis and symptoms do not impact their career and job opportunities

<sup>5</sup> Ibid.

(12%) or education and school experience (13%), the majority still feel it does have a negative impact on both careers and jobs opportunities (86%) and school and education experiences (82%).<sup>6</sup>

**Figure 4: To what extent did endometriosis/symptoms affect your...?**

Endometriosis symptoms and diagnosis negatively impacts many aspects of people's lives, most frequently an extremely negative impact on relations and partnerships and mental health



*The table above uses Scotland specific data from the BBC survey*

**Mental health has been negatively affected by diagnosis and symptoms for the majority of endometriosis patients.** Of those who responded to the survey, whilst 38% stated they had never had suicidal thoughts (38%), 52% stated they had had suicidal thoughts due to their endometriosis, either on occasion (30%), regularly (9%) or once (13%).<sup>7</sup>

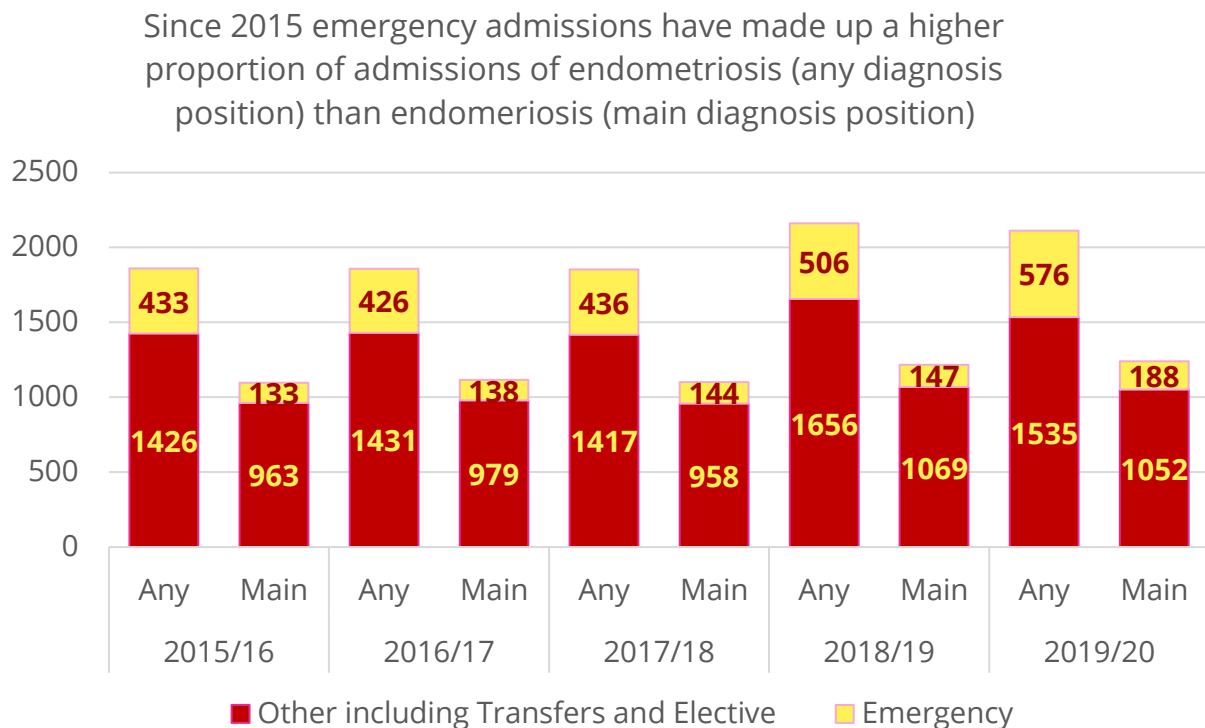
<sup>6</sup> Data throughout paragraph is from the BBC survey - BBC Endometriosis Survey, 2019, <https://www.endometriosis-uk.org/news/bbc-research-announced-today-wake-call-provide-better-care-15-million-endometriosis-37606>

<sup>7</sup> Data throughout paragraph is from the BBC survey - BBC Endometriosis Survey, 2019, <https://www.endometriosis-uk.org/news/bbc-research-announced-today-wake-call-provide-better-care-15-million-endometriosis-37606>

## 3.2 Endometriosis admissions

Over the past five years, 2019/20 had the highest number of emergency admissions of endometriosis patients and 2018/19 had the highest number of elective admissions of endometriosis patients (both endometriosis as any diagnosis position and main diagnosis position).<sup>8,9</sup>

**Figure 5: Number of endometriosis admissions across Scotland from 2015/16 to 2019/20**



**The table above uses Public Health Scotland data**

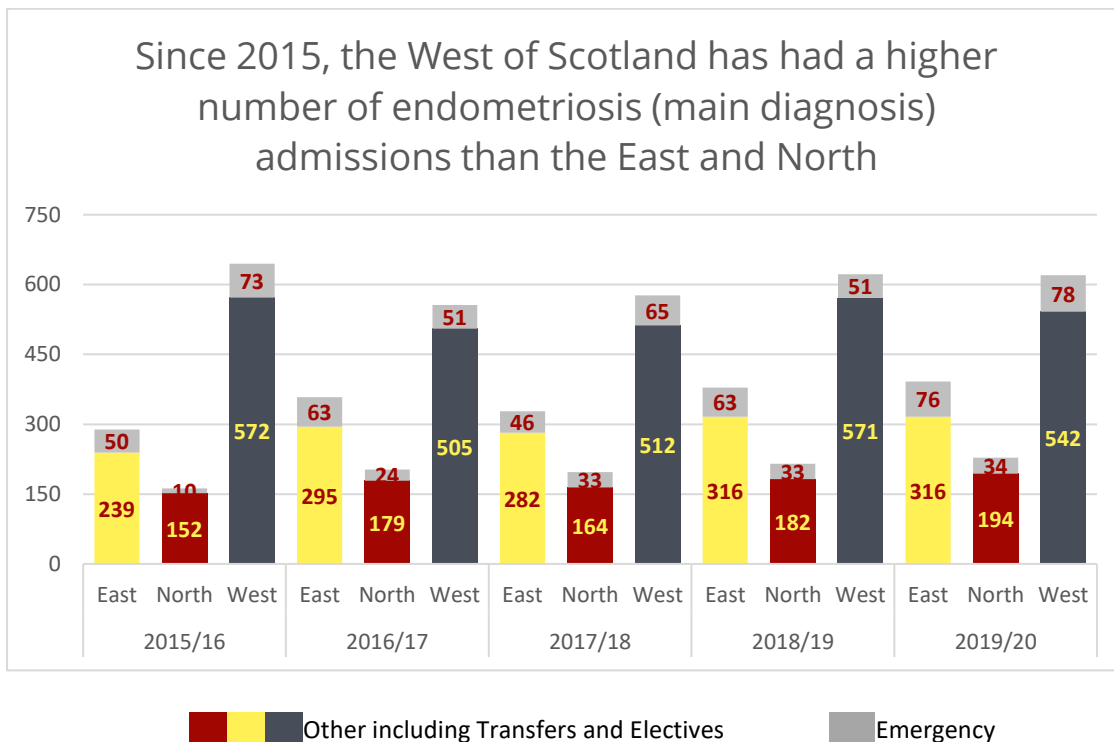
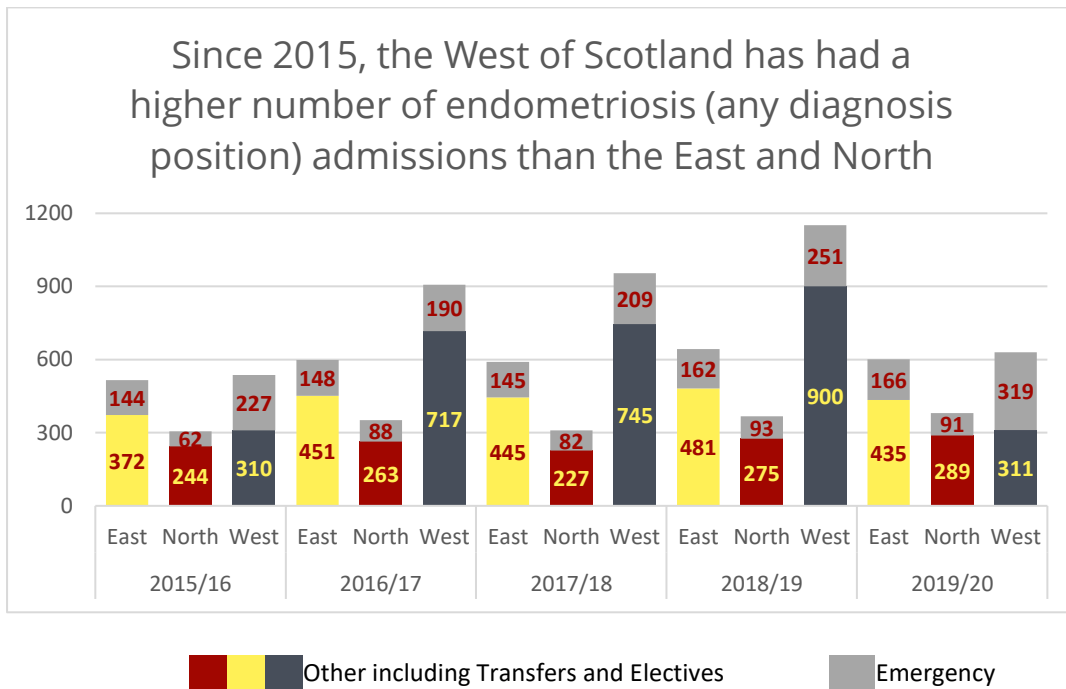
Since 2015, the West of Scotland has had a higher number of endometriosis (any diagnosis position and main diagnosis) admissions than the East and North.

<sup>8</sup> This data is split via endometriosis (any diagnosis position) and endometriosis (main diagnosis). "Main diagnosis" refers to the [primary diagnosis](https://datadictionary.nhs.uk/attributes/primary_diagnosis.html). "The primary diagnosis is the main condition treated or investigated during the relevant episode of healthcare; or where there is no definitive patient diagnosis, the main symptom, abnormal findings or problem." -

[https://datadictionary.nhs.uk/attributes/primary\\_diagnosis.html](https://datadictionary.nhs.uk/attributes/primary_diagnosis.html)

<sup>9</sup> These statistics are derived from data collected on discharges from non-obstetric and non-psychiatric hospitals (SMR01) in Scotland. Only patients treated as inpatients or day cases are included. The specialty of geriatric long stay is excluded.

**Figures 6 and 7: Number of endometriosis admissions across regions of Scotland from 2015/16 to 2019/20. The first chart shows ‘any diagnosis position’ and the second shows ‘main diagnosis’**

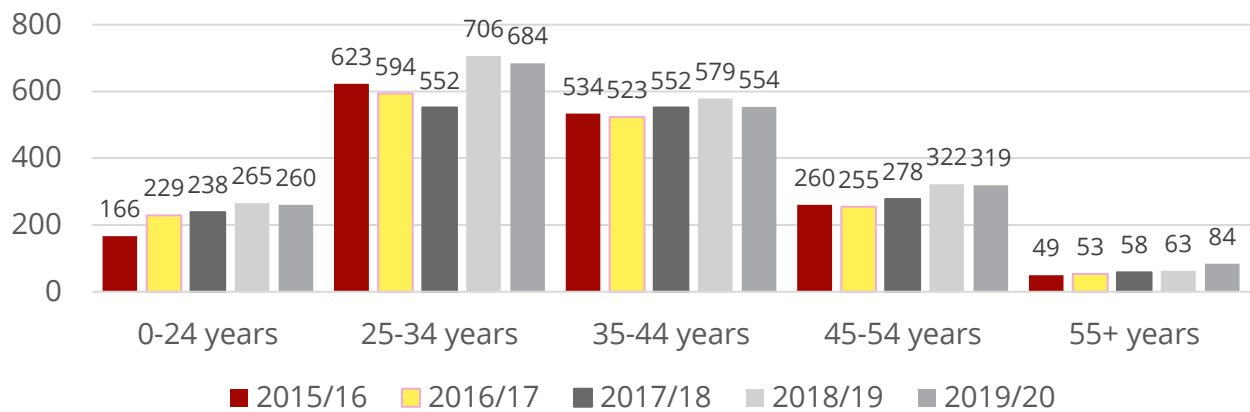


*The tables above use Public Health Scotland data*

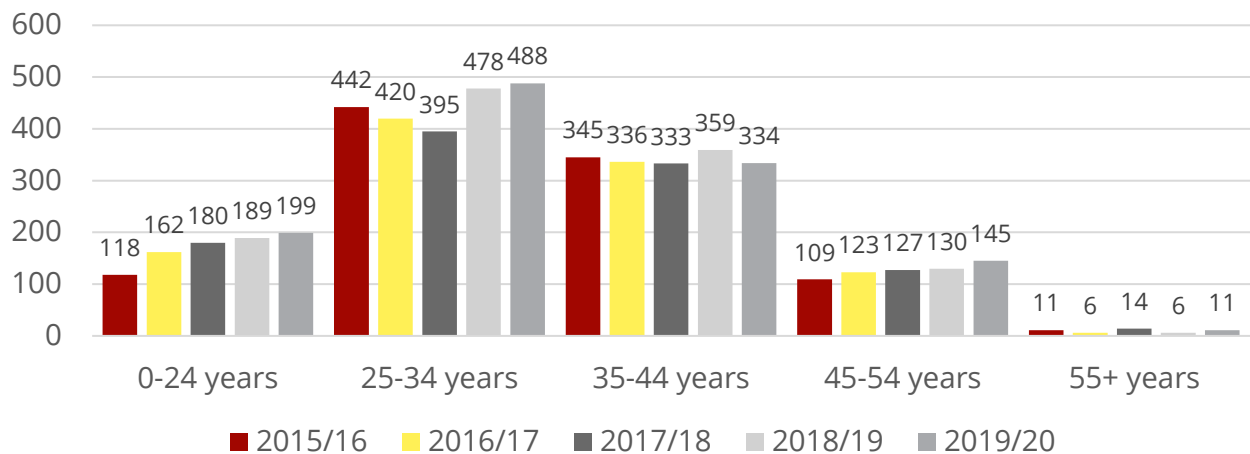
Endometriosis affects a range of ages, however the most common age group of patients in Scotland are 25-34 years old. This has been the case for both endometriosis (any diagnosis position) and endometriosis (main diagnosis) over the past five years.

**Figures 8 and 9: Age of endometriosis patients across Scotland from 2015/16 to 2019/20. The first chart shows ‘any diagnosis position’ and the second shows ‘main diagnosis’**

Since 2015, 25-34 years old has been the most common age group amongst endometriosis patients (any diagnosis position) in Scotland



Since 2015, 25-34 years old has been the most common age group amongst endometriosis patients (main diagnosis) in Scotland

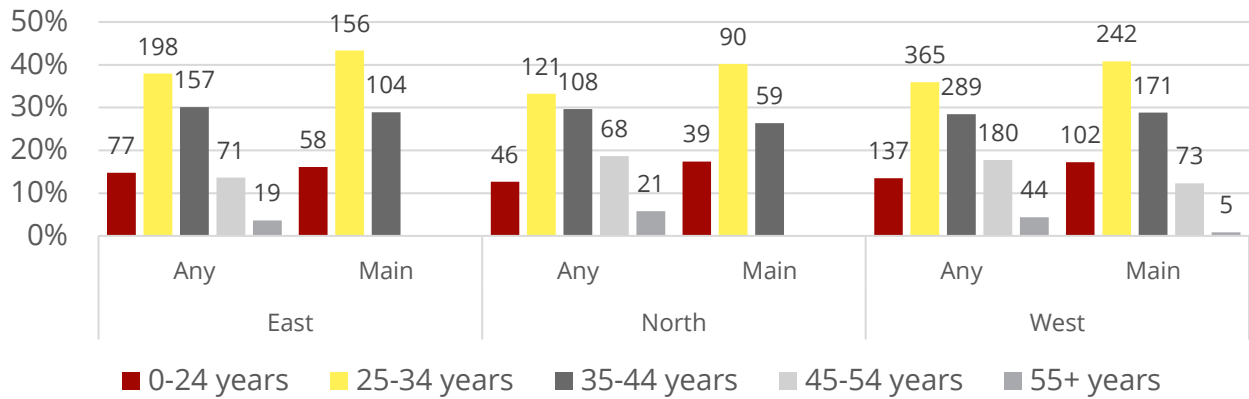


**The table above uses Public Health Scotland data**

This trend was apparent across all regions of Scotland as 25-34 years old was the most common age group amongst endometriosis patients (both any diagnosis position and main diagnosis) in 2019/20. Whilst the majority of patients are 25 -44 year olds, the tables highlight that those younger and older can still be impacted by endometriosis, highlighting the need to overcome the myth that adolescents and young adults do not get endometriosis.

**Figure 10: Ages of endometriosis patients across regions of Scotland in 2019**

In 2019/20, across East, North and West Scotland, 25-34 years old was the most common age group amongst endometriosis patients (both any diagnosis position and main diagnosis position)



The table above uses Public Health Scotland data

### 3.3 NICE guideline and quality standard on endometriosis

The NICE Guideline (NG73) *Endometriosis: diagnosis and management (2017)* outlines the baseline standard of care that is recommended to be delivered, including in Scotland where the guideline has been adopted. According to NICE:

*“This guideline covers diagnosing and managing endometriosis. It aims to raise awareness of the symptoms of endometriosis, and to provide clear advice on what action to take when women with signs and symptoms first present in healthcare settings. It also provides advice on the range of treatments available.”*

The guideline includes recommendations on:

- Organisation of care
- Information and support
- Endometriosis symptoms and signs
- When to refer
- Diagnosing endometriosis
- Pharmacological management
- Surgical management



Recommendations include information on prompt diagnosis and treatment, access to health professionals with the appropriate skill level required to diagnose and treat patients, access to pain management support and fertility services, the provision of information for patients with suspected or confirmed endometriosis, and how to proactively respond to symptoms or signs of endometriosis. The NICE guideline also details expectations on health professionals regarding the referral of patients, the investigations performed, pain management options offered, and surgical options available.

The NICE *Endometriosis Quality Standard* (QS172, 2018) covers diagnosing and managing endometriosis, including those aged 17 and under. The quality standard lists three quality statements:

- *“Statement 1: Women presenting with suspected endometriosis have an abdominal and, if appropriate, a pelvic examination.*
- *Statement 2: Women are referred to a gynaecology service if initial hormonal treatment for endometriosis is not effective, not tolerated or contraindicated.*
- *Statement 3: Women with suspected or confirmed deep endometriosis involving the bowel, bladder or ureter are referred to a specialist endometriosis service.”<sup>10</sup>*

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<https://www.nice.org.uk/guidance/qs172/chapter/Quality-statements>

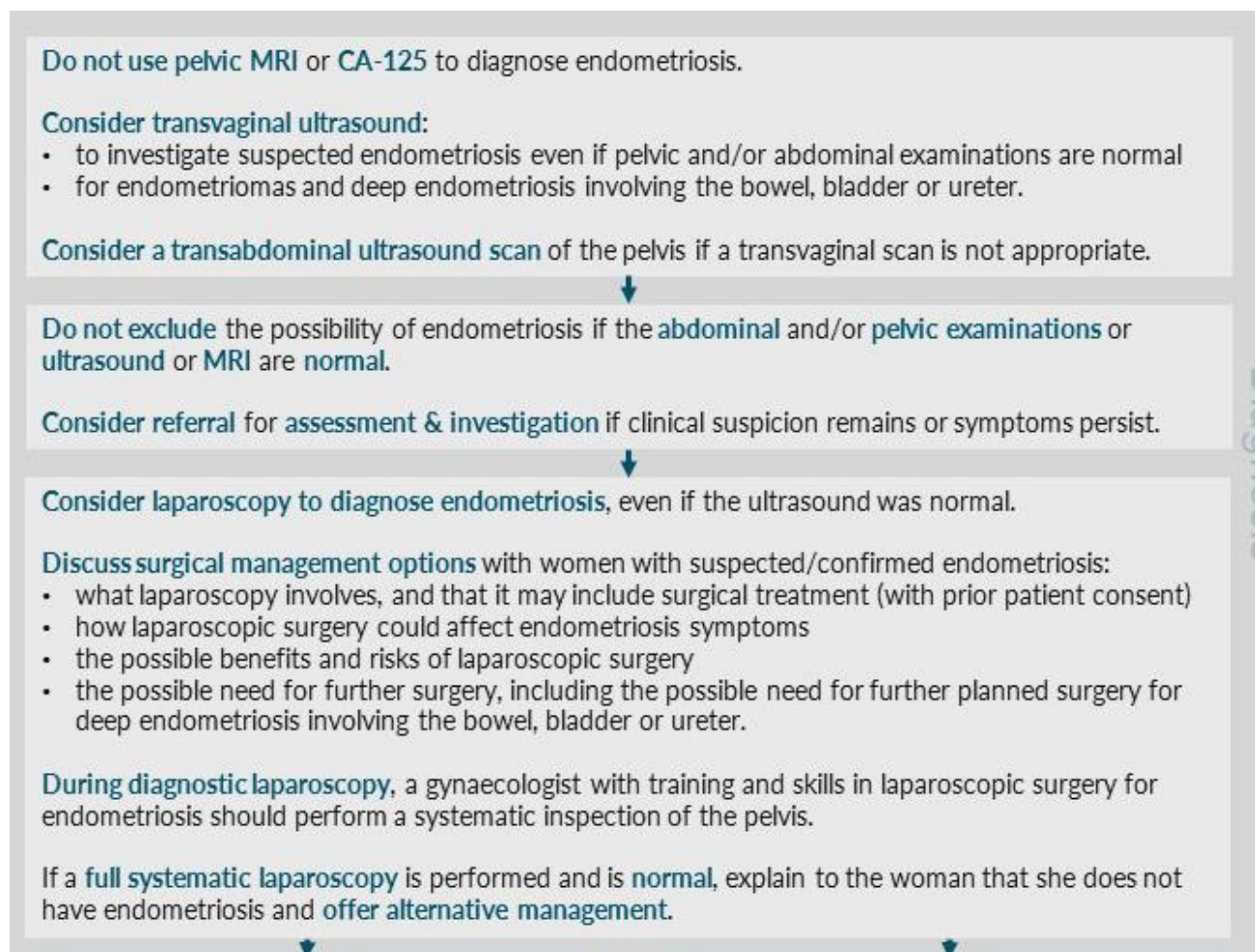
## 4. Current service provision: Diagnosis

This chapter outlines current service provision in relation to the diagnosis of endometriosis.

### 4.1 Method of diagnosis

The NICE guideline outlines the following recommendations for diagnosis of endometriosis<sup>11</sup>:

**Figure 11: NICE guideline (NG73) Endometriosis: diagnosis and management - Diagnosis**



This guideline highlights two methods for diagnosis, ultrasound and diagnostic laparoscopy, noting that a normal ultrasound does not exclude endometriosis. Laparoscopy with biopsy is considered the ‘gold standard’ way to diagnose endometriosis.

<sup>11</sup> <https://www.nice.org.uk/guidance/ng73/chapter/Recommendations#organisation-of-care>

However, it is important to note that not all patients with suspected endometriosis will receive a formal diagnosis. The majority of endometriosis patients are diagnosed via laparoscopy (80%) and a minority by a doctor but without a laparoscopy (10%). In some cases, diagnosis was made during surgery other than laparoscopy.<sup>12</sup>

A laparoscopy must be carried out for a certain diagnosis of endometriosis, and as specified in the guideline, a gynaecologist with training and skills in laparoscopic surgery for endometriosis should perform a systematic inspection of the pelvis. This means that a diagnostic laparoscopy must take place within secondary or tertiary care and should be carried out either by an endometriosis specialist, or a general gynaecologist with specific training and skills for endometriosis and laparoscopic surgery. This procedure cannot take place in a primary care setting. Healthcare professionals commented on the difficulty of only being able to diagnosis endometriosis through surgery for both patients and healthcare services. For patients, the diagnostic laparoscopy (with or without adjunct treatment) and can require a long wait time from when symptoms are first raised with primary care. For healthcare services, conducting laparoscopies to diagnose endometriosis can be seen as time consuming and a challenge with theatre space.

*“Access to theatres is limited. [We need] easier access to laparoscopy diagnosis [or a] way of diagnosing endometriosis that doesn’t require operating, it would be easier to diagnose without surgery”*

**Healthcare professional: non-specialist gynaecologist (interview)**

Within secondary care, diagnostic laparoscopies are carried out by general gynaecology services, whereas in tertiary care, they are carried out by endometriosis specialists. Reported benefits of laparoscopies taking place in secondary care included that patients are seen in a more timely manner; and if endometriosis is found and is not complex, treatment may be given. However, treatment given will depend on the level of skills and expertise of the gynaecologist doing the laparoscopy, which is not consistent. If complex endometriosis is found during a laparoscopy in a non specialist secondary care setting, referral to an endometriosis specialist centre will be required, necessitating the patient to have further

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<sup>12</sup> Note that endometriosis may be diagnosed via methods other than laparoscopy e.g. ultrasound, however these other methods are not certain and cannot rule out endometriosis if they seem ‘normal’ (For more information see NICE guideline on Endometriosis - <https://www.nice.org.uk/guidance/ng73/chapter/Recommendations>)

surgery along with increased wait time for referral for an appointment with a specialist gynaecologist and then referral for surgery.

The main reported benefit of laparoscopies taking place in tertiary care was that they are generally carried out by endometriosis specialists. If endometriosis is found, they are better equipped to identify and operate alongside the diagnostic laparoscopy, or to plan if further surgery including with a multidisciplinary team is needed. Going to an endometriosis specialist can provide a sense of security for patients who are aware there are specialists, especially if they have previously had multiple visits to primary and/or secondary care.

Support at the time of diagnosis appears to be inconsistent and insufficient for patients. Three quarters of patients (75%) did not receive any written information on diagnosis. Of those that did, only a minority of patients were satisfied with the information they were provided with (17%) whereas over half (56%) were either 'very dissatisfied' or 'dissatisfied'<sup>13</sup>

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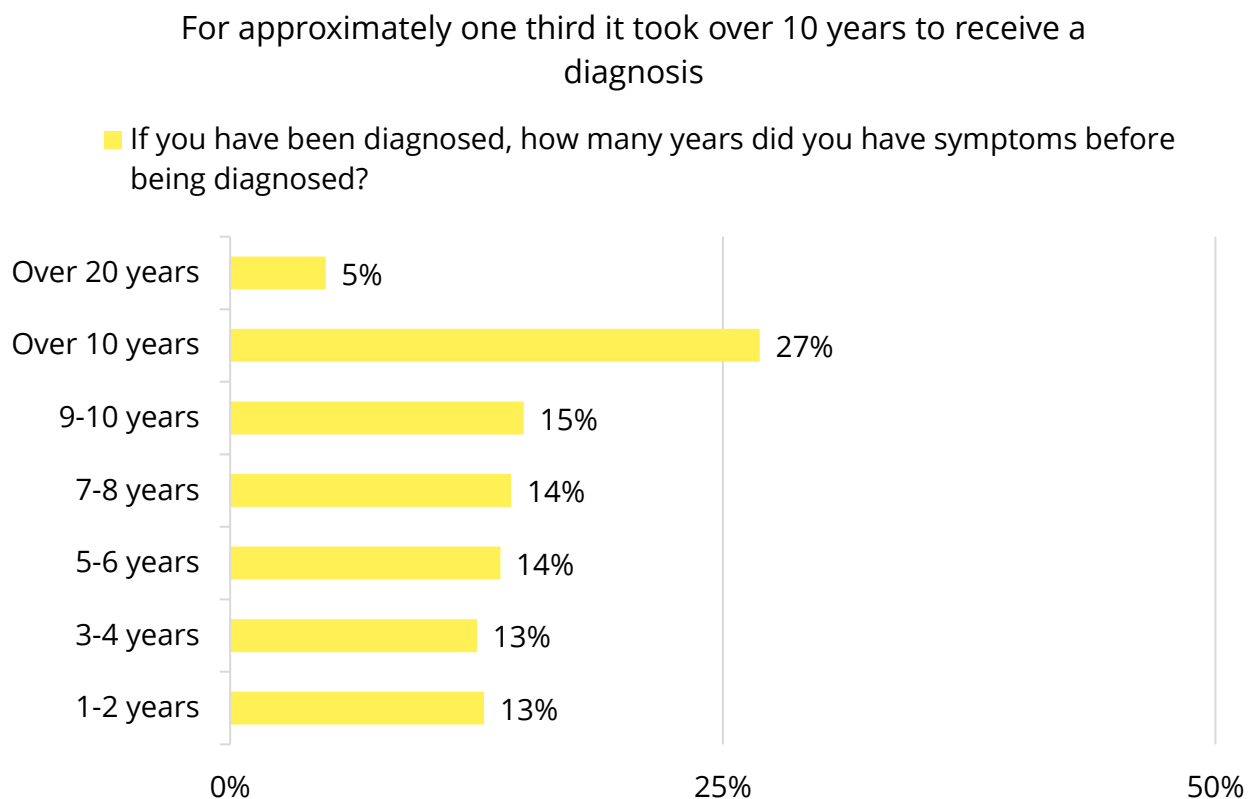
<sup>13</sup> Data throughout paragraph is from the APPG survey - Endometriosis APPG report, Endometriosis in the UK: Time For Change, 2020, <https://www.endometriosis-uk.org/sites/endometriosis-uk.org/files/files/Endometriosis%20APPG%20Report%20Oct%202020.pdf>

## 4.2 Waiting times

Prior to receiving a diagnosis, those with endometriosis tend to live with symptoms for a varied length of time before being diagnosed, with the average length of time from onset of symptoms to diagnosis taking 8.5 years in Scotland.<sup>14</sup> This average length of time to diagnosis is taken from the APPG survey, undertaken in February/March 2020. Over 10,000 responses were received from those who had a confirmed diagnosis of endometriosis, of which 947 were from Scotland. The survey was promoted widely on social media through a range of routes, and respondents self-selected to answer.

It is common for people to have had to wait more than ten years before being diagnosed, with one study finding that of those diagnosed, 32% waited over 10 years with symptoms for a diagnosis (see Figure 6 below). In contrast, 13% received a diagnosis in under 2 years, and a total of 26% in under 4 years.

**Figure 12: If you have been diagnosed, how many years did you have symptoms before being diagnosed?**

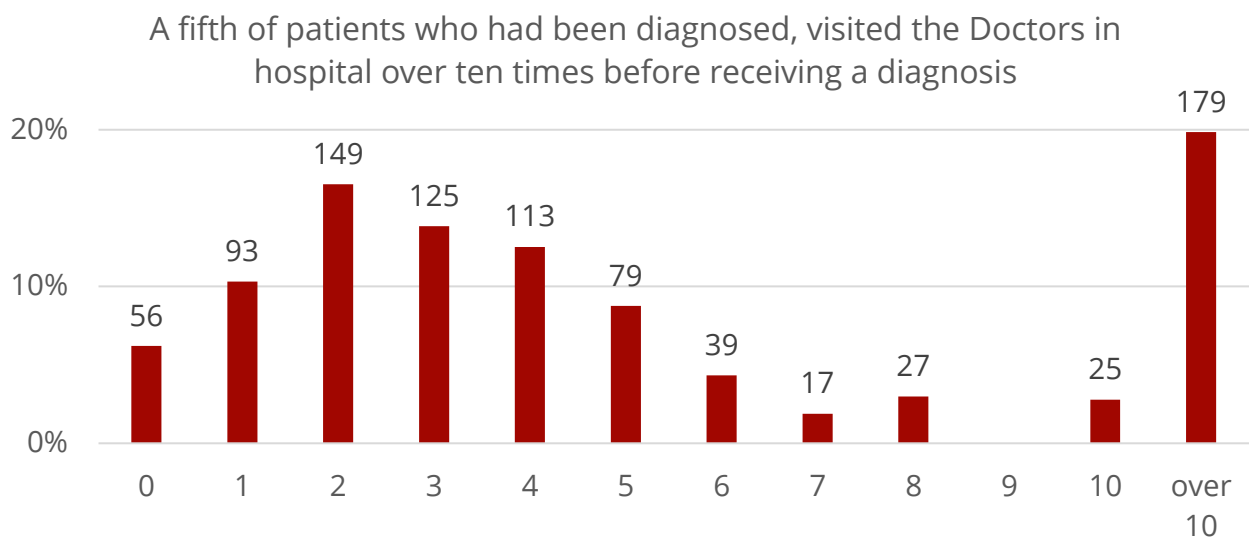


<sup>14</sup> Ibid.

*The table above uses Scotland specific data from the BBC survey*

It is also common for endometriosis patients in Scotland to have visited doctors multiple times with symptoms of endometriosis before receiving a diagnosis. With symptoms but prior to diagnosis, just over half (51%) had visited their GP more than ten times. Just over half of patients (51%) had visited A&E with endometriosis symptoms before diagnosis; 37% had visited more than once and over a quarter (26%) had visited three or more times. Additionally, a fifth (20%) of patients in Scotland had visited doctors in hospital over 10 times before receiving a diagnosis.<sup>15</sup>

**Figure 13: If you have been diagnosed, approximately how many times did you visit the Doctors in hospital for your symptoms of endometriosis, before you received a diagnosis for endometriosis?**



*The table above uses Scotland specific data from the APPG survey*

Healthcare professionals expressed concern over the waiting times for patients with endometriosis to be diagnosed. Without diagnosis and treatment, the disease may progress.

This concern was centred around two key factors:

- The length of time it takes for GPs to refer patients into secondary or tertiary care.
- The waiting lists for diagnostic laparoscopies

<sup>15</sup> APPG survey Scottish specific data - Endometriosis APPG report, Endometriosis in the UK: Time For Change, 2020, <https://www.endometriosis-uk.org/sites/endometriosis-uk.org/files/files/Endometriosis%20APPG%20Report%20Oct%202020.pdf>

**The length of time it takes for GPs to refer patients into secondary or tertiary care:** Patients are referred for diagnostic laparoscopies from primary care either to general gynaecology (secondary care) or to endometriosis specialist centres (tertiary care). However, the GP may not be aware of there being endometriosis specialist centres, and so patients with symptoms that may indicate complex or deep endometriosis may be referred to general gynaecology. It was felt that the quality of referrals from primary care to general gynaecology were varied and often not done in a timely manner. This was attributed by general gynaecology and specialist endometriosis services as due to limited knowledge of endometriosis amongst GPs, symptoms not being recognising, and lack of awareness of diagnosis and treatment pathways.

General gynaecology may refer on to endometriosis specialist centres. There was a sense that typically referrals from general gynaecology to endometriosis specialist centres were made in a timely manner due to high levels of knowledge amongst non-specialist gynaecologists about when would be an appropriate point to refer a patient on to tertiary care. However, from a patient perspective this increases the time to getting appropriate diagnosis and/or treatment.

*“I think primary care has a very big role and I do think the GPs locally are very good and trying very hard, but there is a big difference in quality of referrals.”*

**Healthcare professional: non-specialist gynaecologist (interview)**

Primary care practitioners also spoke of difficulties in referring to gynaecology. Whilst some were clear on the process of how to refer to gynaecology, there seemed to be a lack of clarity on when to do this and under what circumstances. In particular, primary care practitioners interviewed did not feel that there were standardised local pathways that they could rely on.

*“No, I don’t think we’ve got a clear pathway... for diagnosis and then referral. There is no clear guidance as to what there would be an expectation for primary care to do before referring and what is appropriate for referral, and there is no guidance on treatment. For another condition they say we want you to do e.g. a blood test, then refer. [For endometriosis there is] nothing; it ends up being very much individual GPs knowledge and response which means its going to be very variable”*

**Healthcare professional: primary care practitioner (interview)**

Another factor which primary care practitioners identified as leading to longer waiting times was that patients often wanted to see a woman as their GP.

*“Definitely find that most of our women prefer to speak with a woman. We’ve had one of our female GPs on maternity leave and it’s been covered with almost exclusively male locums which has meant some women are waiting quite a while to try and see me rather than any of the men working in the practice. There is an unwillingness to discuss some of the symptoms with male doctors [which] I think is possibly part of it.”*

**Healthcare professional: primary care practitioner (interview)**

**The waiting lists for diagnostic laparoscopies:** The majority of endometriosis diagnosis is done via laparoscopic surgery, there is not currently a non surgical route to a definitive diagnosis. To receive a diagnostic laparoscopy a patient will have to go to their GP, be referred to secondary or tertiary care and then be put on a waiting list for a diagnostic laparoscopy. As the multiple visits to GPs and doctors in hospitals shows, this is not always a smooth or prompt process. However, some healthcare professionals expressed that pre-Covid the waiting lists for diagnostic laparoscopy were not a major issue. Waiting lists have now been exacerbated by Covid-19 with healthcare professionals reporting that they were seeing patients generally a year after referral.

*“With Covid the waiting time is huge, [it could be] 9 months. [In that time patients] have to work so much harder to control symptoms... There is a huge delay, we are still seeing patients referred in February who continue to have pain and scarring.”*

**Healthcare professional: non-specialist gynaecologist (interview)**

Covid-19 has lengthened waiting times due to the cancellation of non-urgent surgery and appointments during the pandemic. As services have resumed, there has been lack of available theatre space for these procedures, because of ongoing pressured due to the pandemic and other surgeries being prioritised. It is likely that the implications of Covid-19 will have a long-term effect on waiting times for patients with endometriosis as the backlog will take time to clear and pressures on NHS resourcing will continue.

*“Long waiting lists. Obviously significantly worse due to Covid.”*

**Healthcare professional: non-specialist gynaecologist (survey)**

*“People who are entering waiting list now [will have to wait] 9-12 months until we can offer them operating time. Impacts of this will go on for years, 2-3 years at least if things manage to go back to normal.”*

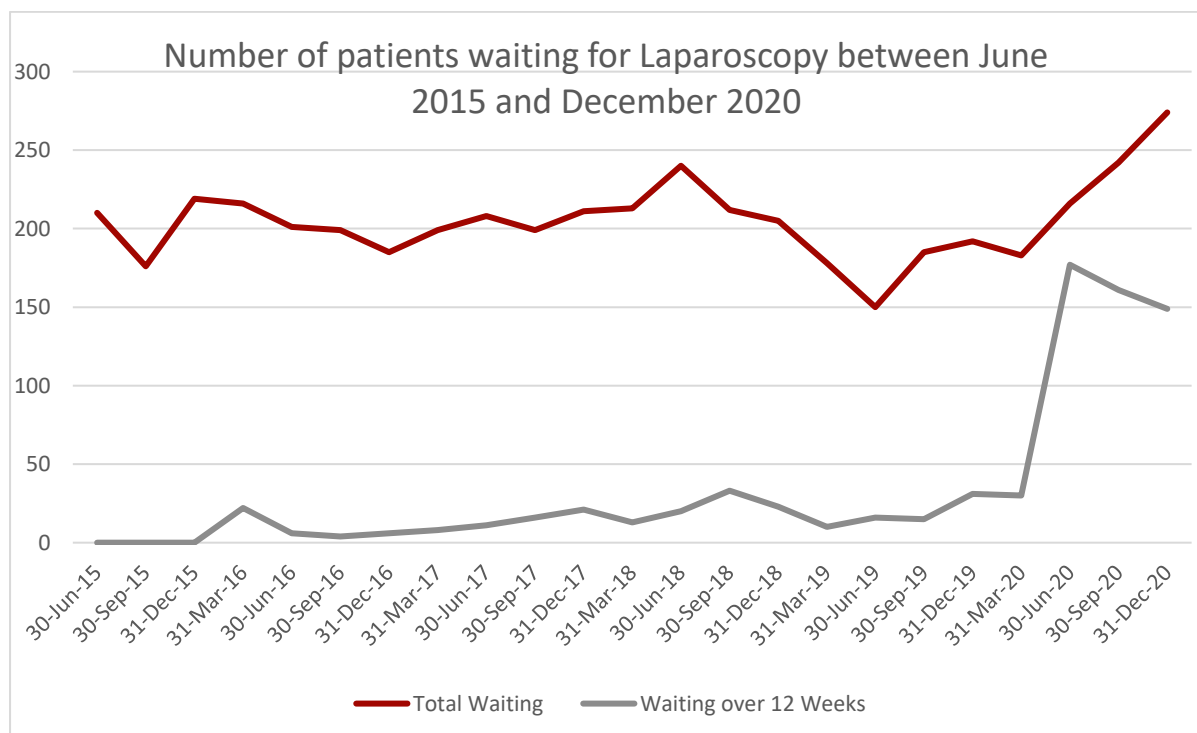
**Healthcare professional: non-specialist gynaecologist (interview)**



The waiting times data used below and for Figures 14-16 has been supplied by Public Health Scotland. Due to the incompleteness in recording of procedure codes, the figures presented may be slightly lower than the actual number of patients waiting. Waiting times data at procedure level is not routinely quality assured by PHS and therefore should be interpreted with caution.

From 31 March 2020, the impact of delaying non-urgent care due to Covid-19 is emphasised by an upsurge of such waits at 30 June 2020. The number of patients waiting over 12 weeks for laparoscopy rose dramatically between March and June 2020, in line with Covid-19 putting pressure on the NHS, resulting in cancelled appointments and surgeries and causing delays to non-emergency procedures. Previously in 2019 those waiting for treatment had decreased.

**Figure 14: Number of patients waiting for Laparoscopy across Scotland from 2015 to 2020**

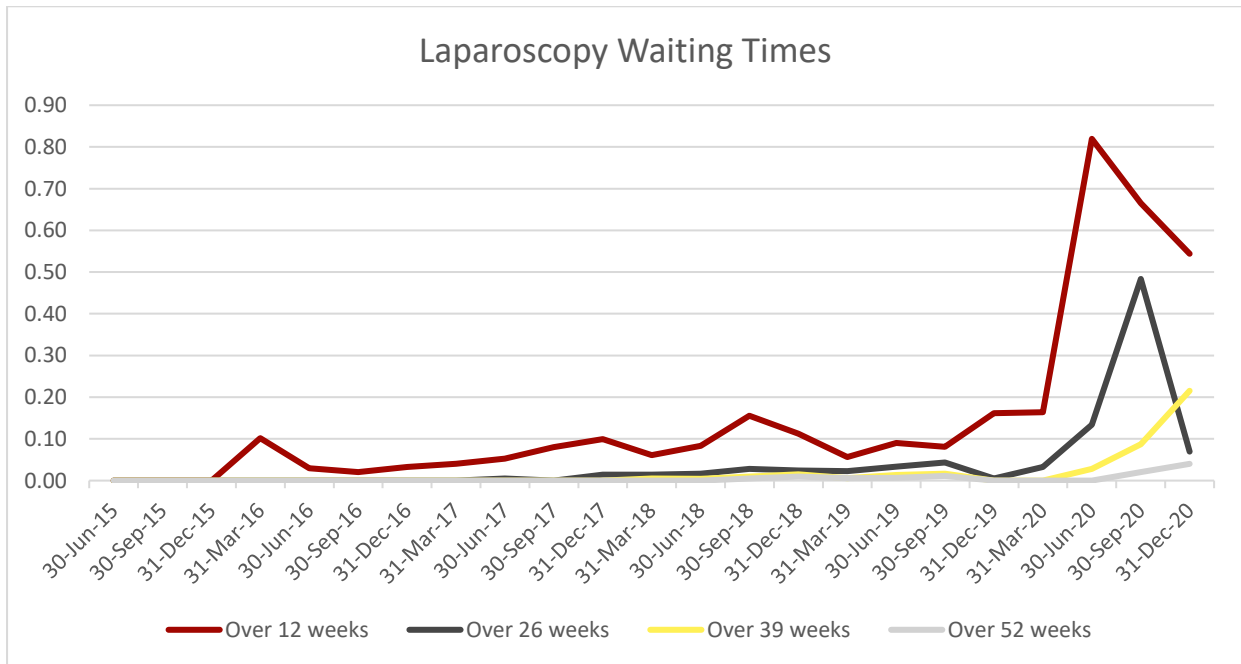


**The table above uses Public Health Scotland data**

*Note: the numbers in Figures 14-16 refer to all patients waiting for inpatient/daycase admission for Laparoscopy. Whilst they will include patients waiting for Laparoscopy to diagnose and/or treat endometriosis, the proportion of such patients cannot be identified.*

The percentage of patients waiting over 12 weeks for Diagnostic Laparoscopy fluctuated prior to March 2020, peaking at 16.51 % in December 2019. By June 2020, 91.9% of Diagnostic Laparoscopy patients were waiting over 12 weeks. This has continued to have a knock-on effect on waiting times with percentages continuing to increase for patients waiting over 39 weeks and 52 weeks for Diagnostic Laparoscopy.

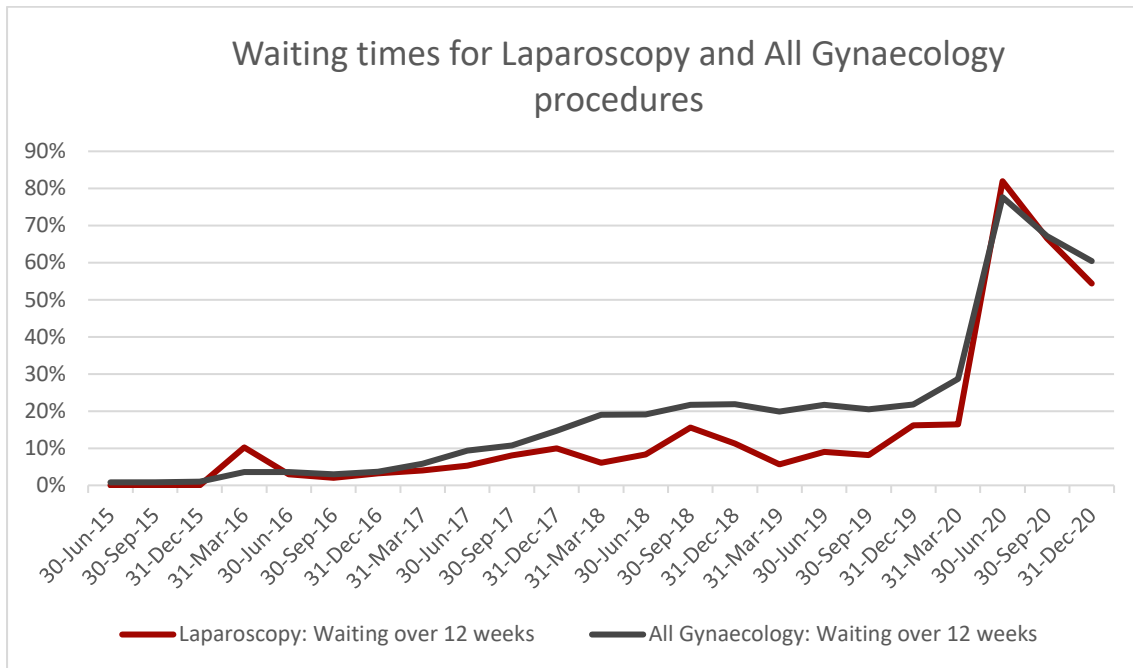
**Figure 15: Waiting times for Laparoscopy across Scotland from 2015 to 2020**



**The table above uses Public Health Scotland data**

Waiting times look different when you compare the waiting times for Laparoscopy compared to waiting times for all gynaecology treatments. Before Covid-19, smaller proportions of Laparoscopy have had to wait over 12 weeks for treatment, with the exception of March 2016. In June 2020, 81.94% of Laparoscopy patients were waiting for over 12 weeks compared to 77.63% of all gynaecology patients.

**Figure 16: Number of patients waiting for Laparoscopy compared to all Gynaecology procedures across Scotland from 2015 to 2020**



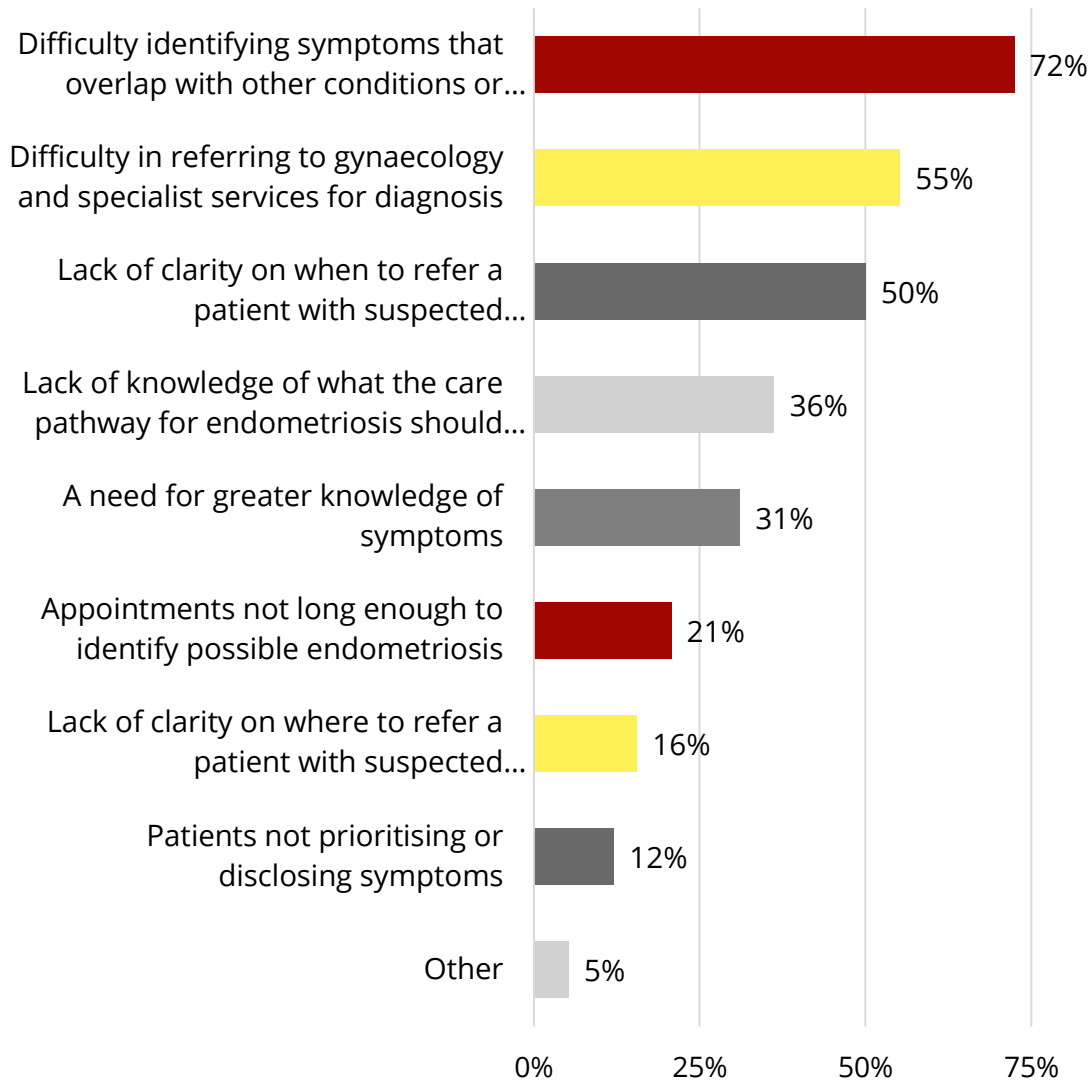
The table above uses Public Health Scotland data

### 4.3 Difficulty identifying symptoms

GPs acknowledged they had difficulty in identifying endometriosis symptoms, as a major barrier to diagnosis. ‘Difficulty identifying symptoms that overlap with other conditions or difficulty in linking up symptoms across different services and appointments’ was most frequently identified as a barrier to diagnosis by primary care practitioners, with 72.4% of respondents selecting this option. Approximately half also felt ‘difficulties in referring to gynaecology and specialist services for diagnosis’ (55.2%) and a ‘lack of clarity on when to refer a patient with suspected endometriosis’ (50%) were barriers to endometriosis diagnosis. Generally, practitioners did not feel that ‘patients not prioritising or disclosing symptoms’ or a ‘lack of clarity on where to refer a suspected patient’ were barriers, with 12.1% and 15.5% selecting these options respectively.

**Figure 17: Primary care survey on barriers to diagnosing patients with endometriosis**

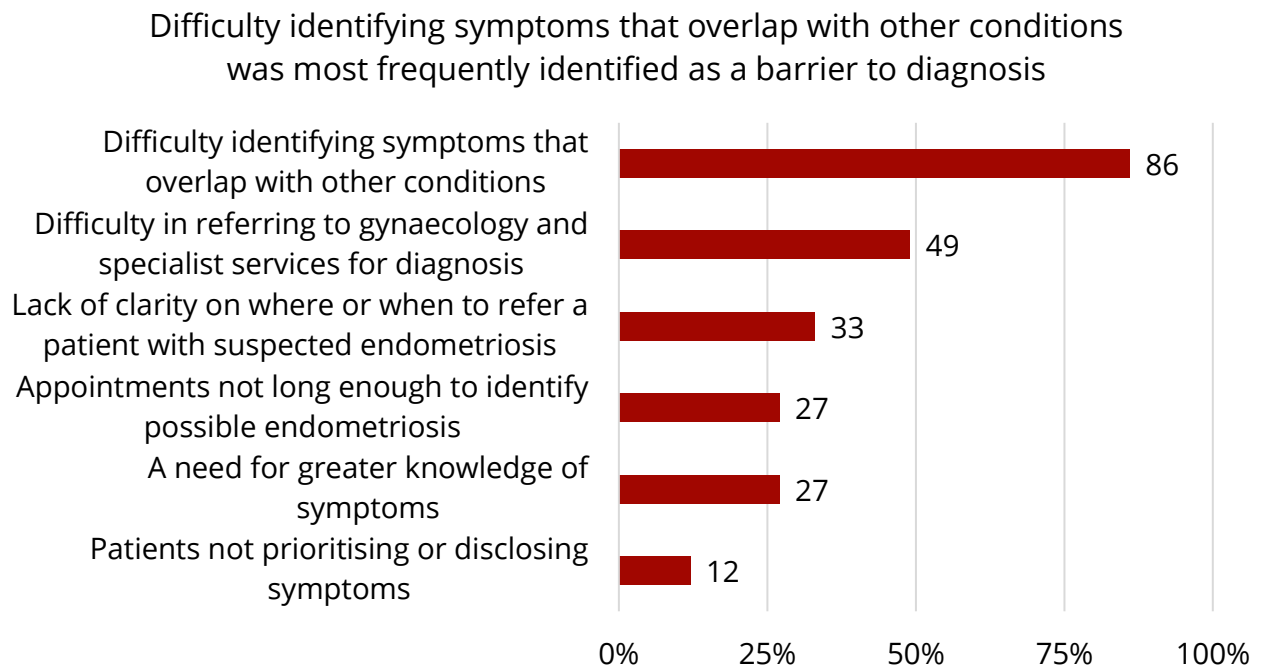
The biggest barrier to diagnosis is identifying symptoms that overlap with other conditions or difficulty in linking up symptoms across different services and appointments



*The table above uses data from the primary care survey*

Primary care staff who responded to a poll in the Endometriosis UK webinar identified overlapping symptoms as the most significant barrier to diagnosing endometriosis (86%).

**Figure 18: Primary care webinar poll on barriers to diagnosing patients with endometriosis**



*The table above uses data from the Endometriosis UK webinar on endometriosis*

Primary care practitioners that were interviewed explained the difficulty of identifying symptoms in more detail. Reasons included the overlap of symptoms with other conditions and the fact that there was not perceived to be a standard set of symptoms for endometriosis. This means that endometriosis is not always obvious to the healthcare professional, and even if they are considering endometriosis as a potential diagnosis it may not present itself in an expected manner.

*“I think the main barrier is... that you have got to think of it, because it doesn’t always present in the textbook way. And there isn’t really a primary care test you can do that says it is or it isn’t; to get a definitive diagnosis you have to refer which obviously takes a lot of time”*

**Healthcare professional: primary care practitioner (interview)**

## 5. Current service provision: Care and management

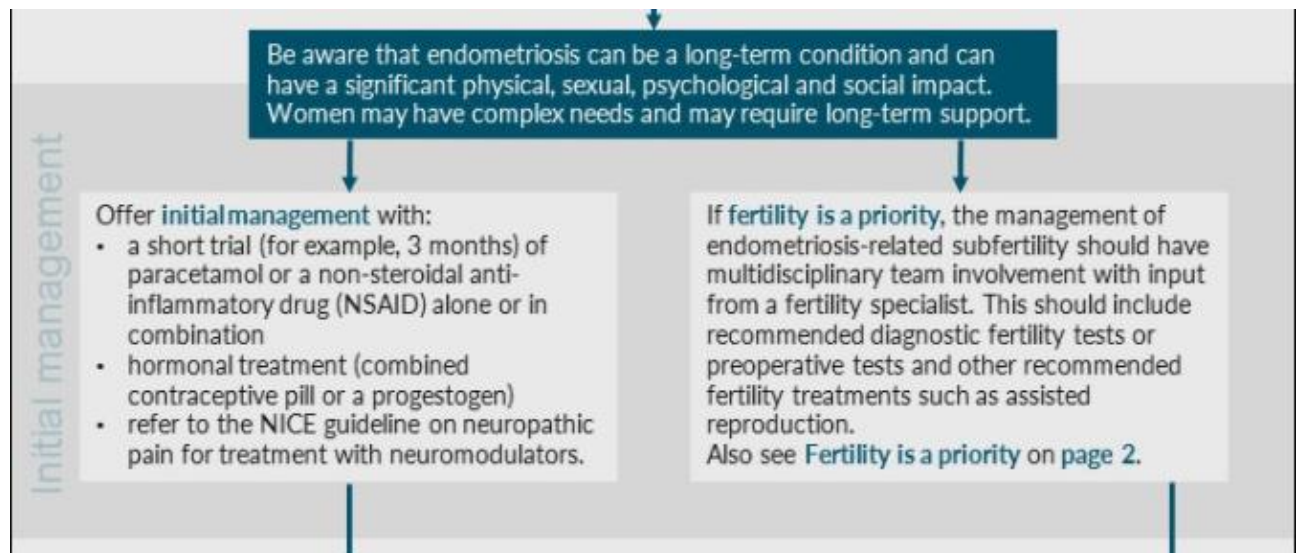
This chapter outlines current service provision in relation to the care and management of endometriosis following a diagnosis.

### 5.1 Care and management methods of endometriosis

The NICE guideline (NG73) Endometriosis: diagnosis and management was published in 2017, and a supporting Quality Standard (QS172) published in 2018. An *Algorithm for diagnosing and managing endometriosis* summarises the care pathway. The full *Algorithm* is given in Appendix A, and key extracts have been included below in the text.

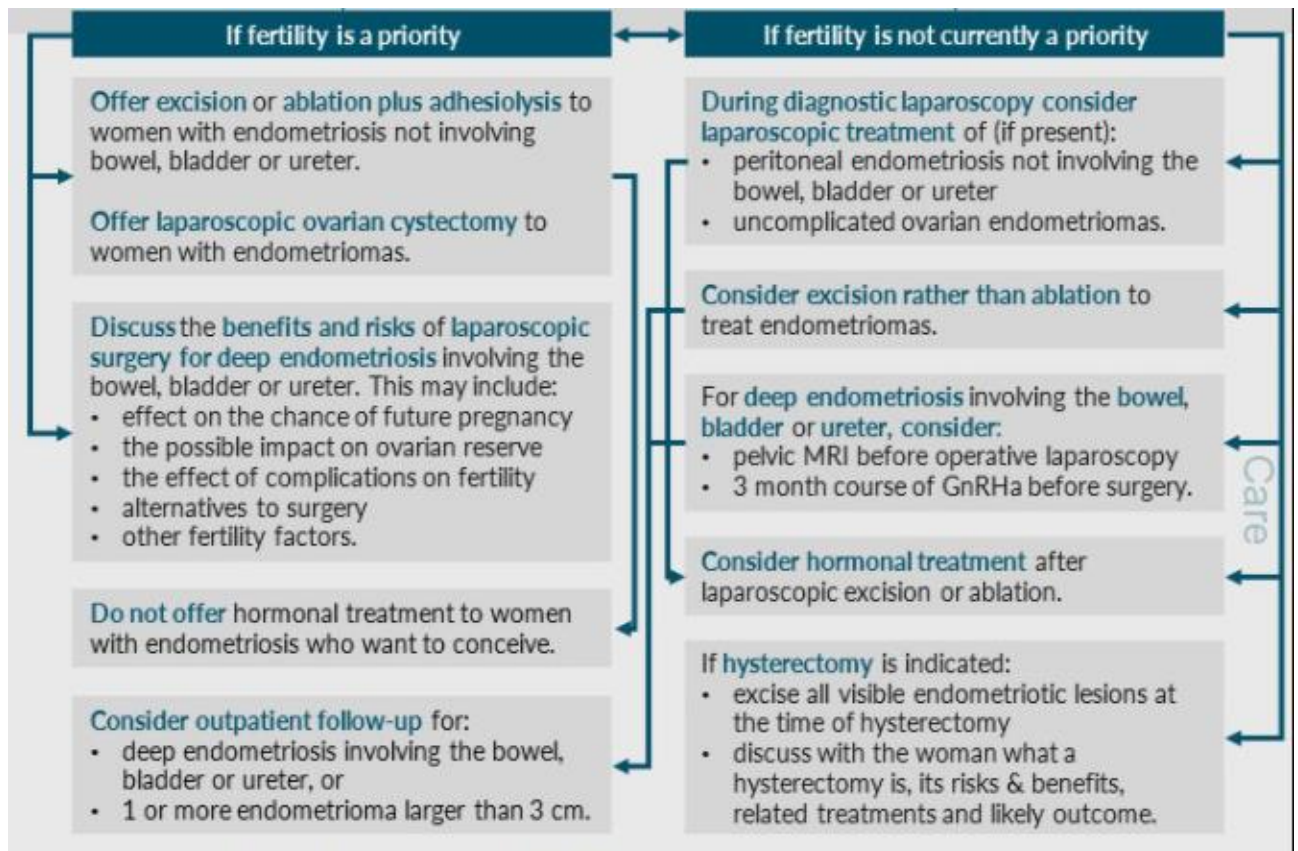
The NICE guideline outlines the following recommendations for initial management of endometriosis (see Figure 9 below) and endometriosis care (see Figure 10 below).<sup>16</sup>

**Figure 19: NICE guideline (NG73) Endometriosis: diagnosis and management – Algorithm for diagnosing and managing endometriosis - Initial management**



<sup>16</sup> <https://www.nice.org.uk/guidance/ng73/chapter/Recommendations#organisation-of-care>

**Figure 20 NICE guideline (NG73) Endometriosis: diagnosis and management – Algorithm for diagnosis and managing endometriosis - Care**



Diagnosis of endometriosis is typically delivered by general gynaecology (secondary care) or endometriosis specialist centres (tertiary care). Whilst endometriosis may be suspected in primary care, a definitive diagnosis requires referral to secondary or tertiary care.

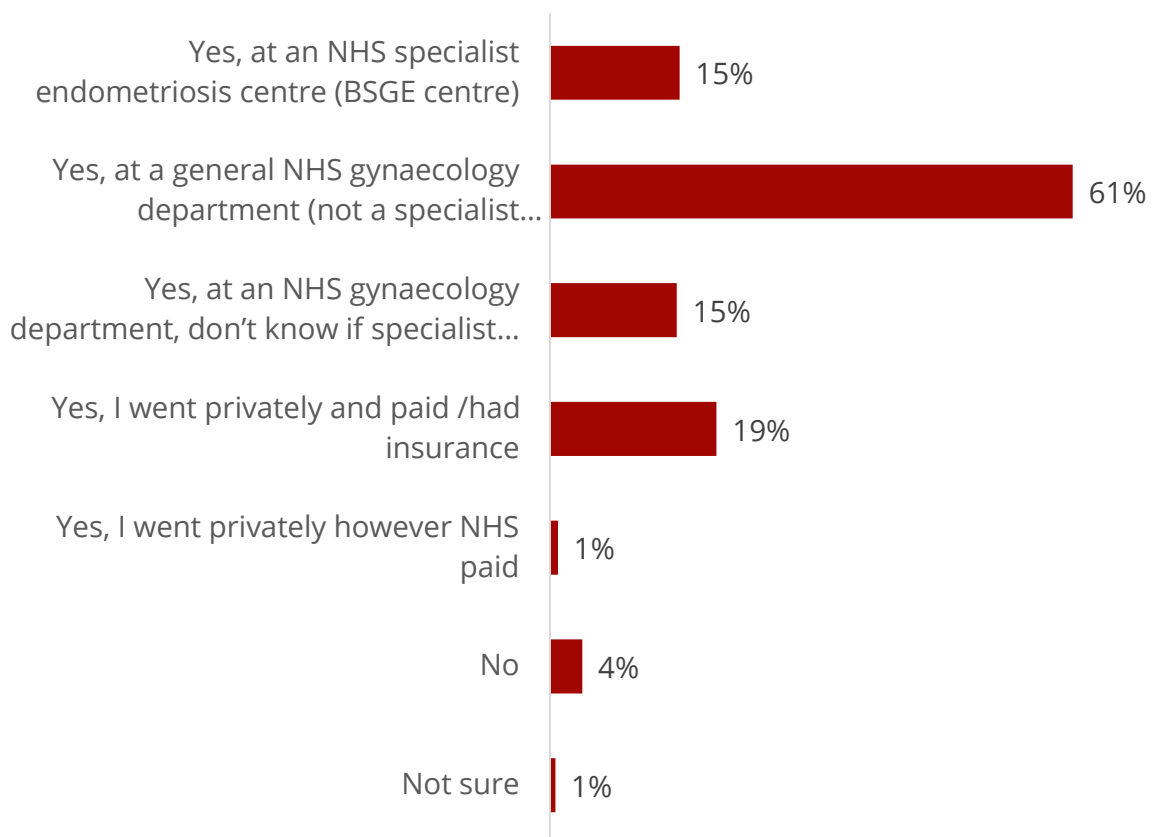
This guideline shows the main treatment and management of endometriosis and its symptoms are via pharmacological pain management, hormonal treatment, and surgical management. In terms of treatments and managements, surgical management must be undertaken in a hospital setting, and certain hormonal treatments may only be available in secondary or tertiary care. Primary care also delivers management of endometriosis, focusing on pharmacological pain management and some hormonal treatments.

The vast majority (95%) of patients have seen a gynaecologist, although only 15% of Scottish patients knowing they had been seen at a specialist endometriosis centre. One fifth are seen privately either through paying themselves, insurance or NHS payment (20%).

According to data collected in 2020, almost one third of patients with endometriosis have had over 10 appointments with a gynaecologist (30%). In general, once referred to a gynaecologist, most patients are seen within 6 months; 37% within 3 months and 34% between 4 and 6 months. Similarly, when agreed with the gynaecologist that surgery is needed, patients are most frequently able to have the surgery within 3 months (42%) and a further third are seen within between 4 and 6 months (31%).<sup>17</sup> However, this data is pre Covid-19, and interviews suggest that waiting times for referrals to see a gynaecologist or to receive surgery have increased considerably throughout the Covid-19 pandemic.

**Figure 21: Have you seen a gynaecologist in a hospital about your endometriosis?**

Most patients had seen a general gynaecologist in a hospital about their endometriosis, but not attended a specialist centre



*The table above uses Scotland specific data from the APPG survey*

<sup>17</sup> Data throughout paragraph is from the APPG survey - Endometriosis APPG report, Endometriosis in the UK: Time For Change, 2020, <https://www.endometriosis-uk.org/sites/endometriosis-uk.org/files/files/Endometriosis%20APPG%20Report%20Oct%202020.pdf>



Regarding procedures, Public Health Scotland collects data on three main groups of endometriosis procedures. These are:

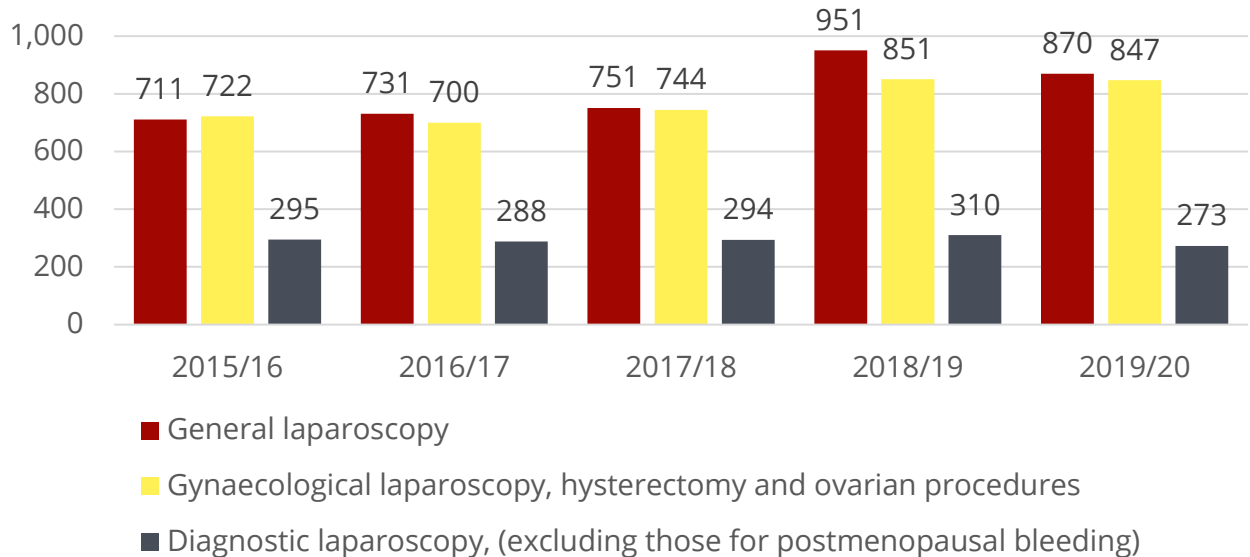
- General laparoscopy
- Gynaecological laparoscopy, hysterectomy and ovarian procedures
- Diagnostic laparoscopy, (excluding those for postmenopausal bleeding)

General laparoscopy is the most frequent procedure for endometriosis patients (both any diagnosis position and main diagnosis), and has been across Scotland since 2015.

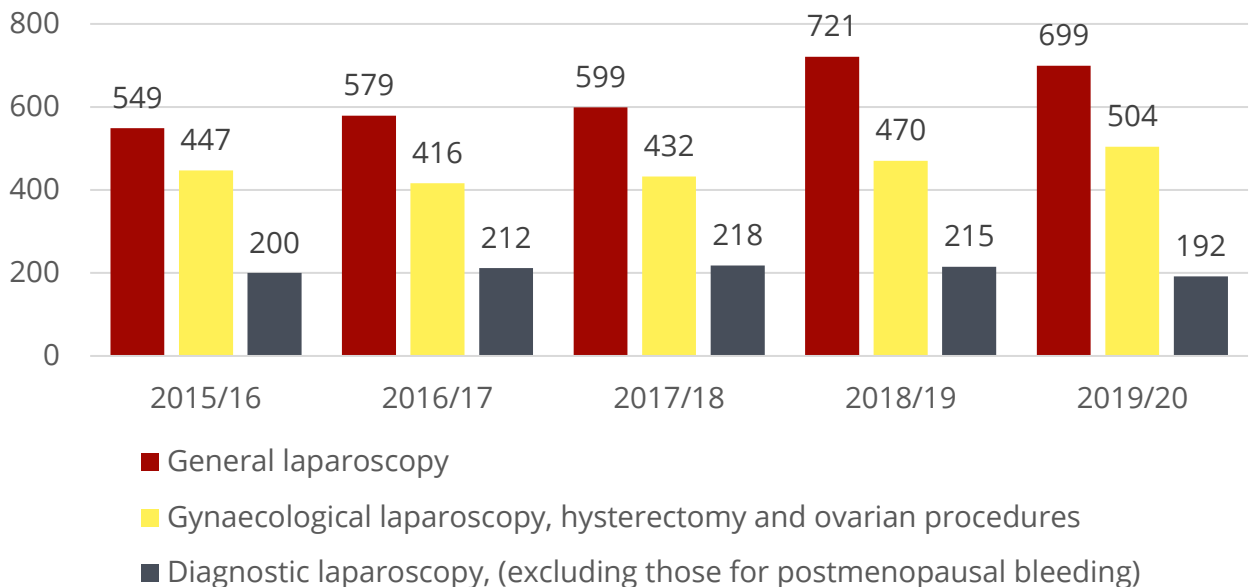
Due to the incompleteness in recording of procedure codes, the figures presented may be slightly lower than the actual number of patients waiting. Waiting times data at procedure level is not routinely quality assured by PHS and therefore should be interpreted with caution.

**Figures 22 and 23: Number of endometriosis procedures across Scotland from 2015/16 to 2019/20. The first chart shows ‘any diagnosis position’ and the second shows ‘main diagnosis’**

Since 2015 general laparoscopy and gynaecological laparoscopy have been over twice as frequent as diagnostic laparoscopy for endometriosis patients (any diagnosis position)



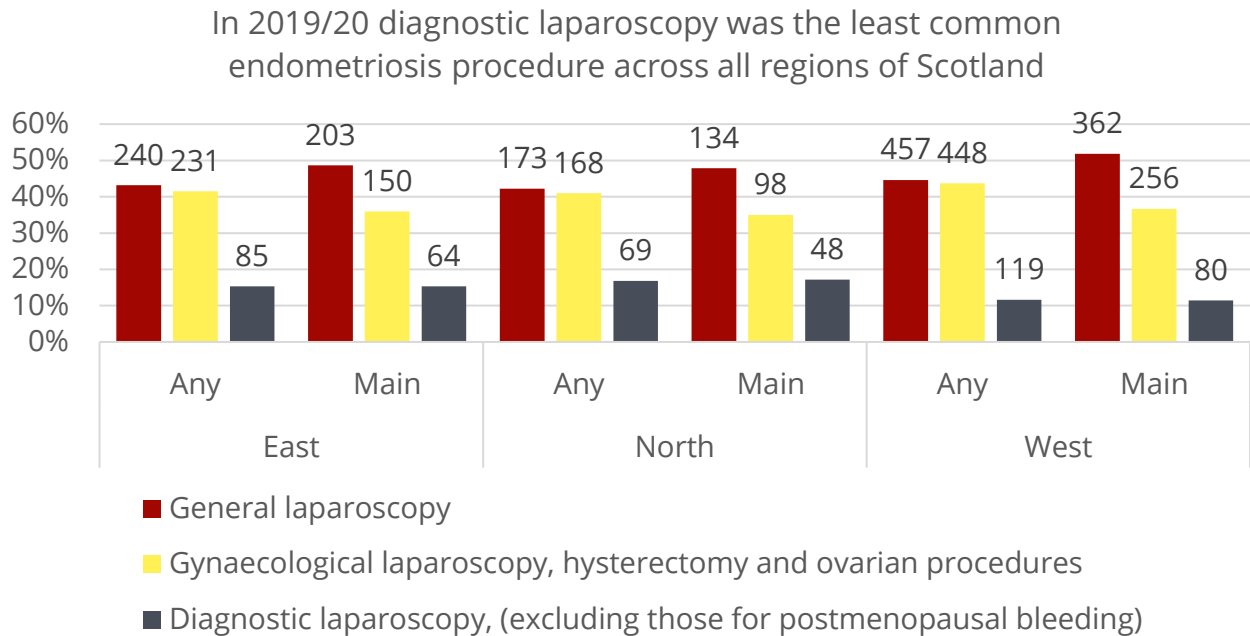
Since 2015, general laparoscopy has been the most frequent procedure for endometriosis patients (main diagnosis)



*The table above uses Public Health Scotland data*

In 2019/20 general laparoscopy was the most common procedure for endometriosis patients (any diagnosis position and main diagnosis) across all three regions of Scotland. For ‘any diagnosis position’ endometriosis patients, diagnostic laparoscopy made up less than 20% of endometriosis procedures across Scotland.

**Figure 24: Number of endometriosis procedures across regions of Scotland in 2019/20**



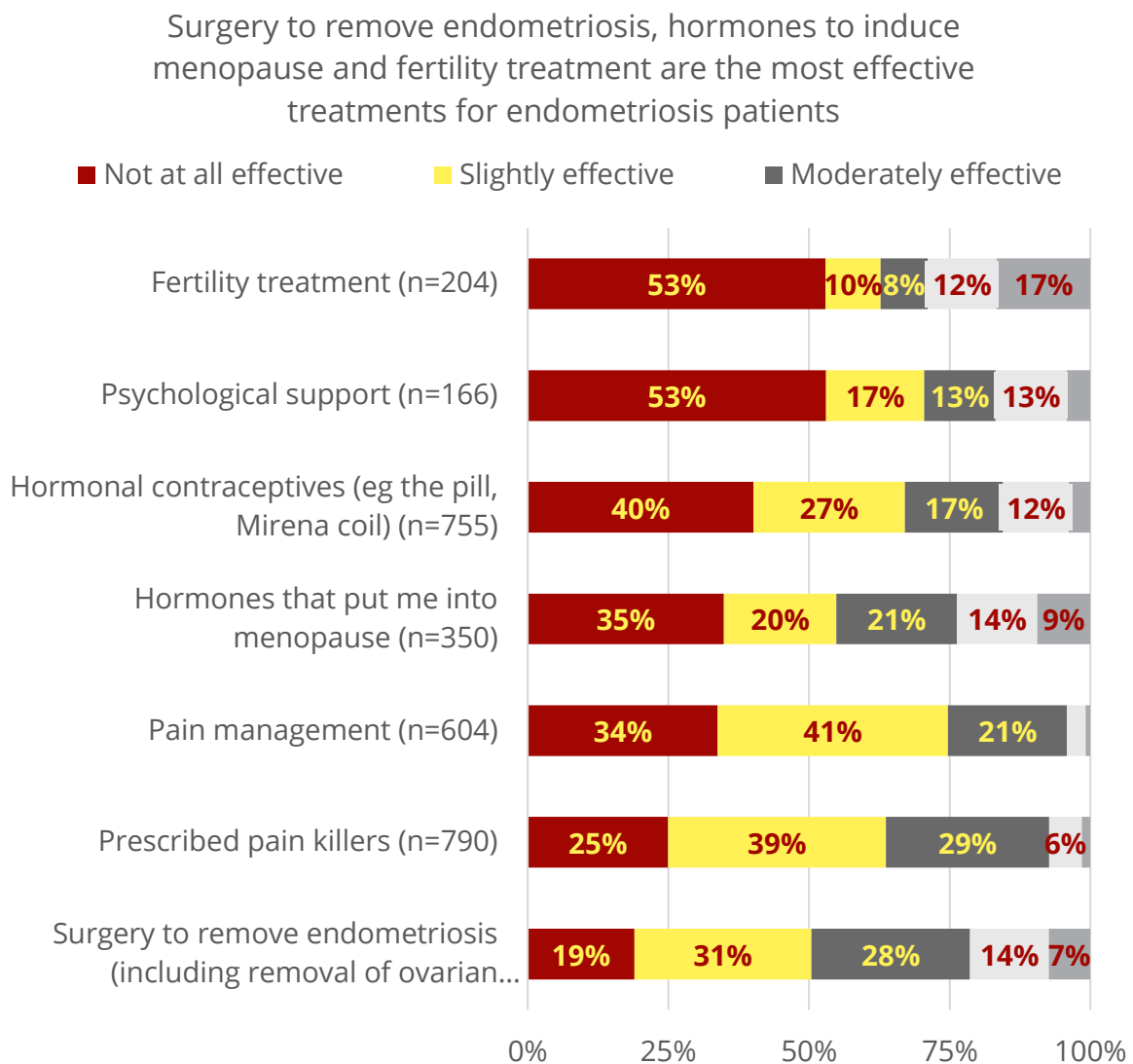
*The table above uses Public Health Scotland data*

Management for endometriosis is also provided by pain management services and sexual health services. Pain management services provide support for patients who have chronic pain through a range of methods, although this would require a referral to access. Sexual health services typically provide support for patients who want/need contraception, which in turn may reduce symptoms of endometriosis, including pain.

## 5.2 Effectiveness of care and management of endometriosis

The effectiveness of endometriosis treatments is varied, with none seeming particularly effective for a majority of those surveyed. A full breakdown of the effectiveness of each treatment can be seen in the graph below.<sup>18</sup> Similarly to diagnosis, management and care of endometriosis has been impacted by Covid-19 leading to longer waiting times and reduced theatre space for surgery.

**Figure 25: Considering all the treatments you have had for endometriosis, how effective do you think they have been in reducing the impact of your symptoms?**



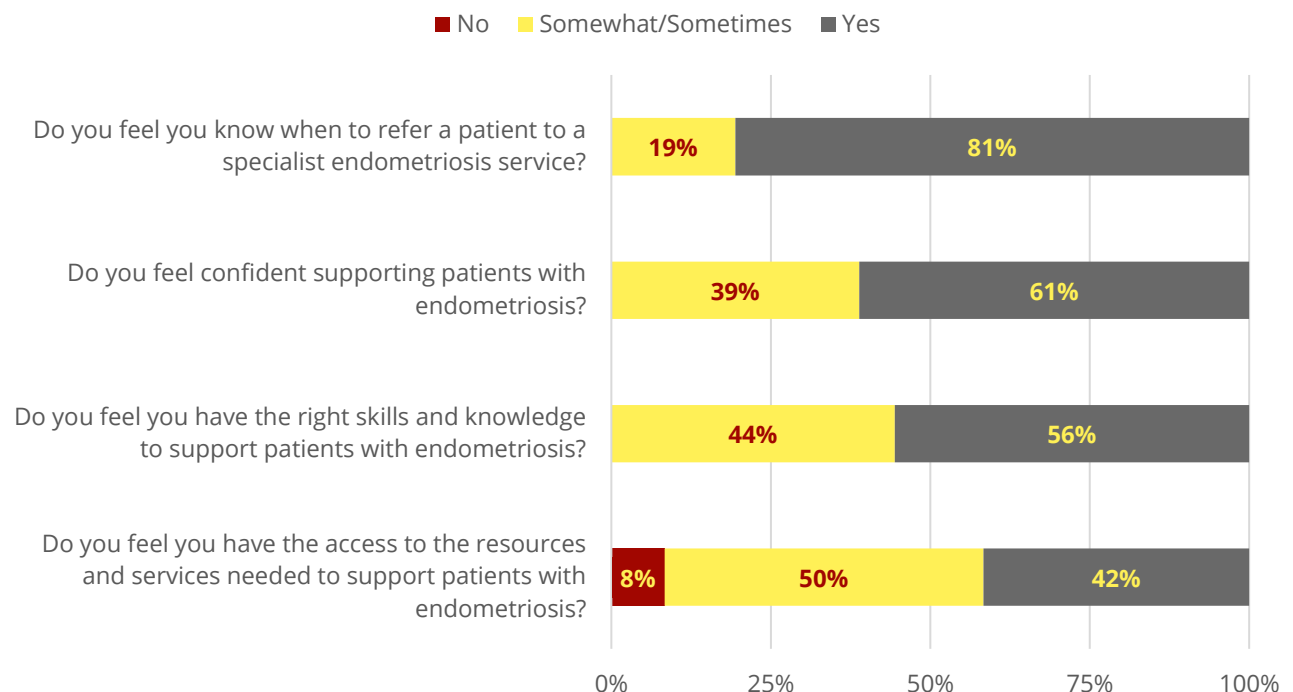
<sup>18</sup> Data used is from the APPG survey - Endometriosis APPG report, Endometriosis in the UK: Time For Change, 2020, <https://www.endometriosis-uk.org/sites/endometriosis-uk.org/files/files/Endometriosis%20APPG%20Report%20Oct%202020.pdf>

*The table above uses Scotland specific data from the APPG survey*

Of the non-specialist gynaecologists who have answered the survey, the majority (56%, n=20) felt they have the right skills and knowledge to support patients with endometriosis, 44% (n=16) felt they somewhat have the right skills and resources, and none felt they did not have any of the skills or resources. This was similar when asked if they had access to the resources and services needed to support patients, with 42% (n=15) having felt they do have access, and half (50%, n=18) having felt they somewhat have access. Only a minority (8%, n=3) felt they have not got access to appropriate resources and services. Confidence levels were high among the health professionals surveyed. Two thirds (61%, n=22) felt confident supporting patients with endometriosis and the other (39%, n=14) felt somewhat confident. When asked what challenges they face in helping patients access the right services, 81% (n=26) said that waiting times for services are long, a further 22% (n=7) said there were no available services in their area.<sup>19</sup>

**Figure 26: Referring and supporting patients with endometriosis**

Over four fifths of non-specialist gynaecologists felt they knew when to refer a patient to a specialist endometriosis service



*The table above uses data from the non-specialist gynaecology care survey*

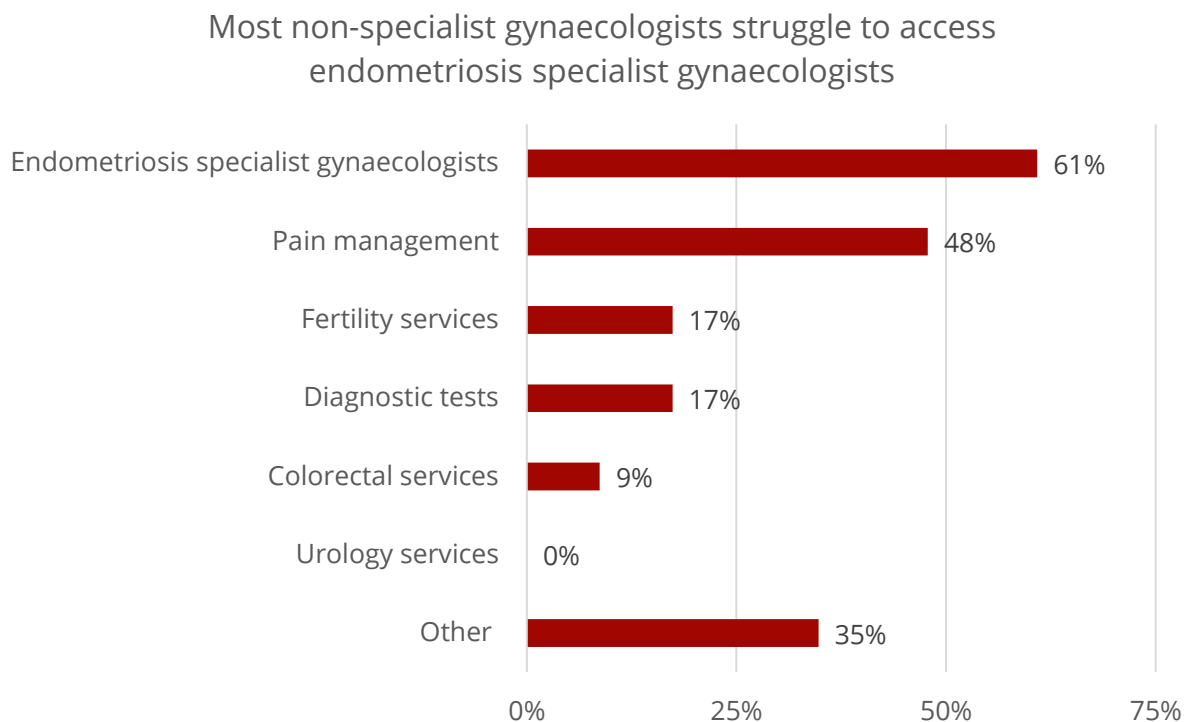
<sup>19</sup> Data throughout this paragraph is from the analysis of Service Provision Survey

*“Waiting times have been a long-term problem and have been worsened by the covid pandemic. There is a good surgical service once the wait is over but there is a deficit in managing patient's acute on chronic pain episodes.”*

**Healthcare professional: non-specialist gynaecologist (survey)**

In terms of referring patients on to other services, of the non-specialist gynaecologists surveyed, most struggle to access endometriosis specialist gynaecologists (61%, n=14). Almost half also struggle to access pain management services (48%, n=11). 17% struggle to access diagnostic tests (n=4) and fertility services (n=4), and 9% struggle to access colorectal services (n=2). Approximately one third (n=6) said they also struggle to access ‘other’ services not listed, these include physiotherapists, psychology services, operative gynaecologists.<sup>20</sup>

**Figure 27: Are there suitable specialist services available in your area for you to refer?**

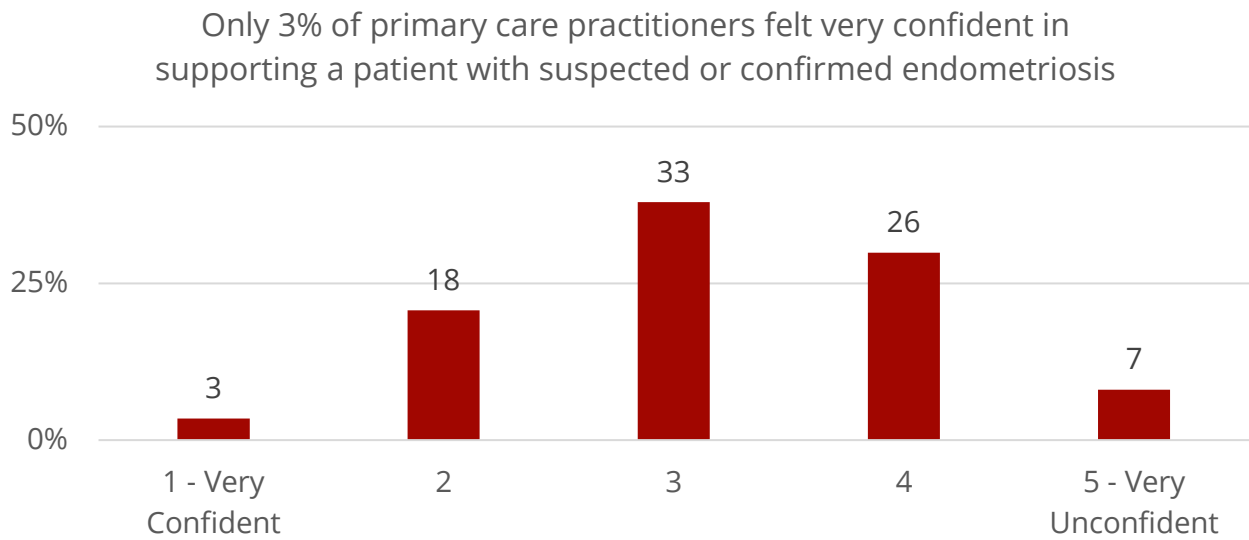


*The table above uses data from the non-specialist gynaecology care survey*

Primary care professionals were asked to rate their confidence in supporting patients with endometriosis out of 5. Over a third (38%) of practitioners selected 3 out of 5 – neither confident nor unconfident, with 38% selecting unconfident or very unconfident. Only 24% selected confident or very confident.

<sup>20</sup> Data throughout this paragraph is from the Analysis of Service Provision Survey

**Figure 28: Primary care webinar poll on confidence in supporting a patient with suspected or confirmed endometriosis**

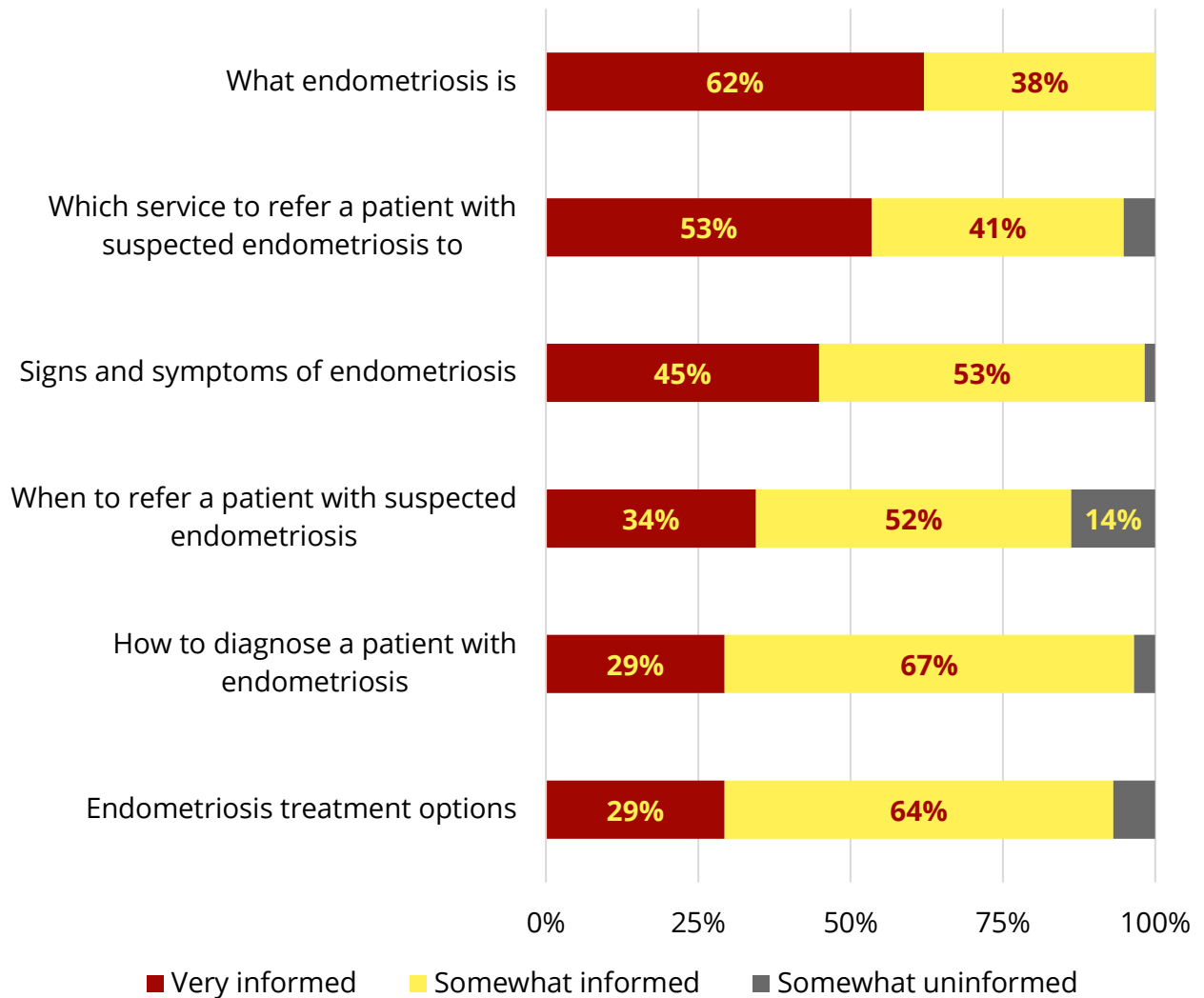


*The table above uses data from the Endometriosis UK webinar on endometriosis*

In a more detailed survey, primary care healthcare professionals were asked about their endometriosis knowledge and ability to refer patients in line with the NICE guideline. Of the primary care healthcare professionals surveyed, a majority felt either ‘somewhat informed’ or ‘very informed’ about each of the surveyed measures relating to endometriosis knowledge. They most frequently identified feeling informed about ‘what endometriosis is’ and ‘which service to refer a patient with suspected endometriosis to’. Overall, almost two thirds (62%) felt ‘very informed’ about what endometriosis is and just over half (53%) felt ‘very informed’ about which service to refer a patient with suspected endometriosis to. Just over half (52%) Primary care practitioners felt only somewhat informed about ‘when to refer a patient with suspected endometriosis’, with 13.8% practitioners feeling somewhat uninformed. Two thirds (67%) felt only somewhat informed about ‘how to diagnose a patient with endometriosis’, with almost two thirds (34%) feeling only ‘somewhat informed’ about treatment options.

**Figure 29: Primary care survey on endometriosis knowledge**

Primary care practitioners felt informed about what endometriosis is and what service to refer a suspected patient to



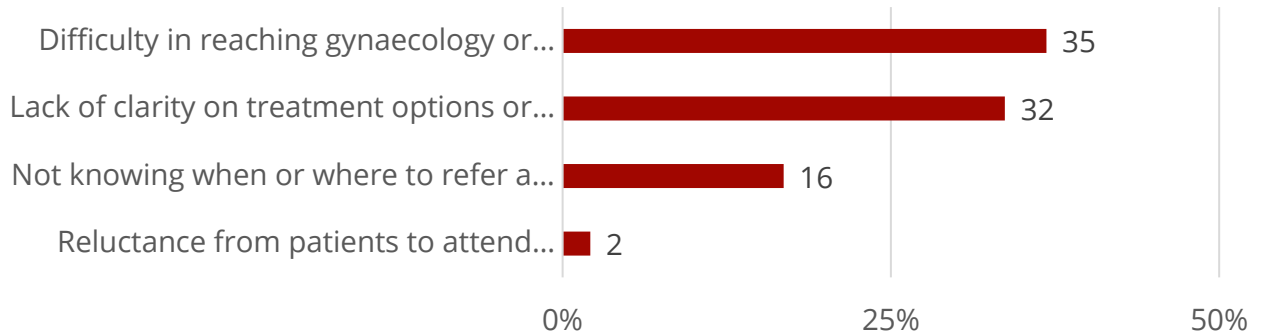
*The table above uses data from the primary care survey*

In terms of barriers on delivering endometriosis care, over a third (41%) of primary care healthcare professionals, selected ‘difficulty in reaching gynaecology or specialist endometriosis services’. Over a third (37%) selected ‘lack of clarity on treatment options or the care pathway for endometriosis’ as the most significant barrier, whilst 19% selected ‘not knowing when or where to refer a patient’.



**Figure 30: Primary care webinar poll on barriers to delivering endometriosis care**

Difficulty in reaching gynaecology or specialist endometriosis services was most frequently selected (41%) as the most significant barrier to delivering endometriosis care amongst primary care practitioners

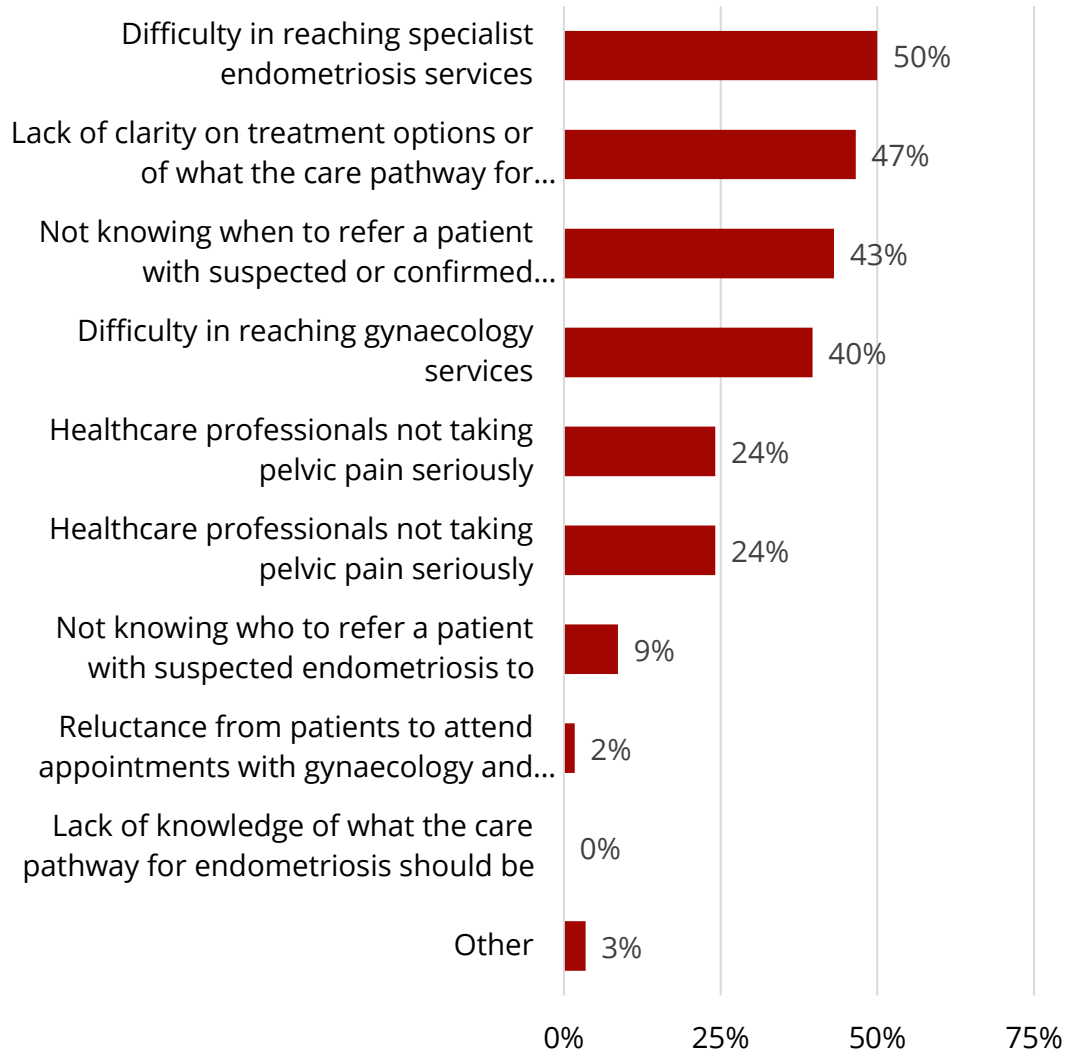


*The table above uses data from the Endometriosis UK webinar on endometriosis*

In a more detailed survey of primary care practitioners, difficulty in reaching specialist endometriosis services (50%) was also most frequently identified as a barrier to delivery care. Other barriers that were most frequently identified included a lack of clarity on treatment options and what the care pathway should be (46.6%), not knowing when to refer a patient with suspected endometriosis (43.1%) and reaching gynaecology services (39.7%). Approximately one quarter also felt that a barrier to care was healthcare professionals not taking pelvic pain seriously (24.1%) and approximately one tenth felt there were barriers around knowing who to refer a suspected patient to (8.6%). Reluctance from patients to attend appointments and a lack of knowledge about the care pathway were not seen as barriers to endometriosis care.

**Figure 31: Primary care survey on barriers to delivering endometriosis care**

Reaching specialist endometriosis services, clarity on treatment options, clarity on when to refer a suspected patient and reaching gynaecology services were the main barriers to care and treatment



*The table above uses data from primary care survey*

Primary care practitioners explained that patient experience would differ quite considerably depending on whether GP staff had gynaecology qualifications or endometriosis knowledge. Interviewees explained that there is not a base level of knowledge on endometriosis meaning whether a primary care practitioner knows about the condition is dependent on whether they are interested or whether they have completed training in obstetrics and gynaecology. Primary care practitioners felt that this variation in knowledge may lead to variation in delivery of care for patients.

*“I would think [it varies] quite a lot... within my practice, if you happen to pick a doctor that didn't have a particular interest, it will be very variable, you might get referred, you might not, you might get some treatment, [you might not].”*

**Healthcare professional: primary care practitioner (interview)**

## 6. Awareness and implementation of NICE guideline and QS on endometriosis

This chapter outlines the level of awareness of the NICE guideline (N73) Endometriosis: diagnosis and management, and the NICE quality standards (QS172) on endometriosis amongst healthcare professionals, the extent to which they are being implemented presently, and the challenges we have identified that health professionals face in implementing them.

### 6.1 Awareness and knowledge of NICE guideline

Staff from endometriosis specialist centres (of those interviewed for this project) were all aware of the NICE guideline and had full knowledge of it. Non-specialist gynaecologists were generally aware of the guideline, but in some cases did not feel fully up to date or knowledgeable about the contents. Some primary care healthcare professionals were aware that the guideline existed (some via the Endometriosis UK webinar), but most were not aware of the contents.

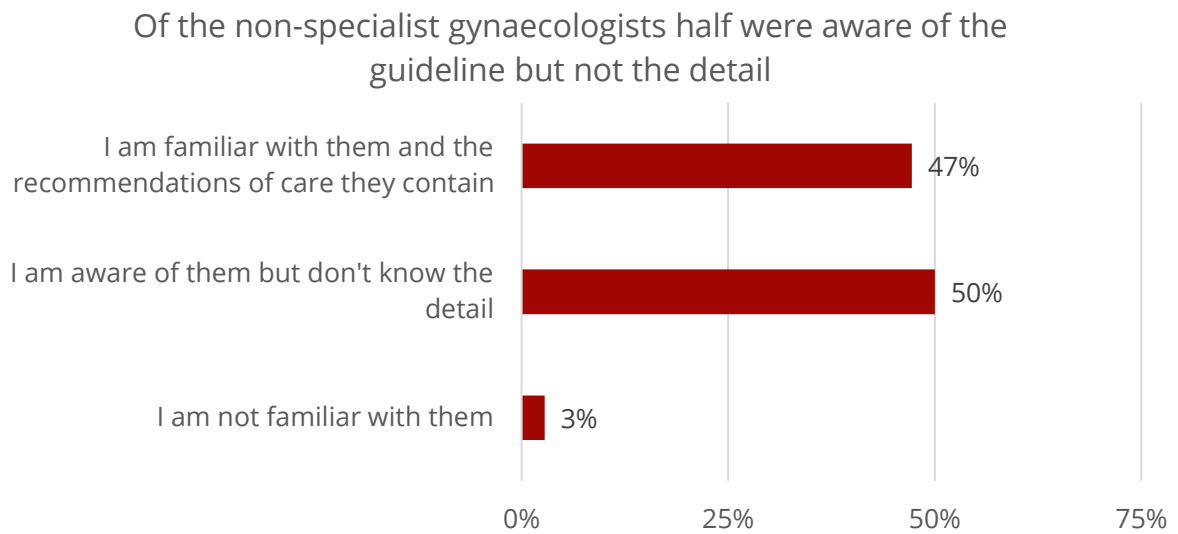
*"[I am aware of them, but] I don't think I've read the guideline on endometriosis since my exams six years ago, I don't think I know what is in those guidelines"*

**Healthcare professional: non-specialist gynaecologist (interview)**

Of the non-specialist gynaecologists surveyed, 47% (n=17) were familiar with the NICE guideline and the recommendations of care it contains, 50% (n=18) were aware of the guideline but not the detail, and only 1 (3%) was not familiar with it.<sup>21</sup>

<sup>21</sup> Data throughout this paragraph is from the analysis of Service Provision Survey

**Figure 32: Are you familiar with the NICE Guideline and Quality Standards for endometriosis?**



*The table above uses data from the non-specialist gynaecology care survey*

Healthcare professionals from pain management and sexual health services who worked with patients with endometriosis were also generally aware of the guideline, but not knowledgeable about the contents. This was because endometriosis is not considered to be one of the primary concerns within their services, and because the guideline did not feel as relevant to them.

*“I’m pretty sure I’ve looked it up some time ago... I think, you know when it comes to specific conditions I’m not convinced this is on our radar... I’m not sure if anybody is really checking, unless they have a lot of patients with endometriosis on their case load”*

**Healthcare professional: pain management service staff member (interview)**

## 6.2 Implementation of the guideline

The provision of endometriosis care in Scotland does not currently align with the NICE guideline recommendations. The average length of time from onset of symptoms to diagnosis for endometriosis is 8.5 years in Scotland. The APPG on Endometriosis have recommended targets of an average of 4 year diagnosis time or less by 2025, and 1 year or under by 2030.<sup>22</sup>

Prior to diagnosis, many with symptoms have interacted multiple times with various health care services in primary and secondary care, including A&E. Following diagnosis treatment wait times can be perceived as long and patients often found the healthcare professionals they interacted with unhelpful.

Confidence amongst staff that they were implementing the NICE guideline varied across services. Specialist endometriosis centres were mainly confident that their services fully or mostly implemented the NICE guideline.

*“In our centre we very much try to follow important national guidelines... Amongst us, we are very aware of the guidelines and very updated. If they were updated we would circulate them... and change practice if guidelines changed”*

**Healthcare professional: endometriosis specialist (interview)**

However, specialists also explained that it was difficult for them to have a sense of how the NICE guideline was being implemented elsewhere due to lack of exposure to other services. It was mentioned that this had been exacerbated by Covid-19 due to the lack of conferences as healthcare professionals are not coming together to discuss provision of care, including implementation of the guideline.

The NICE guideline includes detail on specialists and services that endometriosis specialist centres should have access to. The table below details the extent to which each of the three endometriosis specialist centres in Scotland has access to these elements.

<sup>22</sup> Endometriosis APPG report, Endometriosis in the UK: Time For Change, 2020, <https://www.endometriosis-uk.org/sites/endometriosis-uk.org/files/files/Endometriosis%20APPG%20Report%20Oct%202020.pdf>

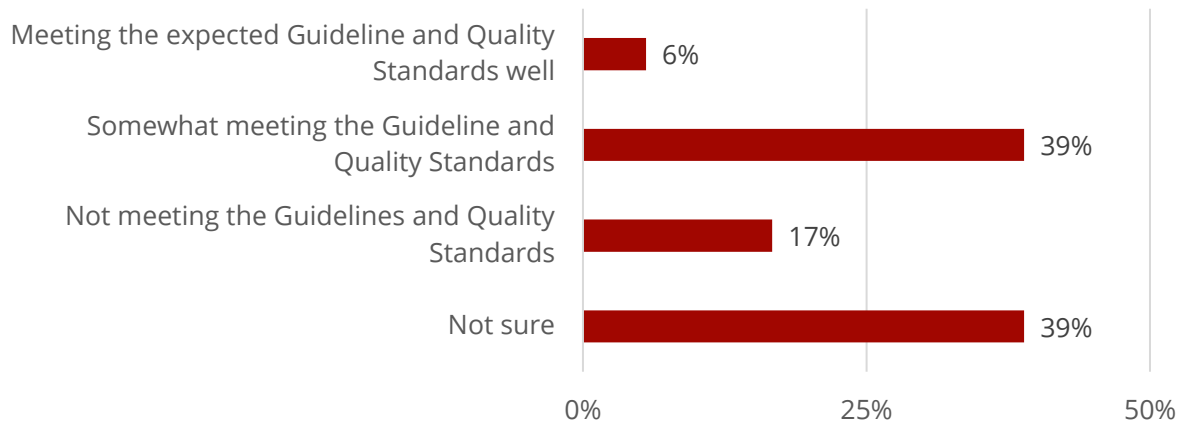
Element of NICE guideline	Lothian	Aberdeen	GGC
Gynaecologists with expertise in diagnosing and managing endometriosis, including advanced laparoscopic surgical skills	Yes	Yes	Yes
A colorectal surgeon with an interest in endometriosis	Yes	Yes (one person said no)	Yes
A urologist with an interest in endometriosis	Yes	Yes	Yes
An endometriosis specialist nurse	Yes	Yes	Yes
A multidisciplinary pain management service with expertise in pelvic pain	Yes	Yes	In development
A healthcare professional with specialist expertise in gynaecological imaging of endometriosis	Yes	Yes (one person said no)	Yes, in early stages
Advanced diagnostic facilities (for example, radiology and histopathology)	Yes	Yes	Yes
Fertility services	Yes	Yes	Yes

Amongst non-specialist gynaecologists, when asked in a survey whether Scottish healthcare was currently meeting the NICE Guideline and Quality Standards, 6% (n=2) felt they were meeting the standards well, 39% (n=14) felt Scotland was somewhat meeting them, 17% (n=6) felt they were not meeting them, and 39% (n=14) were not sure.<sup>23</sup>

**Figure 33: To what extent do you feel Scotland is meeting the NICE Guideline and Quality Standards in relation to the diagnosis and care of endometriosis?**

<sup>23</sup> Data throughout this paragraph is from the analysis of Service Provision Survey

Only 6% of non-specialist gynaecologists felt they were meeting the standards well



*The table above uses data from the non-specialist gynaecology care survey*

Feedback from interviews with non-specialist gynaecologists aligned with these figures showing that they were most frequently either unsure of the implementation of NICE guideline or felt it was being somewhat implemented, but not fully. Those that felt the NICE guideline was not fully implemented often put this down to resourcing constraints.

*“The guidelines are based on an ideal world, where we don’t have to wait for scans or laparoscopies. They are gold standards but are not always practical “*

**Healthcare professional: non-specialist gynaecologist (interview)**

The above quote talks of NICE guidelines as ‘gold standard’, whereas from a patient perspective they may be considered as the baseline, or minimum standard, expected.

Access to specialists and specialist services as outlined in the NICE guideline varied across health boards, and in particular, whether there was an endometriosis specialist centre present within the health board. Non-specialist gynaecologists based in health boards with a specialist centre reported finding it easier to access and communicate with these services. Healthcare professionals also explained that it was difficult for more rural areas to access these services because they often would not have an endometriosis specialist or someone with an interest in endometriosis in-house. Funding for patients to attend an endometriosis specialist centre was found to be an issue, especially where they were in a different Health Board.



*“Edinburgh [specialist centre] denied the last patient [I referred] because they were full or they were returned as they were unable to be funded.”*

*“The pressures that we have are treating people locally and length of wait and also budget pressures; pressures to keep to budget. The more we refer out of hospital, the higher your budget, [if we kept doing this, it] would become unsustainable for Edinburgh and ourselves”*

*“I’m a bit spoilt because I work in the unit where the endometriosis centre is for the West of Scotland. [It’s] easy to get an opinion in place”*

**Healthcare professional: non-specialist gynaecology (interview)**

Primary healthcare practitioners generally reported that they didn’t think their services were able to apply the guidelines well. One primary care practitioner explained that they were not aware of the detail in the NICE guideline as they did not feel it was relevant. In particular, they explained that lack of accessible local services meant the guideline could not be applied.

*“To a certain extent, guidelines are irrelevant if I don’t have the local service. I’ve only got what I’ve got.”*

**Healthcare professional: pain management service staff member (interview)**

## 6.3 Gap analysis

Below is an outline of key sections of the NICE guideline which are not currently implemented. This explanation follows the structure and numbering of the NICE guideline to help make it clear which elements of the guideline are being discussed.

(Paragraph numbers from [NICE guideline NG73 – Endometriosis: diagnosis and management](#))

### 1.1 Organisation of care

1.1.1: The NICE guideline specifies that there should be *“a managed clinical network for women with suspected or confirmed endometriosis, consisting of community services, gynaecology services and specialist endometriosis services.”* This is not currently implemented across Scotland. Primary care, secondary care and tertiary care staff spoke of the disconnect between services and the difficulty that this caused in knowing when to refer patients. A managed clinical network would support healthcare practitioners to overcome these difficulties in communication.

1.1.2: The guideline also explains that *“community, gynaecology and specialist endometriosis services should... have processes in place for prompt diagnosis and treatment of endometriosis, because delays can affect quality of life and result in disease progression”*. Prompt diagnosis is clearly not implemented given the average waiting time for diagnosis is 8.5 years in Scotland.

1.1.3: The guideline states that *“gynaecology services for women with suspected or confirmed endometriosis should have access to a gynaecologist with expertise in diagnosing and managing endometriosis, including training and skills in laparoscopic surgery; a gynaecology specialist nurse with expertise in endometriosis; a multidisciplinary pain management service; a healthcare professional with an interest in gynaecological imaging; fertility services.*

There was no evidence that this has been systematically, if at all, implemented in general gynaecology services. For example, there were no specialist nurses with expertise in endometriosis referred to outside of specialist endometriosis centres. Secondary care healthcare practitioners explained that the ability to implement this aspect of the guideline is influenced by location, with a view that it was harder to recruit gynaecologists with a specialist interest in endometriosis in rural areas.

1.1.4: The endometriosis specialist centres are mostly meeting the requirements of practitioners that they should have in post that are stated in the guideline. However, some

posts are still being filled e.g. in Greater Glasgow and Clyde the multidisciplinary pain management service with expertise in pelvic pain is still in development. This is to be expected with newer endometriosis specialist centres, however it is important to ensure that these services are able to fulfil the guideline. Equally, it is important to ensure that specialist centres are available to all those in Scotland that need them, not just patients in the area the centre is located.

## 1.2 Endometriosis information and support

1.2.3: The guideline states:

*Provide information and support for women with suspected or confirmed endometriosis, which should include:*

- *what endometriosis is*
- *endometriosis symptoms and signs*
- *how endometriosis is diagnosed*
- *treatment options*
- *local support groups, online forums and national charities, and how to access them.*

The majority of patients (73%) report that they did not receive written information on endometriosis when they were diagnosed. Anecdotally, many reported being given no information or advice at all, and for those that were ‘I was told to go home and google it’ a common comment. Given the impact of covid and virtual appointments, the need for effective signposting to appropriate online content and how to communicate this should also be considered. Many of the GPs that were interviewed were aware of Endometriosis UK (possibly as recruited via the Endometriosis UK webinar), however, were not aware of any local support groups. This means that they would be unable to link endometriosis patients into local support, where it is available.

## 1.3 Endometriosis symptoms and signs

1.3.1: The guideline states that healthcare practitioners should “*suspect endometriosis in women presenting with 1 or more of the following symptoms or signs: chronic pelvic pain; period-related pain (dysmenorrhoea) affecting daily activities and quality of life; deep pain during or after sexual intercourse; period-related or cyclical gastrointestinal symptoms, in particular, painful bowel movements; period-related or cyclical urinary symptoms, in particular, blood in the urine or pain passing urine; infertility in association with 1 or more of the above.*”

In the primary care webinar poll 86% of primary care staff selected “difficulty identifying

symptoms that overlap with other conditions” as the main barrier to diagnosing patients with endometriosis (see Figure 18). This, alongside the long times for diagnosis and multiple visits with symptoms prior to diagnosis, demonstrates that there is not currently a clear link from presentation of these symptoms to a suspicion of endometriosis.

1.3.2: Practitioners are asked to *“inform women with suspected or confirmed endometriosis that keeping a pain and symptom diary can aid discussion”*. This was not mentioned by any of the healthcare practitioners interviewed throughout this research project when asked about the processes of diagnosis, referral and treatment. This is a relatively simple element of the NICE guideline to implement, suggesting there should be awareness raising amongst healthcare practitioners that asking patients to keep a pain diary should be part of the approach to diagnosis and managing endometriosis. It is possible that this does happen in some cases, however it was not mentioned in interviews.

#### **1.4 Referral for women with suspected or confirmed endometriosis**

1.4.1: This section explains that patients should be referred to gynaecology services if *“they have severe, persistent or recurrent symptoms of endometriosis; they have pelvic signs of endometriosis; or initial management is not effective, not tolerated or is contraindicated.”* With many patients having multiple GP, hospital and/or A&E visits with symptoms but prior to diagnosis of endometriosis, and the lengthy diagnosis times many report, it indicates this is not consistently happening.

1.4.2: This section of the guideline states that patients should be referred to a specialist endometriosis centre *“if they have suspected or confirmed deep endometriosis involving the bowel, bladder or ureter.”* This is not happening equally across Scotland. Regional differences are of importance when it comes to who refers patients onto specialist centres. Gynaecology services in more rural areas explained that it is not as simple to refer a patient to the endometriosis specialist centres, including due to concerns they perceive about the cost of accessing these services. It is important that specialist endometriosis centre funding is provided to ensure all patients across Scotland who need to can access endometriosis specialist centres, irrespective of if they live in an area in which the specialist centres are located.

## 1.5 Diagnosing endometriosis

This section of the diagnosis includes *“consider laparoscopy to diagnose endometriosis in women with suspected endometriosis, even if the ultrasound was normal ..... during a diagnostic laparoscopy, a gynaecologist with training and skills in laparoscopic surgery for endometriosis should perform a systematic inspection of the pelvis.”* Assessment of the pelvis for endometriosis at laparoscopy is part of routine O&G training (see RCOG curriculum). Those undertaking diagnostic laparoscopic surgery for endometriosis should be supported to develop their skills and experience to recognise and effectively treat those with endometriosis, including keeping up to date with latest best practice and techniques.

### 1.10 Surgical management

1.10.1 The guideline states that healthcare practitioners should *“ask women with suspected or confirmed endometriosis about their symptoms, preferences and priorities with respect to pain and fertility, to guide surgical decision making”*. From those interviewed, practitioners in secondary and tertiary care do ask patients about their symptoms, preferences, and priorities and although this information does guide surgical decision making, there are other factors at play. In particular, the length of waiting times for laparoscopies means some people will try alternative methods of management.

### 1.11 Surgical management if fertility is a priority

The guideline states that *“management of endometriosis-related subfertility should have multidisciplinary involvement with input from a fertility specialist.”* However, only 50% of patients were asked by a medical practitioner if fertility was important to them, as part of their endometriosis diagnosis or treatment.<sup>24</sup>

### Gaps in the NICE guideline

Endometriosis UK has identified areas not covered in the NICE guideline but of importance to patients. The two most significant are:

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<sup>24</sup> Endometriosis APPG report, Endometriosis in the UK: Time For Change, 2020, <https://www.endometriosis-uk.org/sites/endometriosis-uk.org/files/files/Endometriosis%20APPG%20Report%20Oct%202020.pdf>

- Non-pharmacological pain management. Endometriosis is recognised as a chronic pain condition, however there is nothing in the guideline on non-pharmacological pain management, for example pelvic physio, acupuncture.
- Endometriosis outside the pelvic cavity. The NICE guideline refers to endometriosis within the pelvic cavity. Up to 10% of those with endometriosis are believed to have endometriosis outside the pelvic cavity, such as the diaphragm and lungs. It is recommended that pathways are to rectify this, starting with diaphragmatic and thoracic endometriosis.

## 6.4 Barriers to implementation of the guideline

Our research identified four key barriers to implementing the NICE guideline: perceived relevance, access to endometriosis specialists, lack of resources, and connections to other services. Note that these primarily apply to primary and secondary care, given endometriosis specialist centres mainly felt they were implementing the guideline.

**Perceived relevance:** Some healthcare professionals supporting patients with endometriosis felt that the NICE guideline on endometriosis was not of relevance to them. Reasons for this included feeling that the NICE guideline was targeted at practices based in England and not having the resources to implement the guidelines (explored further below). It is important to note, that practitioners did not feel that the guideline could not be relevant to them, it was that they felt the guideline was not written with their circumstances in mind.

*“First of all, NICE guidelines do not hold much clout North of the border...[NICE guidelines are] more England based... and have a big focus on interventions”*

**Healthcare professional: pain management service staff member (interview)**

Additionally, it was felt by some that the NICE guideline was designed for endometriosis specialist centres rather than being focused on primary or secondary care. The guideline was also considered to miss out relevant information for pain management services by focusing on the diagnosis of endometriosis and not considering the bio-psychosocial elements of the condition. Therefore it is important that practitioners are supported to know which elements of the guideline are most relevant to them.

*“To be honest when I read [the guideline] I didn’t feel [it was] aimed at primary care, [I thought there was] far too much emphasis on endometriosis specialists... It seemed much more about specialist advice, rather than basic things.*

**Healthcare professional: non-specialist gynaecologist (interview)**

*“The flow chart NICE has come up with for endometriosis is probably more to do with diagnosis, before they come to me, I get patients who have been diagnosed and have seen secondary gynaecology. [The guideline is] not specifically looking at bio psychosocial which is where we are going.”*

**Healthcare professional: pain management service staff member (interview)**

**Access to endometriosis specialists:** Access to endometriosis specialist centres or endometriosis specialists outside of the centres was reported as another important barrier to implementing the NICE guideline on endometriosis. For non-specialist gynaecologists who were easily able to refer onto an endometriosis specialist centre the implementation of the NICE guideline seemed easier. However, for non-specialist gynaecologists without a specialist centre in their health board, or for those who did not have strong established relationships with a specialist centre this was made more difficult. Lack of funding for those without a specialist centre in their health board was also identified.

*“When I read them, I just felt they were too London centric. [There are] lots of endometriosis centres in London. If you look at the map, there is loads of centres [gynaecologists] can refer to that are up and running, it’s missing what was happening in the rest of the country... [In Scotland] there is a huge geography for patients to travel to centres.”*

**Healthcare professional: non-specialist gynaecologist (interview)**

*“Edinburgh [specialist centre] denied the last patient [I referred] because they were full or they were returned as they were unable to be funded.”*

**Healthcare professional: primary care practitioner (interview)**



Additionally, non-specialist gynaecologists explained that the implementation of the guideline within their services was made more difficult due to not having an endometriosis specialist in-house.

*“I think [the guideline is] quite general, I’ve read them fairly recently, [we are] as compliant as we can be. The main constraints are not having an endometriosis specialist in house and there is [a specialist] service we can refer eligible [patients] to but it’s not that widely available.”*

**Healthcare professional: non-specialist gynaecologist (interview)**

Primary care practitioners also highlighted the cost implication of travelling to specialist centres making them less accessible for certain patients.

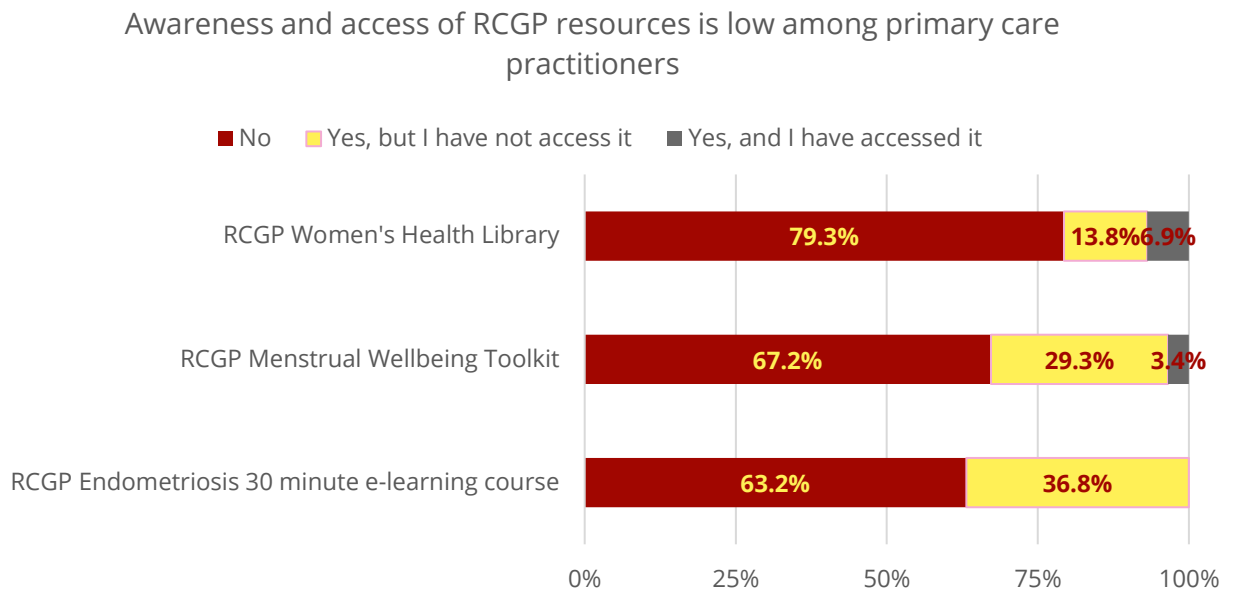
*“[There is] huge cost of travel to tertiary care centres [making it] prohibitive of allowing GPs to make referrals. [It costs around] £600 to get to Aberdeen.”*

**Healthcare professional: primary care practitioner (interview)**

**Lack of resources:** Lack of resources and lack of awareness of existing resources were both raised as issues. There were low levels of awareness of educational resources amongst primary care practitioners. Practitioners were asked about their awareness of and access to three resources:

- **RCGP Endometriosis 30 minute e-learning course:** Of those surveyed, none of the primary care practitioners had accessed the RCPH Endometriosis 30 minute e-learning course. 37% were aware of the course, but had not accessed it and 63% were not aware.
- **RCGP Women’s Health Library:** Primary care practitioners were most likely to have accessed the RCPG Women’s Health Library of the three resources at 7%. However 79.3% of respondents were not aware of this resource.
- **RCGP Menstrual Wellbeing Toolkit:** Approximately two thirds had not heard of the RCPG Menstrual Wellbeing Toolkit (67%). Almost one third had heard of it but not accessed it (29%) and just 3% had accessed it.

**Figure 34: Primary care survey on awareness of educational resources**



*The table above uses data from the primary care survey*

**Connections to other services:** Healthcare professionals reported that one of the main challenges in trying to implement the NICE guideline on endometriosis was meeting the requirement to set up a managed clinical network consisting of community services, gynaecology services and specialist endometriosis services. They explain that this was difficult because of the number of different disconnected services that had to act in unison with each other for the guideline to be fully met. For example, for a patient journey to run smoothly, they would have to be referred by their GP in a timely manner, to either to a non-specialist gynaecologist in secondary or a specialist centre if complex endometriosis suspected. If seen in non-specialist gynaecology, there may need to be a further referral on to a specialist centre. Receiving the correct diagnosis and management in a timely manner would be dependent on length of time to recognition of symptoms, length of time to referral(s) and existing waiting lists. The potentially multiple practitioners involved in primary, secondary and tertiary care highlights that support is needed to set up managed clinical networks.

*“I’m aware of them and do know about them. Having them there is great, [but it’s] hard to match your services to the advice in them for reasons like waiting lists and when patients are referred”*

**Healthcare professional: pain management service staff member (interview)**

## 7. Recommendations to improve service provision for endometriosis

There were four key recommendations for increasing awareness of the NICE guideline and bringing service provision closer to the recommendations it sets out:

1. implementing the NICE guideline
2. facilitating relationship development between healthcare services
3. increasing education at a primary and secondary care level
4. investing in school education and a public health campaign to increase awareness.

**Ensure the NICE Guideline (NG73) and Quality Standards (QS 172) on endometriosis are implemented consistently across Scotland:** We found that the base level of care for endometriosis as outlined in the NICE guideline is not currently being met.

Areas that need implementation and would support overcoming the barriers identified include, but are not limited to, the following areas of the NICE Guideline:

- All areas to have a managed clinical network to coordinate endometriosis care.
- All with suspected or confirmed endometriosis having access to:
  - a gynaecologist with expertise in diagnosing and managing endometriosis, including training and skills in laparoscopic surgery. Developing the role and appointing a Gynaecologist with a Special Interest in Endometriosis in all general gynaecology departments is vital to support those with endometriosis seen in general gynaecology
  - a gynaecology specialist nurse with expertise in endometriosis (endometriosis specialist nurse)
  - a healthcare practitioner with an interest in gynaecological imaging
  - a multidisciplinary pain management service
  - fertility services, for those who require them
- Provide information and support for women with suspected or confirmed endometriosis.
- Ensure all with suspected or confirmed deep endometriosis are referred to a specialist centre.

The Quality Standards should be used to support implementation of the Guideline. Integral to implementing the NICE guideline is ensuring appropriate funding for the specialist

endometriosis centres to provide their service for the whole of Scotland, enabling appropriate access for patients than need it wherever they live in Scotland.

It is also recommended that the following gaps in the NICE guideline are recognised and pathways developed for:

- Non-pharmacological pain management.
- Endometriosis outside the pelvic cavity, starting with thoracic endometriosis.

**Increase education on endometriosis to all healthcare professionals, at a primary and secondary care level:** As highlighted in both the NICE guideline and Quality Standards, endometriosis symptoms should be recognised by all healthcare practitioners, and endometriosis to be suspected with one or more of the symptoms, including in adolescents.

Amongst endometriosis specialists and non-specialist gynaecologists it was felt that the main issues relating to implementing the NICE guideline started within primary care. Therefore, tackling this lack of knowledge about endometriosis, symptoms and the NICE guideline and quality standards amongst GPs is key to ensuring that the guideline is implemented more broadly. The more GPs are aware of signs and symptoms of endometriosis, the more effectively they will be able to refer patients into relevant services.

*“People who need to know about all of this are probably primary care because they are referrers into the service”*

**Healthcare professional: pain management service staff member (interview)**

Importantly, GPs themselves were in favour of more education and training and explained that running sessions would be a productive and efficient method of increasing knowledge. For those that are not formally trained in obstetrics and gynaecology, training sessions were considered to be the main place from which GPs would source information.

*“Most GPs will target their CPD due to seeing what is going on in current practice and where there might be knowledge gaps. Something as simple as doing learning module or attending a course can alter someone’s practice or awareness of endometriosis. For the average GP rather than someone who has done significant work in gynaecology, that is likely to be more where [their information] comes from.”*

**Healthcare professional: primary care practitioner (interview)**

Suggestions of how this education could be delivered included lecture-based learning, seminars or dynamic question and answer sessions between endometriosis specialists and GPs. It was considered important that GPs get something out of the education to encourage them to take part due to already busy schedules. Similarly, healthcare professionals felt that events would be more beneficial than online resources because they were more engaging. Though, there was some concern that this would only attract GPs with a prior interest in endometriosis so targeting education at GP trainees was suggested as a way to avoid this.

*“GPs need more education in the condition, [but this is] easier said than done. [One way to do this is to], take one of us (an endometriosis specialist) to engage and provide some education, provide our time to speak with GPs. This is something we should do but it’s not as easy to set up.”*

**Healthcare professional: endometriosis specialist (interview)**

*“GPs are busy, [if you give them something to read] online, they will put to end of task list, if it’s an event they will probably attend”*

**Healthcare professional: endometriosis specialist (interview)**

However, it should be noted that education is also needed in secondary care, where healthcare practitioners need knowledge about endometriosis, symptoms and the NICE guideline. Only 56% of non-specialist gynaecologists felt confident they had the right skills and knowledge, 44% did not. We recommend that education should be increased for non-specialist gynaecologists to ensure every patient can access the care they need.

**Facilitate relationship development between healthcare services:** It was felt that if relationships between primary care and non-specialist gynaecologists, and non-specialist gynaecologists and endometriosis specialist centres were stronger, it would improve the provision of endometriosis diagnosis and care. Services which felt they were able to easily refer patients or discuss who a patient should be referred to, often put this down to strong and established working relationships with other healthcare professionals. There is an opportunity for this best practice to be implemented across Scotland to allow for smoother referrals for healthcare professionals and transitions between services for patients. Improved knowledge of other services and more accurate referrals will make the implementation of the

NICE guideline on endometriosis easier for healthcare professionals and more likely. The implementation of Managed Clinical Networks will facilitate this.

*“I do think that there is nothing quite to beat building up relationships between GPs, gynaecologists etc. There is a local element to it, having room for discussion, questions, pathway management etc. Lots of us read stuff and go through these things, [we] read through guidelines [and other information, but it] gets washed aside if it’s not tied in to our day to day”*

**Healthcare professional: pain management service staff member (interview)**

### **Increase public awareness by investing in a public health campaign and menstrual wellbeing**

**materials for schools:** The role of the patient was also considered important when thinking about how the NICE guideline could be implemented. Although the direct provision of healthcare is out of the patient’s control, it was felt that the more patients know about their menstrual wellbeing and endometriosis, the more they will ask about symptoms, seek help, and engage with the healthcare system to ensure that they get a diagnosis and are being delivered the right care. Healthcare professionals felt people knowing more about the signs and symptoms of endometriosis could help understand and distinguish between ‘normal’ period pain, and pelvic pain which could be due to endometriosis (or another menstrual condition), and that this was especially important for adolescents and young adults. The importance of providing appropriate education was identified, as we educating school nurses.

*“Maybe something educationally for school nurses in terms of how they can educate kids. Sex education shouldn’t just be sex education, it should be general gynaecology, bladder, bowel etc. with a sex element. [Sex education] takes away from the fact that no one has any idea about this part of their body... that education side is completely missing. [Young people knowing] what’s normal for periods etc. is tied in with recognising when things aren’t normal [and as such being able to recognise endometriosis.”*

**Healthcare professional: pain management service staff member (interview)**

A public health campaign would also reduce the risk that patients would find information on endometriosis from unreliable sources. As well as patients, it is important that awareness is raised amongst other members of the public, for example families and employers. By developing a society in which endometriosis is known about commonly, people are more likely

to consider it as something they may be experiencing, and are less likely to be disregarded when they bring it up as a potential diagnosis.

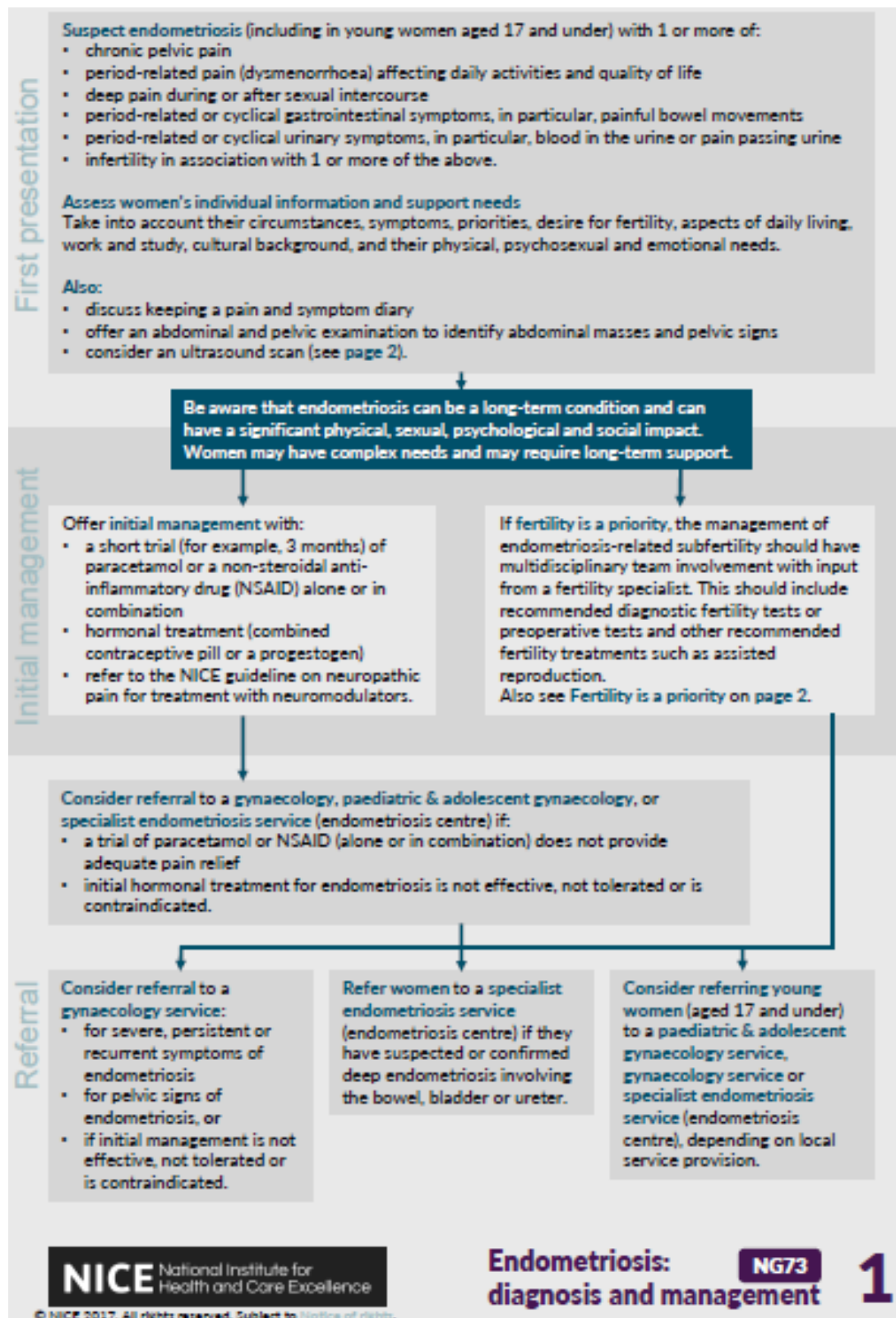
*“Patients [should be] encouraged to look at them and be aware... When I ask [patients] what they’ve read, they say they read on social media. I would bet most of them hadn’t read the NICE guideline.”*

**Healthcare professional: non-specialist gynaecologist (interview)**

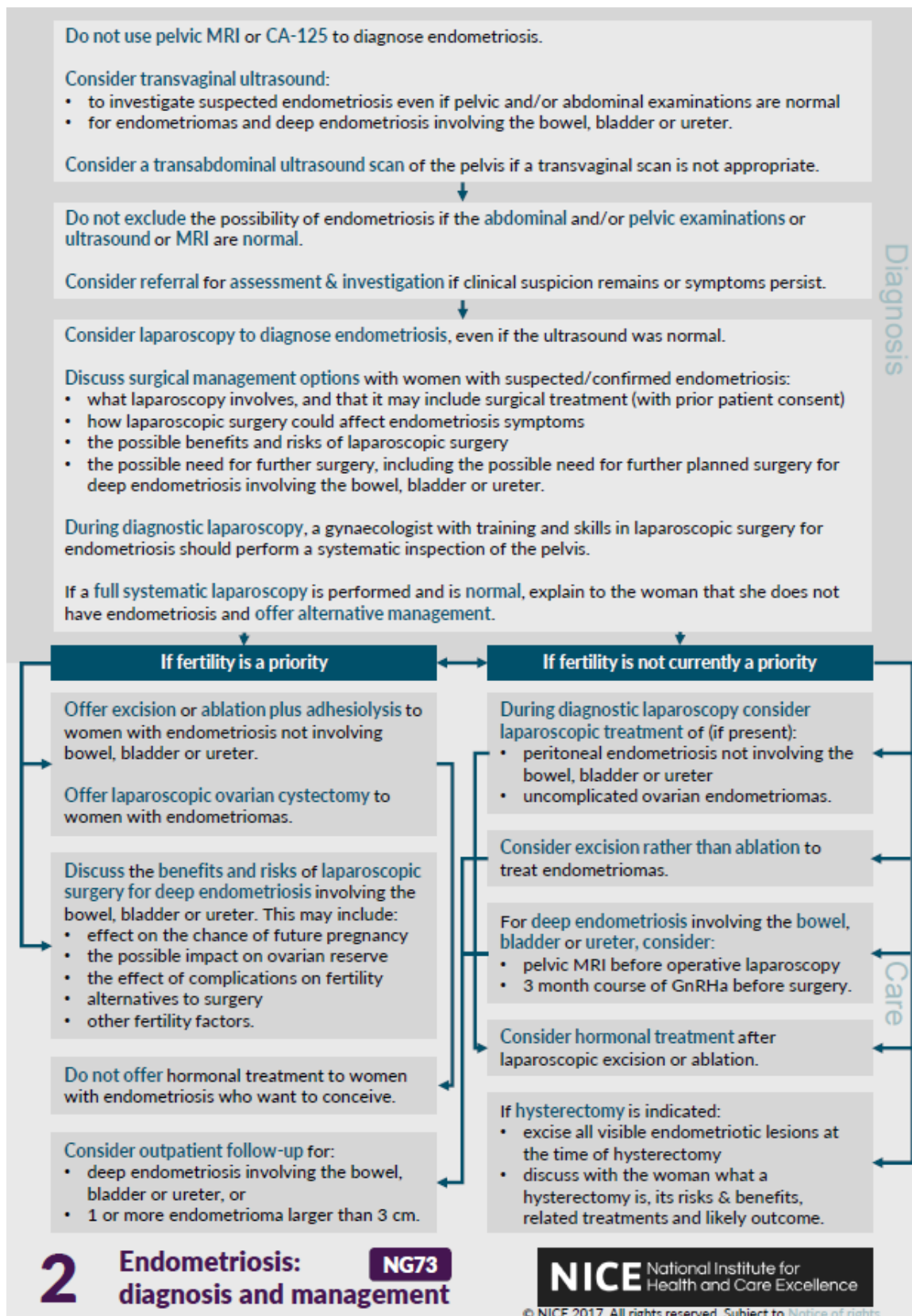
*“I’d be thinking about... a focus on improving patient awareness; encouraging people who have got symptoms to actually ask their GPs “could this be endometriosis?”... I don’t think that is something that I’ve particularly seen in the way that we have seen it about cancer or strokes. I’d wonder how much infertility might be preventable if patients were presenting at earlier stages.”*

**Healthcare professional: primary care practitioner (interview)**

# Appendix 1 – NICE Guideline - Algorithm for diagnosing & managing endometriosis







<https://www.nice.org.uk/guidance/ng73/resources/algorithm-for-diagnosing-and-managing-endometriosis-pdf-4595719645>