

Accepted Manuscript

British Journal of General Practice

Navigating possible endometriosis in primary care: a qualitative study of GP perspectives

Dixon, Sharon; McNiven, Abigail; Talbot, Amelia; Hinton, Lisa

DOI: <https://doi.org/10.3399/BJGP.2021.0030>

To access the most recent version of this article, please click the DOI URL in the line above.

Received 13 January 2021

Revised 19 March 2021

Accepted 24 March 2021

© 2021 The Author(s). This is an Open Access article distributed under the terms of the Creative Commons Attribution 4.0 License (<http://creativecommons.org/licenses/by/4.0/>). Published by British Journal of General Practice. For editorial process and policies, see: <https://bjgp.org/authors/bjgp-editorial-process-and-policies>

When citing this article please include the DOI provided above.

Author Accepted Manuscript

This is an 'author accepted manuscript': a manuscript that has been accepted for publication in British Journal of General Practice, but which has not yet undergone subediting, typesetting, or correction. Errors discovered and corrected during this process may materially alter the content of this manuscript, and the latest published version (the Version of Record) should be used in preference to any preceding versions

Title:

Navigating possible endometriosis in primary care: a qualitative study of GP perspectives

Authors:

Sharon Dixon (corresponding author) GP and researcher, BA (Hons Cantab), MBBS, MRCP, MSc¹, Abigail McNiven qualitative researcher BA (Hons) Dunelm, MA Dunelm, PhD (Dunelm)¹, Amelia Talbot Rosamund Snow DPhil researcher, BA(hons), MA¹, Lisa Hinton, Senior Research Associate, (BA(Hons Cantab) DPhil²

1=Nuffield Department of Primary Care Health Sciences, University of Oxford
Radcliffe Primary Care Building, Radcliffe Observatory Quarter, Woodstock Rd, Oxford OX2
6GG

2= The Healthcare Improvement Studies Institute (THIS Institute), University of
Cambridge. THIS Institute is supported by the Health Foundation, an independent charity
committed to bringing about better health and healthcare for people in the UK.

Address for correspondence: Sharon.dixon@phc.ox.ac.uk

Accepted Manuscript – BJJ

Title: Navigating possible endometriosis in primary care: a qualitative study of GP perspectives

Abstract:

Background: Endometriosis affects approximately 10% of women, with well-documented delays between initial presentation with symptoms and diagnosis. In England, women typically seek help first in primary care, making this setting pivotal in women's pathways to diagnosis and treatment. English General Practitioner (GP) perspectives on managing possible endometriosis have not been previously reported.

Aim: To explore what GPs identify as important considerations when caring for women with symptoms that raise the possibility of endometriosis.

Design and Setting: English primary care.

Method: Semi-structured scenario-based telephone interviews with 42 GPs based around a fictional scenario of a woman presenting to primary care with symptoms suggesting possible endometriosis. Interviews were thematically coded and analysed.

Results: Managing possible endometriosis in primary care brings challenges. While knowledge and awareness were pre-requisites for considering endometriosis, other important considerations were raised. Symptoms suggestive of endometriosis are non-specific, making endometriosis one possible consideration of many. GPs move through a diagnostic hierarchy to exclude sinister causes and utilise trials of treatment as both therapeutic interventions and diagnostic tools – processes which take time.

An endometriosis label or diagnosis has advantages and risks. GPs reported sharing decisions about investigation and referral whilst holding women's priorities as pivotal. These conversations were underpinned by their knowledge of uncertainties and unknowns, including the wide spectrum and unpredictability of endometriosis.

Conclusion: GPs considerations are more complex than simply lacking awareness. The unknowns surrounding endometriosis matter to GPs. Further research and tailored resources for primary care, where women present with undifferentiated symptoms, are needed.

Keywords: Endometriosis, Qualitative Research, Dysmenorrhea, Primary Care.

What is known and what does this add?

There are documented time lags between women presenting to primary care with symptoms suggesting endometriosis and receiving a diagnosis. It has been suggested that increasing GPs awareness will improve this situation. As GPs perspectives on these care journeys are not known, how best to educate health professionals to reduce delays in diagnosis is unclear. Even with awareness of the possibility of endometriosis, GP accounts suggest that journeys are complex and can involve navigating significant uncertainties, including when managing women whose symptoms are well controlled with primary care treatment or who do not want to have referral or operative investigation.

Introduction:

Endometriosis is the abnormal presence of endometrial tissue outside the uterus¹. Although the true prevalence is unknown, estimates suggest it affects approximately 6-10% of women of reproductive age^{2,3}. Endometriosis is seen in approximately 50% of women who present with sub-fertility and women who live with chronic pelvic pain^{2,3}. Endometriosis is definitively diagnosed in secondary care by surgical laparoscopy², a procedure associated with risks⁴. But the route to diagnosis usually starts in primary care with initial symptom assessment and possible referral. General practitioners (GPs) hold the care for women with endometriosis throughout their life-course, including during periods of involvement with specialist services and beyond.

Women face significant and well-documented delays between their first visit to a doctor about symptoms and receiving a diagnosis of endometriosis⁵⁻⁹. These delays can be associated with debilitating symptoms and worry^{5,10} and with increased healthcare costs⁹⁻¹¹. Retrospective case studies demonstrate a time lag between women presenting to a GP with symptoms and being given a diagnosis of endometriosis^{7,8}. Whilst these studies can reveal consulting patterns about symptoms prior to diagnosis that might suggest endometriosis⁷⁻¹⁰, they do not provide insights into the deliberative processes in primary care that might help account for these documented delays; a knowledge gap this study sought to address.

It has been suggested that increased GP awareness and knowledge are needed to address these documented delays in diagnosis^{7,8,10,12}. The 2017 James Lind Alliance Priority Setting Partnership identified the need to understand how to effectively educate health professionals to reduce times to diagnosis and improve care for women with endometriosis as one of their top three research priorities¹³. By developing an understanding of how GPs approach the management of women with symptoms suggesting possible endometriosis, we aimed to identify ways to support these care journeys in primary care. These insights can support the development of resources and education tailored for primary care and which evolve beyond a simple call for increased awareness.

Methods:

Study Design:

A qualitative study was conducted using semi-structured telephone interviews based around a fictional scenario about a woman presenting to primary care with symptoms suggesting possible endometriosis (**Box 1**). We used a fictional scenario to create an arena for GPs to consider responses to possible issues they might face¹⁴. The scenario was co-developed with input from primary care (two GPs), a gynaecologist, and Public and Patient Involvement (PPI).

Box 1:

Sampling and recruitment:

With the support of the NIHR Local Clinical Research Network (LCRN) teams, we recruited GPs in five LCRN regions: Thames Valley and South Midlands, East Midlands, South West Peninsula, Greater Manchester, and North-West Coast. These were selected aiming for a mixture of urban and rural settings, and areas with varied access to secondary and tertiary care and to support a sample as close to the real-world situation as possible. The sample comprised of 42 GPs (19 male, 23 female). Recruitment was enhanced through snowballing.

Data collection and analysis: Telephone interviews were conducted by SD (GP and researcher) between April 2019 and January 2020.

With consent, interviews were audio-recorded and transcribed verbatim. Field notes were taken which informed analysis if participants chose not to be recorded (1GP). A coding framework was iteratively developed in NVivo12 based on expected and emergent themes and analysed thematically¹⁵ using mind-mapping techniques¹⁶. All authors contributed to data analysis.

How our findings could be best represented and utilised was reviewed with: (i) an expert stakeholder panel comprising two gynaecologists with expertise in endometriosis and two GPs, and (ii) ten PPI collaborators with lived experience of endometriosis, primarily recruited via the Royal College of Obstetricians and Gynaecologists Women's Voices Network. With our PPI collaborators, we co-developed some practical tips based on our findings for GPs to consider when caring for women with possible endometriosis (Box 2).

Results:

We use the patient journey through primary care to present our analysis under the following thematic headings:

- (i) Managing the initial consultation(s)**
 - **Introducing the possibility of endometriosis**
- (ii) Decisions about investigation and referral**
 - **Value of a diagnostic label**
 - **GP explanations for delays in diagnosis/the journey to diagnosis**
- (iii) The long-term/enduring role(s) of primary care**

(i) Managing the initial consultation(s)

In our scenario, "Alice" presented with symptoms that had not been previously assessed, investigated, or diagnosed. For the GP, navigating the wide range of possible explanations for Alice's symptoms was the first stage on the journey from symptom evaluation to considering possible diagnoses. This was a complex process of working through a clinical hierarchy, where possible "red flags" needed to be evaluated and excluded before other diagnoses (including endometriosis) could be brought into active consideration.

Always as a GP, we're terrified of missing something horrible, so you think about red flags.
(GP30)

In parallel with considering possible explanations for Alice's symptoms, GPs reflected that endometriosis can present in multiple ways, with a wide range of possible gynaecological and non-gynaecological symptoms. This clinical inconsistency and unpredictability presented GPs with added complexity during the initial evaluation.

The symptoms can be very vague, from simple chronic pain, pelvic pain to pain related to periods, dysmenorrhoea to dyspareunia, bowel problems, chronic fatigue, other symptoms and consequences such as infertility, So the presentations are very different and that makes it challenging. And obviously you still have to consider a lot of diagnoses when you have a patient presenting in front of you. (GP26)

GPs initial assessment included exploring any medications Alice had tried already and the impact of her symptoms on her emotional well-being and social functioning. This included exploring her expectations of the consultation, for example symptom control, diagnosis, or addressing specific concerns such as fertility or fear of malignancy.

Because endometriosis is not a diagnosis that can be made in primary care, the tests GPs ordered were predominantly to rule out other potential causes.

Introducing the possibility of endometriosis

GPs reflected on how and when they might introduce endometriosis as a potential cause for Alice's symptoms during the clinical journey from symptoms presentation to investigations and/or treatment.

If there's something quite clear in the history that put endometriosis at the top of my list, then I might float it as a possible, yes. But I'd have to be quite sure that that was what's going on. (GP27)

Several GPs felt they were unlikely to raise endometriosis as a possible diagnosis during the first consultation. They described waiting to assess the impacts of treatments or until they judged that it was an appropriate moment, having developed a trusting relationship with Alice.

It can help sometimes if you build up a bit of a relationship. [...] They might not want to tell you the first time they meet you that they're actually having really painful sex, and they might be quite worried about that. Or they might not want to open up to you about that, but maybe once you've seen them once or twice, they might say. (GP21)

Some GPs described their caution, concerned that by mentioning the word 'endometriosis' patients risked being adversely affected by researching and worrying about the potential consequences of endometriosis (for example regarding fertility), when they might not have this diagnosis at all.

You're going to keep it generalised because you don't want people to go away worrying that it's X, Y or Z, when actually at that point you might not know. (GP33)

Some worried that once endometriosis was mentioned, GPs would feel pressure to "follow through" and refer to secondary care for a diagnosis to remove uncertainty.

When I start that conversation, then I should be prepared to refer her for further investigations. Now, if I don't do that, I think I would be in a very difficult situation having raised that diagnosis. (GP41)

Others felt raising endometriosis as a possibility offered a doorway to an open conversation which could enable women to respond to emerging or evolving symptoms, or about potential risks and benefits of referral.

“I’m only mentioning it so you know I’d thought of it, and so that you know what to watch out for.” (GP42)

GPs described a range of strategies including introducing endometriosis as one possibility within a list of potential diagnoses or creating opportunities for the woman to raise endometriosis first. Sharing and discussing their thinking helped GPs ensure the patient understood what tests they were going for and why.

Many felt that resources based on symptoms which offered balanced, accurate information that they could confidently signpost women to at this pre-diagnosis stage would help them with these conversations.

ii) Decisions about investigation and referral

GPs described how women’s priorities were paramount when navigating and discussing treatment, investigation and referral decisions. For example, if Alice wanted contraception then hormonal therapy would be appropriate to offer, but this would usually not be the case if she wanted help because of fertility concerns.

Several described using trials of treatment (either prior to or in parallel with referral), usually with hormonal treatments (including contraceptive pills or the intrauterine system), as both a therapeutic intervention and one which could add information to the diagnostic process. To be effective in this way, these trials of treatment needed to be underpinned by continuity of care (ideally) and supported by effective communication both with the patient and any other clinicians who might see her at subsequent consultations.

You have to really try and positively engage the patient to come back and really convince them that you want them to come back. Because you know if you give them a three-month trial of treatment, it doesn’t help, and they think ‘Well nothing really happened last time, I’m not bothered, I’m going to leave it six months, and then I’m going to come back’, the years slip so quickly in that kind of time scale. (GP39)

Referral was straightforward in some situations including if there were concerns about fertility (including established sub-fertility), severe symptoms that could not be adequately controlled with treatment available in primary care, symptoms suggesting extra-pelvic spread of endometriosis, and when the woman asked for referral for specialist care or a diagnosis.

Some GPs felt that all women with possible endometriosis should have referral offered. However, GPs also described how they approached caring for women whose symptoms were well-controlled with primary care treatments or who said they did not want a referral to hospital. This would be a shared decision with the woman where she was offered choice.

It is very much led by [...] do they want to actually find out the underlying cause, or do they just want to treat the symptoms; it’s very much dependent on them. (GP22)

GPs were mindful that diagnosis requires an invasive procedure, and that laparoscopies have potential risks, including pelvic pain and adhesions.

The only way you can really make it is with a laparoscopy and you don’t really want to put a woman through that unless you’ve reached the absolute end of the road. (GP6)

Several GPs described experiences where referral into secondary care had resulted in the specialist electing to focus on symptom management, rather than undertaking any investigation to seek a diagnosis, which they could have done themselves in primary care. This could influence GPs expectations and approach to referral decisions.

Sometimes they're just discharged, aren't they, with their oral contraceptive pill and I think they're just a bit like, "Well my GP could have done that." And I think sometimes GPs will feel 'well can't we just put them on the pill and then it'll be what they were going to treat them with anyway'. (GP3)

Value of a diagnostic label

GPs were largely supportive of the value of a diagnosis and identified its benefits for informing both current and future management (Figure 1). These included support for informed shared decision making, offering access to specialist advice and treatment, and as a framework to support on-going care needs, including new or emergent symptoms or concerns.

Figure 1. GP perspectives on what a diagnosis can enable.

However, the recognition of significant unknowns and uncertainties underpinned many GPs approach to treatment and pursuit of a diagnosis. These included the variability of women's experiences of endometriosis, the unpredictability of clinical sequelae, and whether a timely diagnosis would change treatment, prevent or reduce future complications.

GPs were aware of the wide spectrum of symptoms and impacts of endometriosis, including the extent to which the endometriosis might be correlated, or not, with future fertility. Knowledge of this uncertainty shaped how they tailored their advice to individual patients. This included uncertainty when caring for women who had been incidentally diagnosed with endometriosis in the course of other investigations.

Often you find spots of endometriosis and actually how much have you really helped someone in that situation? They've got a diagnosis, they've got worry, they know that they've got an increased risk of infertility possibly, of course data, it's not necessarily applying quite as well to them if they've got a couple of spots. (GP10)

When primary care treatment could not effectively manage Alice's symptoms or concerns, this was considered clear grounds for onwards referral. However, if primary care treatment effectively managed her symptoms, whether further action was necessary or appropriate was an uncertainty reflected on by many GPs, and an area where they wished for guidance.

Am I reassured that even the pill will defer their endometriosis? I don't know the answer to that really. So, if it [endometriosis] was busy doing it's dastardly deed despite the pill, then... (GP42)

While GPs told us that they would "never stand in the way" of a woman who wanted a diagnosis, some cautioned that having a diagnosis might not address all of her questions or concerns.

Sometimes it's a burden, well sometimes it's a freedom. [...] People can be relieved to have a name, and I guess frustrated sometimes when there's no name. But you know it goes both ways, doesn't it? Because if they start looking for information, you know there's a lot of

devastating news out there. Because it can bring about more anxiety as well. [...] Although it's a diagnosis, everyone is so different with their experience of endometriosis, it isn't really that helpful, in a way. (GP34)

In the original scenario, Alice was aged 28; we then asked GPs whether they would have different considerations if Alice was 17 when she first presented with dysmenorrhoea. GPs reflections on managing a teenage Alice included the uncertainty about what "normal" dysmenorrhoea is in adolescence, the balance between the benefits and risks of laparoscopy at this stage of life, and whether long term outcomes would be influenced by an earlier diagnosis or treatment. GPs worried about holding responsibility for Alice's fertility concerns both in adolescence and for what she might (or might not) want in her future.

If it's someone quite young, then at what point do you intervene and send them in for a laparoscopy? It might be that it can easily managed with the combined pill or something like that, the symptoms, but then you're kind of worried in the back of your mind [...] is that ultimately doing them any good? Is this endometriosis going to get worse while you're doing that? (GP27)

GP explanations for delays in diagnosis/the journey to diagnosis:

Potential explanations for the lag between presentation to primary care with symptoms and achieving diagnosis are presented in Figure 2. Some of these have already been discussed, including the need to follow a clinical hierarchy of diagnoses, the variability of the symptoms and impacts of endometriosis, concerns about laparoscopy, managing trials of treatment (as sanctioned in National Institute for Health and Care Excellence (NICE) guidance)¹⁷, and supporting women who at points in their care journey do not wish for referral, for example, if their symptoms are well controlled in primary care.

Additional explanations for delays in diagnosis included GPs lack of awareness of or familiarity with endometriosis, lack of regular or focussed education on women's health and endometriosis, and challenges when negotiating the primary care/specialist interface.

Figure 2: GP explanations for delays in diagnosis.

iii) The long-term/enduring role(s) of primary care

Moving from initial presentation to primary care with symptoms to a diagnosis of endometriosis was experienced by GPs as a longitudinal journey which required iterative appraisal of both existing and evolving symptoms and priorities. GPs identified a long-term primary care role for women with both possible and confirmed endometriosis. This included supporting women through their diagnostic journey (including whilst they were also being cared for in secondary care) and managing emergent symptoms or concerns (for example about fertility), and care needs in later life such as potential impacts of hormone replacement therapy on experiences of symptoms. While having a confirmed diagnosis could be a helpful tool to underpin this long-term role, it was not always seen as essential.

Actually, whether you call it endometriosis, to a certain extent is what you do about it maybe more important for the woman. (GP1)

GPs identified that building rapport, developing trust, and holding enduring primary care relationships were central to supporting this longitudinal care process, which could be facilitated by fostering and promoting continuity of care.

You try to set up a bit of rapport beforehand because even though they'll go to the gynaecologist and maybe get their diagnosis, even then it seems they kind of are given a treatment and discharged. (GP3)

Box 2: Tips that GPs could consider when caring for women with possible endometriosis, developed with women with lived experience of endometriosis:

Discussion:

Summary:

GP's descriptions of their assessment and support for women presenting to them with symptoms suggesting possible endometriosis reveals the complexity of this process.

GPs recounted how symptom severity, personal impacts, and clinical needs associated with symptoms could vary widely, both between individual patients and throughout their life-course. While a diagnosis could be helpful for both women and clinicians, acquiring one required invasive testing, necessitating careful consideration of the balance between risks and benefits. GPs sought to navigate this process by sharing decision making with women, a process complicated by the variability of endometriosis and uncertainties about the long-term impact of interventions. GPs identified potential explanations for the documented delays in diagnosis, which offer opportunities for targeted interventions. Both the GPs interviewed in the study and our PPI collaborators emphasised the value of continuity of care and developing trusting primary care relationships to support these longitudinal journeys.

Strengths and Limitations:

Strengths: This is the first study asking GPs working in England to offer their accounts for the process of evaluating and managing a woman with possible endometriosis. Presenting a scenario based on symptoms rather than a diagnosis offered insights into how GPs accounted for their decision making, including how they account for delays in diagnosis. We spoke to GPs with a range of experiences and locations, and a good balance between male and female GPs. Insights from our PPI collaborators have helped us use our research findings to co-create practical advice for GPs.

Limitations: Participating GPs knew the study was about possible endometriosis, which might have influenced their responses or decision to participate, for example if they had a pre-existing interest in endometriosis. To ensure a sample which was as representative of the GP population as possible, we recruited GPs through the Clinical Research Network and did not recruit through women's health

networks. We told GPs what the study was about because the interview was not a test of knowledge, but an exploration of how GPs used their knowledge. Our scenario was based around dysmenorrhoea, whereas endometriosis has many other potential presenting symptoms; however, this limitation was identified and discussed by GPs which helped mitigate against this. This is a qualitative study, and we do not suggest that our findings are generalisable but consider that these GP perspectives offer valuable insights in an area where there has been scant previous research.

Comparison with literature:

Retrospective studies conducted using UK primary care databases demonstrate a time lag between presentation to primary care with symptoms and receiving a diagnosis of endometriosis^{7,8}. These studies offer valuable insights into the constellations of symptoms or patterns of consultation that might suggest possible endometriosis⁷⁻¹⁰. Some conclude that increased GP awareness of these patterns of symptoms might reduce diagnostic delays^{7,8,10,12,18}.

Qualitative studies exploring women's experiences of endometriosis also call for GPs to have greater knowledge and awareness of endometriosis symptoms¹⁹⁻²² and research highlights the importance of not "normalising" menstrual pain^{5,23-24}. However, these studies arguably reflect partial samples²⁵. The majority of qualitative research reporting women's experiences of endometriosis includes participants recruited from specialist clinics or support groups, with none directly from primary care¹⁹.

Endometriosis journeys in primary care typically start with presentation of undifferentiated symptoms which could indicate (or be identified as) a number of potential conditions^{7,10}. Our study strengthens this observation and adds GPs accounts of their decision making about the diagnostic journey, including decisions about referral and investigations. Ultrasound investigation (usually negative in endometriosis) has been identified as a potential contributory factor for delays in primary care^{7,8}; however, GPs in our study were aware of this likelihood and were predominantly and knowingly referring for ultrasound to exclude other causes which could account for the (as yet undiagnosed and undifferentiated) symptoms.

A questionnaire study with Dutch GPs found that they did not consider endometriosis as the diagnostic impression from the first consultation with symptoms¹⁸. This potentially aligns with the accounts we report of a progression through the clinical hierarchy and contributes a possible explanation for this observation.

Focus groups with GPs, also in the Netherlands reported lack of knowledge and training about endometriosis was a potential barrier to referral, and also identified GPs uncertainty about the benefits of referral, notably for younger women. The study authors concluded there was a "low sense of urgency for timely diagnosis"²⁶, whereas in our study, GPs identified a number of significant advantages of having a diagnosis, for themselves and their patients, albeit underpinned by known uncertainties. While the value of continuity of care and therapeutic relationships when supporting women with endometriosis has been previously documented in work with clinicians²⁷, we did not find other studies describing how GPs characterise the process of shared decision-making in this clinical context.

Presentation with sub-fertility is likely to trigger a prompt referral by GPs has been previously described⁷ and is supported by what we report here.

There is an existing narrative in the literature on endometriosis about suppression of symptoms with hormonal treatment being identified or constructed as a potential contributory factor for delays in

diagnosis^{5,8}. Others have noted that this could represent adequate symptom suppression control with primary care treatment and identify the importance of ensuring a shared understanding of trials of treatment so that they are effectively followed up and do not result in delays⁷. This aligns with the 2017 NICE guidance on endometriosis, which advises clinicians to “consider referring women to a gynaecology service for an ultrasound or gynaecology opinion” if “[patients] 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”¹⁷. Supporting trials of treatment within a framework of shared understanding about the possibility of endometriosis, with planned proactive follow up, alongside nurturing continuity of care was identified by our PPI collaborators as an important message for GPs. We did not identify further guidance about what to do if treatment is effective in symptom management – a key area of uncertainty and reflection amongst the GPs in our study, which we are not aware has been previously documented. The GP accounts we present here suggest that although some care pathways could be characterised as delays in diagnosis when viewed retrospectively from the point of diagnosis, when viewed contemporaneously within a process of responding to evolving care needs, for example in the context of shared decision making where there is effective symptom control. These may not necessarily represent avoidable or inappropriate delays.

Implications for research and practice:

Longitudinal studies starting prospectively from symptoms are needed to develop knowledge about the likelihood of important possible outcomes associated with dysmenorrhoea, including whether treatment has any prognostic impact on these. These studies should explore whether there is variability in management or outcomes by demographic variables that might suggest potential unmet or unexplored care needs. Aligned with this, there is a pressing need for qualitative research with women and professionals to further develop an understanding of the processes of seeking and receiving care for menstrual symptoms in to inform evidence-based, co-created, shared decision-making resources. This needs to seek, hear and represent voices and experiences across a range of care experiences, including for example age, location, ethnicity, language, care setting and decision-making about referral and investigation.

Evidence is needed to inform the question of whether the most critical variable is time to diagnosis, or whether it may be more valuable to consider time to effective treatment and symptom control.

Improving GPs awareness of menstrual well-being and when to consider endometriosis is vital but needs to recognise the complexity of the process and the decisions being made. GPs need evidence-based education and resources which are developed for primary care and which will resonate with their experiences, including supporting them in navigating uncertainties. Validated resources focussed on symptoms rather than diagnoses could support this process. These GP perspectives on journeys to diagnosis, mirrored by women’s advice for GPs based on these will support the development of these resources. Whilst increasing awareness of the value of diagnosis for both clinicians and patients is vital, this must be accompanied by adequate and timely access to specialist services – both at the point of diagnosis and beyond. To assume that all delays reflect poor care is overly simplistic. As our PPI collaborators highlighted, by keeping minds (and doors) open, primary care is ideally situated to support the longitudinal care and enduring advocacy for patients with suspected or confirmed endometriosis.

Funding statement:

This research was funded by the National Institute for Health Research School for Primary Care Research (project no. 403). The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

LH is based in The Healthcare Improvement Studies Institute (THIS Institute), University of Cambridge. THIS Institute is supported by the Health Foundation, an independent charity committed to bringing about better health and healthcare for people in the UK.

References:

1. Farquhar CM. Endometriosis. *BMJ*. 2000 May 27;320(7247):1449-52.
2. Giudice LC. Endometriosis. *N Engl J Med*. 2010 Jun 24;362(25):2389-98.
3. Rogers PA, D'Hooghe TM, Fazleabas A, et al. Priorities for endometriosis research: recommendations from an international consensus workshop. *Reprod Sci*. 2009 Apr 1;16(4):335-46.
4. Chapron C, Querleu D, Bruhat MA, et al. 1998. Surgical complications of diagnostic and operative gynaecological laparoscopy: a series of 29,966 cases. *Hum Reprod (Oxford, England)*, 13(4), pp.867-872.
5. Ballard K, Lowton K, Wright J. What's the delay? A qualitative study of women's experiences of reaching a diagnosis of endometriosis. *Fertil Steril*. 2006 Nov 1;86(5):1296-301.
6. DiVasta AD, Vitonis AF, Laufer MR, Missmer SA. Spectrum of symptoms in women diagnosed with endometriosis during adolescence vs adulthood. *Am J Obstet Gynecol*. 2018 Mar 1;218(3):324-e1.
7. Pugsley Z, Ballard K. Management of endometriosis in general practice: the pathway to diagnosis. *Br J Gen Pract*. 2007 Jun 1;57(539):470-6.
8. Ghai V, Jan H, Shakir F, et al. Diagnostic delay for superficial and deep endometriosis in the United Kingdom. *J Obstet Gynaecol*. 2020 Jan 2;40(1):83-9.
9. Burton C, Iversen L, Bhattacharya S, et al. Pointers to earlier diagnosis of endometriosis: a nested case-control study using primary care electronic health records. *Br J Gen Pract* 2017 Dec 1;67(665):e816-23.
10. Ballard KD, Seaman HE, De Vries CS, Wright JT. Can symptomatology help in the diagnosis of endometriosis? Findings from a national case-control study—Part 1. *BJOG* 2008 Oct;115(11):1382-91.
11. Simoons S, Dunselman G, Dirksen C, et al. The burden of endometriosis: costs and quality of life of women with endometriosis and treated in referral centres. *Hum Reprod*. 2012 May 1;27(5):1292-9.
12. Johnston JL, Reid H, Hunter D. Diagnosing endometriosis in primary care: clinical update. *Br J Gen Pract*. 2015 Feb 1;65(631):101-2.
13. <http://www.jla.nihr.ac.uk/priority-setting-partnerships/endometriosis/top-10-priorities.htm>
14. Dixon S, Hinton L, Ziebland S. Supporting patients with female genital mutilation in primary care: a qualitative study exploring the perspectives of GPs' working in England. *Br J Gen Pract*. 2020 Oct 1;70(699):e749-56.
15. Pope C, Ziebland S, Mays N. Analysing Qualitative Data. Chapter in Pope C, Mays N. (Eds) *Qualitative Research in Health Care* (4th Edition). Wiley-Blackwell, Oxford (6 Feb. 2020). ISBN-10: 1119410835
16. Ziebland S, McPherson A. Making sense of qualitative data analysis: an introduction with illustrations from DIPEX (personal experiences of health and illness). *Med Educ* 2006; 40(5): 405-14.
17. NICE (National Institute for Health and Care Excellence), Endometriosis: diagnosis and management NG73, published September 2017. <https://www.nice.org.uk/guidance/ng73>
18. van der Zanden M, Nap AW. Knowledge of, and treatment strategies for, endometriosis among general practitioners. *Reprod Biomed Online*. 2016 May 1;32(5):527-31.
19. Young K, Fisher J, Kirkman M. Women's experiences of endometriosis: a systematic review and synthesis of qualitative research. *J Fam Plann Reprod Health Care*. 2015 Jul 1;41(3):225-34.
20. Huntington A, Gilmour JA. A life shaped by pain: women and endometriosis. *J Clin Nurs*. 2005 Oct;14(9):1124-32.

21. Denny E, Mann CH. Endometriosis and the primary care consultation. *Eur J Obstet Gynecol Reprod Biol* . 2008 Jul 1;139(1):111-5.
22. Cox H, Henderson L, Andersen N, et al. Focus group study of endometriosis: Struggle, loss and the medical merry-go-round. *Int J Nurs Pract* . 2003 Feb;9(1):2-9.
23. Hudelist G, Fritzer N, Thomas A, et al. Diagnostic delay for endometriosis in Austria and Germany: causes and possible consequences. *Hum Reprod* . 2012 Dec 1;27(12):3412-6.
24. Seear K. The etiquette of endometriosis: stigmatisation, menstrual concealment and the diagnostic delay. *Soc Sci Med* . 2009 Oct 1;69(8):1220-7.
25. Perez, Caroline Criado. *Invisible women: Exposing data bias in a world designed for men*. Random House, 2019.
26. Van Der Zanden M, Teunissen DA, Van Der Woord IW, et al. Barriers and facilitators to the timely diagnosis of endometriosis in primary care in the Netherlands. *Fam Pract* . 2020 Feb;37(1):131-6.
27. Grundström H, Kjølhede P, Berterö C, Alehagen S. “A challenge”–healthcare professionals' experiences when meeting women with symptoms that might indicate endometriosis. *Sex Reprod Healthc* . 2016 Mar 1;7:65-9.

Box 1.

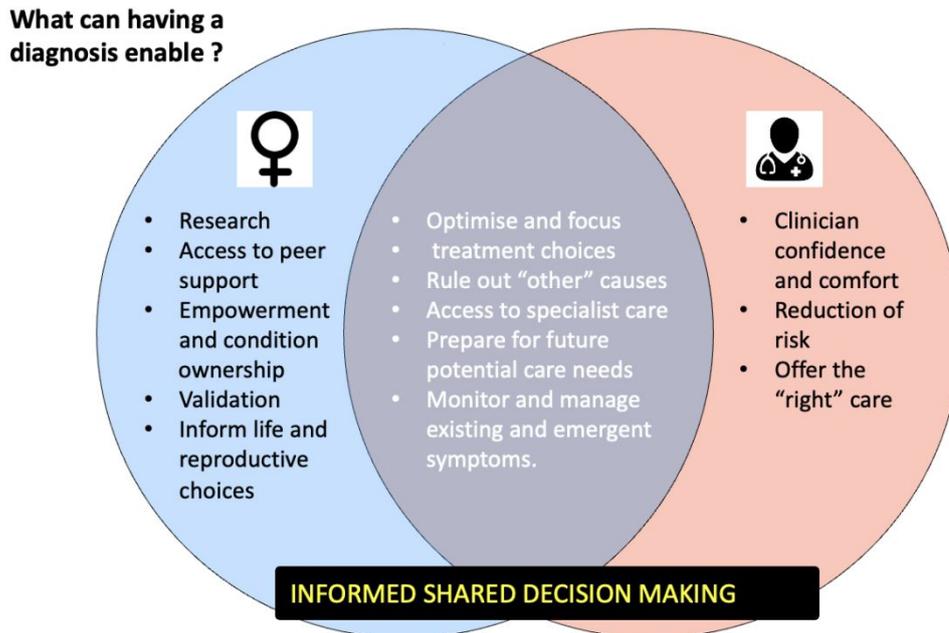
Clinical scenario

Alice is 28 years old. She has made an appointment to talk to you because she is “fed up” with having very painful periods. She has not seen a doctor about this before. She describes her periods as feeling “like knives stabbing from the inside”. She says that the pain has been so bad recently that she has had to take time off work.

Extensions to the clinical scenario:

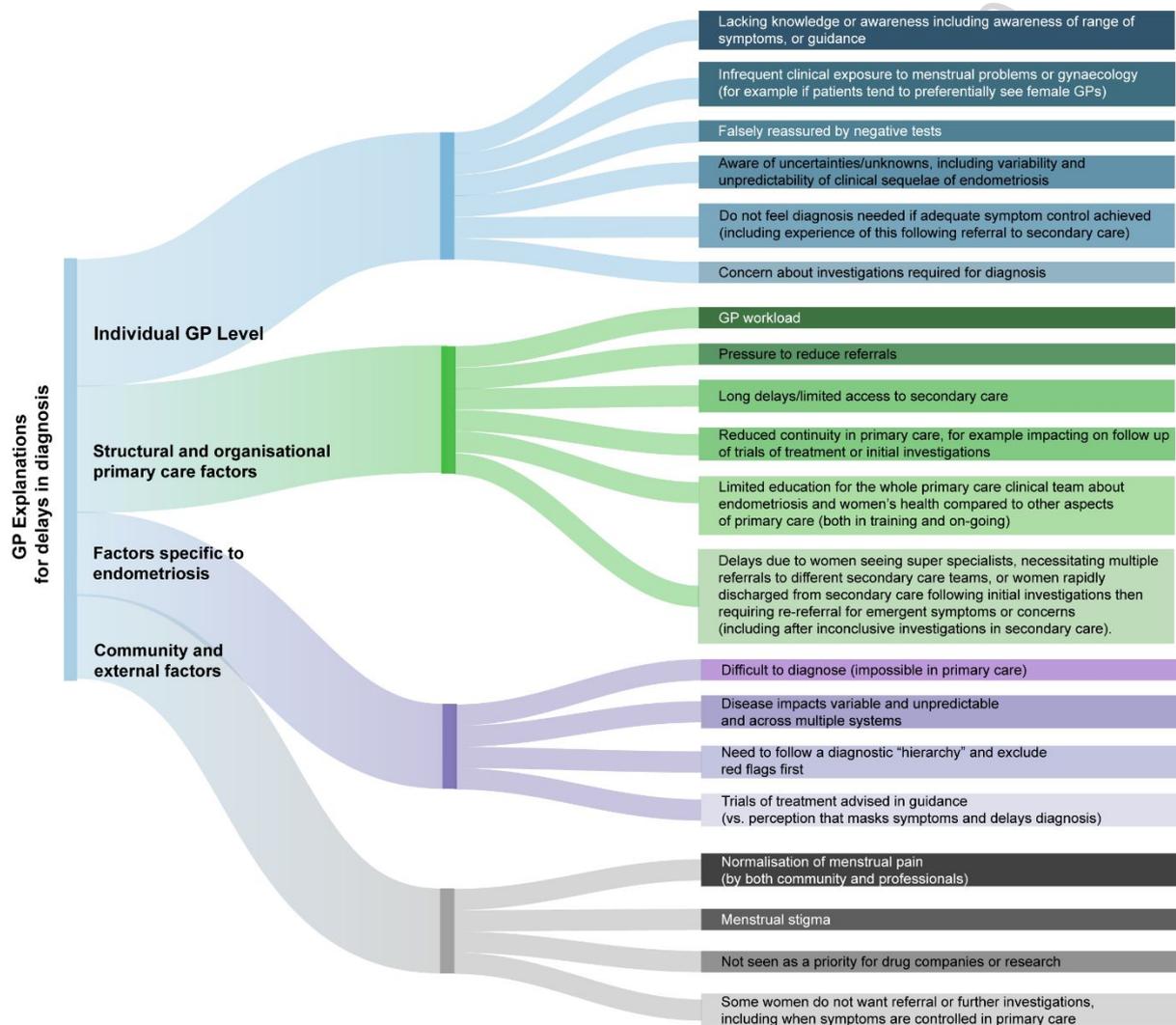
- (1) Alice becomes tearful when she describes the impact of her period pain on her quality of life.
- (2) Alice says she has looked online about her painful periods and is worried about what might be causing them.
- (3) Would you do or approach anything differently if Alice was aged 17?

Figure 1. GP perspectives on what a diagnosis can enable.



Accepted Manuscript – BU

Figure 2: GP explanations for delays in diagnosis.



Accepted Manuscript

Box 2: Tips that GPs could consider when caring for women with possible endometriosis, developed with women with lived experience of endometriosis:

1. Recognise that women may have experienced painful symptoms for months or years *before* they make an appointment.
2. Listen to the whole account of the woman's experiences, including considering patterns of symptoms across more than one system (pelvis, bowels, bladder, fatigue) and that these might be dominant. Recognise that symptoms can be constant or cyclical.
3. Ask women to compile or use symptom accounts or diaries to help spot symptom patterns and monitor changes, including in response to interventions.
4. Support and continuity of care from GPs helps women. Arranging follow-up appointments can demonstrate your interest in helping.
5. Don't make assumptions about women's concerns or priorities (including about sexuality and reproductive intentions both now and in the future); ask them.
6. Don't assume that distress is driving pain – it can be the other way round.
7. It is good to respond to women's concerns if they raise endometriosis. GPs should introduce the word and possibility if women do not.
8. Trials of treatment require clear communication to be effective. GPs need to explain their thinking and ensure there is a robust shared follow-up plan including a clear time scale for review. To not do this risks women feeling "fobbed off" and not coming back.
9. Offer information and resources about endometriosis, even if this is only a possibility, as this can help women advocate for themselves.
10. Keep an 'open door' and hold an on-going advocacy role in primary care to help women navigate their care journeys, with recognition that endometriosis can be difficult to diagnose.