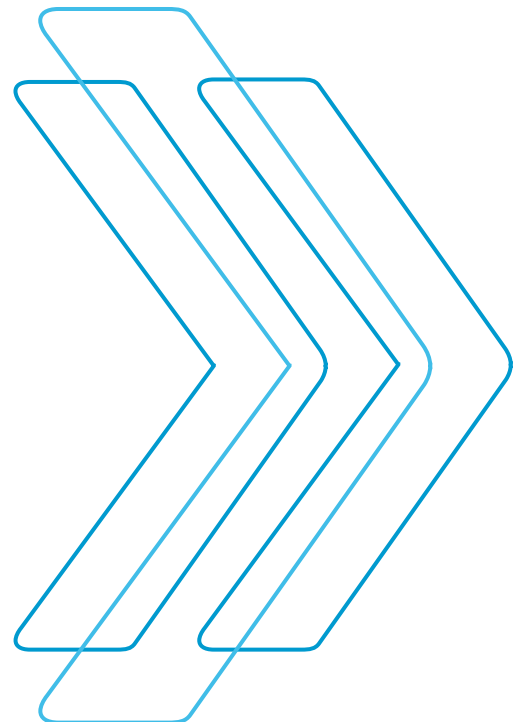


# **Women's experience of gynaecological and urogynaecological services in primary and secondary care**

**Shilpa Ross  
Beccy Baird**

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This independent report was commissioned by the Department of Health and Social Care. The views in the report are those of the authors and all conclusions are the authors' own.

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# 1 Introduction

In January 2019, the Department of Health and Social Care commissioned The King's Fund to undertake a scoping review of the published evidence about women's experience of health services with a specific focus on gynaecological and urogynaecological services in primary and secondary care.

The Department's team asked The King's Fund to focus on the following conditions and asked for a search of the published evidence on: informed consent; patient experience (not outcomes); and clinician–patient communication:

- urogynaecology (including pelvic floor injury, injury after birth, prolapse incontinence)
- gynaecology
- endometriosis
- fibroids
- heavy periods
- menopause.

They asked for a literature review to help identify:

- whether or where issues have been identified and how well understood they are (including an indication of the size, scope and recency of the literature)
- whether there are gaps in the evidence base for policy decisions.

## **Our approach**

Within the literature review, we were asked to explore:

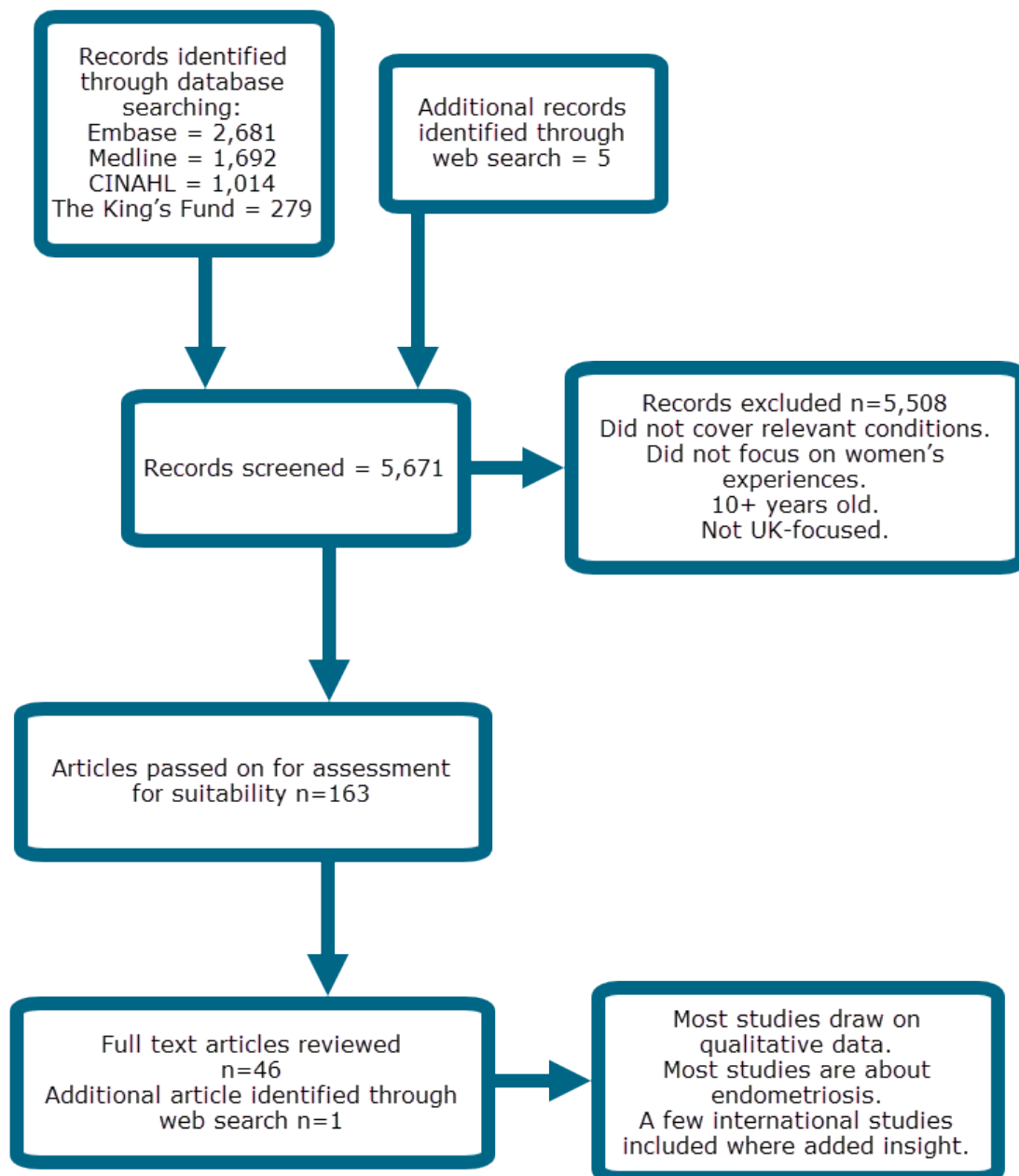
- women's experiences of health services for urological and gynaecological conditions (particularly those women who were felt not to 'have a voice', for example, those from deprived backgrounds or minority ethnic communities)
- any barriers to seeking help from health services.

We did not carry out a fully systematic review, rather we designed a scoping review that would identify key issues and allow further exploration of policy questions. We carried out a search of four databases (see Appendix 1 for full search strategy and Figure 1, below, for the diagram) to identify studies published in the past 10 years and within the UK. Most of these studies drew on qualitative data (four of the 169 references were systematic reviews). In a few cases, studies published before 2009 or outside the UK were included if they offered particularly relevant and/or interesting insights.

This report is based on our review of these studies. As a research team, we identified and developed themes through discussion and have outlined the cross-cutting themes across all the conditions and experiences.

For reference, Appendix 2 gives some brief descriptions of the conditions we have focused on.

Figure 1 Literature search strategy



## 2 Findings

In this section, we discuss the following themes (and sub-themes) that emerged from our literature review:

- perceptions that prevent or delay women seeking help from health care services
- barriers to getting a diagnosis
- women's treatment preferences
- women's experiences of services.

### **Perceptions that prevent or delay women seeking help from health care services**

Researchers have explored women's views about talking to other people about the symptoms of urological and/or gynaecological conditions, including heavy menstrual bleeding, painful periods, stress incontinence, weight gain, vaginal/vulvar dryness and more. Here 'other people' refers to partners, family members and friends as well as health care professionals.

#### ***Lack of information***

Consistently within the literature, women have reported a lack of information about urological and gynaecological conditions that are in fact widely prevalent within the female population (All Party Parliamentary Group on Women's Health 2017; Hadjiconstantinou *et al* 2017; Pakbaz *et al* 2010; Eilber *et al* 2013).

#### ***'Normalising' pain***

It is evident from the literature that how women feel about symptoms can influence whether they seek help and treatment – ie, women can 'normalise' certain symptoms (believing they are experiencing something normal for a woman) (All Party Parliamentary Group on Women's Health 2017). Women report putting off seeking help because they think pain or heavy menstrual bleeding is common or something to be endured, which is a notion that family members or friends sometimes reinforce (including those experiencing similar symptoms themselves) (Young *et al* 2015).

In a study exploring the reasons for delays in women being diagnosed with endometriosis, a number of 'individual patient-level' reasons were identified including women believing their period experiences were normal and pain very rarely being disclosed to family members because of embarrassment or a fear of appearing weak and unable to cope (Ballard *et al* 2006). In a different study of women diagnosed with endometriosis, women's initial reluctance to seek medical help was, in part, due to the difficulty in distinguishing between 'normal and pathological' symptoms – perhaps because levels of awareness of endometriosis pre-diagnosis were low (Culley *et al* 2013). The struggle to distinguish between normal and pathological chronic pelvic pain (in women and men) is exacerbated by a culture of secrecy (Toye *et al* 2014).

Also, some women were afraid that disclosure would lead to embarrassment or to them being perceived as weak because menstrual irregularities were something 'to be endured'. There was some pressure from family members or friends for women to 'conceal' what they were going through (although, paradoxically, family members and friends can also be instrumental in encouraging women to seek help) (Culley *et al* 2013).

Sociodemographic characteristics can also factor in to women's help-seeking behaviour. An audit of patient-reported outcomes for heavy menstrual bleeding found that the severity of symptoms varied at first gynaecology outpatient visit: Black and Asian women reported less severe symptoms than women from white ethnic backgrounds – despite the fact that Black women are two to three times more likely to have fibroids and endometriosis than women from other ethnic backgrounds. The disparity in reporting the severity of symptoms could therefore be due to some normalisation of heavy menstrual bleeding (Kiran *et al* 2018).

### **Embarrassment**

Another barrier to seeking help is that women can feel embarrassment or shame about their symptoms. In the scoping exercise, this particularly applied to women with polycystic ovary syndrome and pelvic organ prolapse. For example, in a study of the experiences of 12 ethnically diverse women with polycystic ovary syndrome, women discussed their sense of embarrassment about symptoms, such as facial hair growth or weight gain, which put them off seeking help (Hadjiconstantinou *et al* 2017). Studies of women experiencing stress urinary incontinence following pelvic organ prolapse highlighted the embarrassment they feel (Eilber *et al* 2013; Howard and Steggall 2010) – as well as the common experience of developing alternative



coping strategies (such as using sanitary pads, reducing fluid intake or 'toilet mapping') instead of seeking medical help (Basu and Duckett 2009).

Studies show some women do not perceive urinary incontinence as a health concern and they therefore delay seeking treatment until the condition worsens (Basu and Duckett 2009; Howard and Steggall 2010; Pakbaz *et al* 2010; Wójtowicz *et al* 2014). This is particularly concerning because treatment is more effective when symptoms are mild (Howard and Steggall 2010).

### ***Perceived attitudes of health care professionals***

In the study of women diagnosed with polycystic ovary syndrome, there was some embarrassment about symptoms and the sense that doctors 'would not be bothered'. This feeling put women off from seeking help (Hadjiconstantinou *et al* 2017).

Another study focused on the experiences of women who had sought treatment in the past for stress incontinence but had chosen not to seek further help even when symptoms persisted. This was linked to the women's beliefs about ageing and their willingness to tolerate symptoms despite the impact on quality of life. The women also reported not wanting to 'bother' health care professionals in primary or secondary care about persistent symptoms (Basu and Duckett 2009).

## **Barriers to getting a diagnosis for gynaecological and urogynaecological conditions**

There was a strong theme within the literature about women experiencing long delays in receiving a diagnosis for gynaecological and urogynaecological conditions once they had sought help. In a survey of 2,600 women, 40 per cent of women with endometriosis needed 10 or more appointments with a GP before they were referred, and 25 per cent of women with endometriosis reported receiving the 'wrong diagnosis' (All Party Parliamentary Group on Women's Health 2017). One study, based on data collected from four general practices, showed one-third of the women in the sample consulted their GP six or more times before being diagnosed with endometriosis (Pugsley and Ballard 2007). Similarly, women with polycystic ovary syndrome reported delays in getting a diagnosis and multiple visits to health care professionals (Gibson-Helm *et al* 2017; Tomlinson *et al* 2017). Repeated appointments before a referral may be expected to some degree as NICE guidance is for

GPs to trial different options before referring to a specialist, but we identified a number of themes underlying these delays.

### ***Professionals' attitudes about gynaecological symptoms***

Echoing the point made above about menstrual pain being normalised by women, studies show that women have been also told by GPs (or other health care professionals) that menstrual pain is normal and something to be endured (All Party Parliamentary Group on Women's Health 2017; Culley *et al* 2013; Young *et al* 2015). Despite repeated visits, women's symptoms can be normalised, trivialised or even dismissed out of hand, understandably resulting in women feeling disbelieved or ignored (Culley *et al* 2013).

In a systematic review of endometriosis services, delay in accurate diagnosis was commonly reported and was more likely in primary care than in secondary care. Several studies within the review found that GPs normalised women's symptoms as 'no more than women should expect' – even when a family history of endometriosis was indicated. In four of the studies included in the systematic review, women reported that their doctors had diagnosed them with irritable bowel syndrome or mental health problems rather than identifying a gynaecological cause (Young *et al* 2015). There were also accounts of women perceiving that health care professionals had given advice that caused offence and upset, for example suggesting marriage or pregnancy as solutions to symptoms. Insensitive communication such as this puts women off consulting doctors (Young *et al* 2015).

*...women's sense of well-being was reduced not only by their symptoms but by the ways in which others (health professionals, partners, family, friends and colleagues) related to them and their condition. Particularly harmful were those health care professionals who defined the symptoms as representing poor mental health, often crudely labelling women as 'crazy' or 'depressed.'* (Young *et al* 2015, p 231).

In addition to the evidence regarding misdiagnosis of endometriosis, some studies reported that doctors did not appraise the overall impact of endometriosis symptoms on women. For example, women diagnosed with endometriosis described initial consultations with doctors who tended to be more interested in the location and level of pain than to ask in-depth questions about quality, duration or impact of pain (Culley *et al* 2013).

In terms of polycystic ovary syndrome, women have reported a similar lack of empathy from health care professionals about symptoms that could be linked to delays in getting a diagnosis (Tomlinson *et al* 2017).

Clinicians' actual perceptions are severely under-researched. One study gave some indication of professionals' attitudes: all the clinicians who participated acknowledged that endometriosis can have a negative impact on some women's mental health; however, there was also some recognition that doctors were not trained well enough to treat the physical side of endometriosis let alone its psychosocial impact (as with many other health conditions) (Young *et al* 2017).

A study about posterior vaginal prolapse (also known as rectocele) and its influence on obstructive defecation symptoms (which has a major impact on the quality of life of women affected by it) highlights a lack of open discussion between women and health care professionals. Health care professionals may not always enquire about bowel symptoms in women affected by vaginal prolapse, and women may not disclose them (Eilber *et al* 2013).

## Women's treatment preferences

### ***Surgical and medical interventions***

NICE guidance for endometriosis recommends pharmacological and/or hormonal management, followed by referral to gynaecology or specialist service for investigation and treatment options. A systematic review of qualitative research found that women prefer surgical treatments over medical ones for endometriosis (Young *et al* 2015). This is because surgery is perceived to relieve the symptoms with fewer side effects compared to medical interventions (although the short- and long-term side effects of surgery were also considered) (Young *et al* 2015).

The All Party Parliamentary Group of Women's Health (2017) reported that there is a tendency towards recommending a hysterectomy for fibroids even though options such as myomectomies (surgical removal of fibroids only) or embolisation are available too.

The importance of informed choice has also been highlighted recently following complaints made by some patients about the severe side effects experienced following the surgical insertion of mesh to treat the symptoms of vaginal prolapse. Women have reported a lack of information and a lack of understanding from health care professionals about the side effects (The

Independent Medicines and Medical Devices Safety Review 2018). An independent medicines and medical devices safety review is currently under way to examine how the health care system has responded to the concerns raised by women and their family members.

## **Women's experiences of services**

### ***Diagnostic delay***

As already outlined, it was very common for women to present many times to health care professionals before being referred to a specialist and/or getting a diagnosis (although it should be noted that the guidelines for fibroids and endometriosis require at least two consultations before diagnosis due to the need to carry out investigations and trial treatment). The results of our literature search offer some indication of the length of the delay some women experience.

Based on a survey of 2,600 women, 42 per cent of women with endometriosis reported having 10 or more appointments with a GP before being referred to a specialist (All Party Parliamentary Group on Women's Health 2017).

Analysis of data collected from four general practices showed the median time from first presentation to diagnosis for endometriosis was nine years (interquartile range = 4.5–13.5 years) (Pugsley and Ballard 2007).

Often women report they have not been listened to or taken seriously by doctors regarding their gynaecological symptoms. This could mean many women have been left to live with debilitating pain, impaired quality of life and potentially adverse effects on mental health and emotional wellbeing (Young *et al* 2015). Delays play a big part in low levels of satisfaction among women diagnosed with polycystic ovary syndrome – although a lack of information about the condition (ie, its links to other physical and mental health problems) is also a factor here (Gibson-Helm *et al* 2017).

Many women who have to live with symptoms of endometriosis and fibroids 'resort to' private health care where they feel they are taken more seriously (although it is not clear what the private treatment options are) (All Party Parliamentary Group on Women's Health 2017).

### ***Painful or uncomfortable examinations in gynaecology and urogynaecology***

We found a small amount of information regarding women's feelings about highly intimate and personal examinations that might put them off seeking medical help for urological or gynaecological issues. For example, there is evidence that women can find cervical screening examinations painful, uncomfortable or even personally threatening (Armstrong *et al* 2012). A study of women experiencing urinary symptoms following pregnancy showed that some women were strongly disinclined to undergo further examination and, at times, women were prepared to lie about symptoms to avoid being examined (Wagg *et al* 2017).

We did not find much information in the literature about women's experiences of undergoing hysteroscopy (a procedure used to examine the inside of the womb). One paper mentioned that hysteroscopy can potentially cause pain severe enough to abandon the procedure; however, a postal survey indicated variable use of pain control by gynaecologists (25 per cent of gynaecologists who responded to the survey reported not using any analgesia) (O'Flynn *et al* 2011).

### **Findings on menopause**

There was very little on women's experiences of services in primary and secondary care for menopause in our literature search results. There was also an absence of literature on barriers to seeking treatment for menopause. We cannot draw firm conclusions as to why this might be but perhaps another literature search specifically focusing on menopause would offer further insights.

## 3 Conclusion

We found relatively little, up-to-date published research (grey literature and peer-reviewed journal articles) focusing specifically on women's experiences of gynaecological and urogynaecological health care services in the UK. The lack of literature on menopause was particularly noticeable. Where the research existed, it was not always recent (ie, from the past 5–10 years) and mostly drew on qualitative methods – although that is appropriate given the sensitive subject matter.

There were better insights from the research about barriers to treatment, particularly in primary care. Again, this was mostly based on qualitative data. It was very rare to find any studies focusing directly on clinicians' perceptions of urological or gynaecological conditions and what factors informed their decision-making about treatment.

It was concerning to find that evidence suggests women who need treatment are not getting it because:

- their conditions/symptoms are stigmatised (by others and sometimes themselves too) and they feel unable to talk openly to those close to them, let alone to health care professionals
- health care professionals may be inadvertently reinforcing the notion that chronic pain, discomfort, poor quality of life due to vaginal prolapse, etc are simply a fact of life for women.

Underpinning all of this is a lack of good-quality evidence about societal perceptions of women's reporting of urological and gynaecological symptoms in the UK. We appreciate there is likely to be wide variation in these perceptions (depending on different sociodemographic characteristics), but nevertheless it would be beneficial to understand better how social and cultural factors influence help-seeking behaviour and care-giving decisions.

## **Considerations for future research**

The following areas have gaps in the evidence and could be priorities for future research:

- promoting awareness and discussion about the availability and efficacy of treatments to allow women a more informed choice
- how clinicians perceive gynaecological and urogynaecological issues (this was a severely under-researched subject)
- given the chronic nature of gynaecological and urogynaecological conditions, what can be learned from long-term conditions management – and from the work on de-stigmatising other chronic illnesses, such as mental health problems
- women's experiences of health care services for menopause treatment.

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# Appendix 1: literature search strategy

## *HDAS Strategies Women's experiences of health services*

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### **Medline Strategy**

<b>#</b>	<b>Database</b>	<b>Search term</b>	<b>Results</b>
1	Medline	exp *"REPRODUCTIVE HEALTH SERVICES"/	39303
2	Medline	exp *"REPRODUCTIVE HEALTH"/	1808
3	Medline	(reproductive ADJ health).ti,ab	10802
4	Medline	(urogyn?colog* OR gyn?colog*).ti,ab	30962
5	Medline	(1 OR 2 OR 3 OR 4)	79539
6	Medline	exp MENSTRUATION/	15451
7	Medline	exp "MENSTRUATION DISTURBANCES"/	26909
8	Medline	exp "PELVIC ORGAN PROLAPSE"/	11216
9	Medline	exp ENDOMETRIOSIS/	20390
10	Medline	exp "URINARY INCONTINENCE"/	30986

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11	Medline	exp MENOPAUSE/	54127
12	Medline	(menstruat* OR incontinen* OR endometriosis OR fibroid* OR menopause OR "pelvic organ prolapse" OR menopause OR "heavy period" OR "period pain" OR menorrhagia OR "pelvic pain").ti,ab	115576
13	Medline	(6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12)	202577
14	Medline	exp *PREJUDICE/	14660
15	Medline	*SOCIAL STIGMA/	3455
16	Medline	(descriminat* OR prejudice* OR stigma* OR attitude* OR judge* OR non-judgemental).ti,ab	236908
17	Medline	exp *SHAME/	968
18	Medline	(embarass* OR ashamed OR shame).ti,ab	4484
19	Medline	(experience* OR perception*).ti,ab	1144210
20	Medline	(barrier* OR challenge*).ti,ab	800949
21	Medline	(awkward* OR self?conscious).ti,ab	1629
22	Medline	exp *HEALTH SERVICES ACCESSIBILITY/	57115

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23	Medline	((access* OR "use" OR using) ADJ2 (healthcare OR "health servic*")).ti,ab	21041
24	Medline	(14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21)	2046942
25	Medline	(5 AND 13 AND 24)	899
26	Medline	(22 OR 23)	75617
27	Medline	(5 AND 13 AND 24 AND 26)	17
28	Medline	gb OR "g.b." OR britain* OR (british* NOT "british columbia") OR uk OR "u.k." OR united kingdom* OR (england* NOT "new england") OR northern ireland* OR northern irish* OR scotland* OR scottish* OR ((wales OR "south wales") NOT "new south wales") OR welsh*	1677591
29	Medline	(nhs OR "national health service").ti,ab	36847
30	Medline	(28 OR 29)	1687286
31	Medline	(25 AND 30)	71
32	Medline	31 [DT 2008-2019]	37
33	Medline	("informed consent").ti,ab	32537
34	Medline	(13 AND 30 AND 33)	37
35	Medline	(5 AND 30 AND 33)	35

## Women's experience of gynaecological and urogynaecological services

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36	Medline	("women's experience*").ti,ab	3021
37	Medline	(13 AND 30 AND 36)	35
38	Medline	(5 AND 30 AND 36)	82
39	Medline	("diagnostic test*").ti,ab	41811
40	Medline	(hysteroscop*).ti,ab	6300
45	Medline	(pain* OR discomfort OR uncomfortable).ti,ab	656975
46	Medline	exp PAIN/	371540
47	Medline	exp HYSTEROSCOPY/	4508
48	Medline	exp "OBSTETRIC SURGICAL PROCEDURES"/	126863
50	Medline	(36 OR 45 OR 46)	802455
52	Medline	(40 OR 47)	7285
53	Medline	(50 AND 52)	942
54	Medline	(50 AND 52) [DT 2008-2019]	560
55	Medline	(45 OR 46)	799771
56	Medline	(36 AND 52 AND 55)	2
57	Medline	(36 AND 52)	3
59	Medline	(5 AND 13 AND 52)	172
60	Medline	(13 AND 36 AND 39)	1

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61	Medline	(Laparoscop*).ti,ab	114214
62	Medline	exp LAPAROSCOPY/	90929
63	Medline	(61 OR 62)	128934
64	Medline	(55 AND 63)	19139
65	Medline	(12 AND 64)	2953
66	Medline	(36 AND 65)	4

### **Embase Strategy**

#	Database	Search term	Results
1	EMBASE	exp *"REPRODUCTIVE HEALTH"/	7201
2	EMBASE	exp *"SEXUAL HEALTH"/	7077
3	EMBASE	(reproductive ADJ health).ti,ab	15323
4	EMBASE	("women's health service*").ti,ab	162
5	EMBASE	(urogyn?colog* OR gyn?colog*).ti,ab	107109
6	EMBASE	(1 or 2 OR 3 OR 4 OR 5)	130827
7	EMBASE	exp MENSTRUATION/ OR exp "MENSTRUATION DISORDER"/	72504
8	EMBASE	exp "PELVIC ORGAN PROLAPSE"/	19044

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9	EMBASE	exp ENDOMETRIOSIS/	34395
10	EMBASE	exp "PELVIC PAIN"/	17373
11	EMBASE	exp "URINE INCONTINENCE"/	68869
12	EMBASE	exp "MENOPAUSE RELATED DISORDER"/	24446
14	EMBASE	exp "FEMALE GENITAL PAIN"/	161
15	EMBASE	exp MENORRHAGIA/	9088
16	EMBASE	exp MENOPAUSE/	43324
17	EMBASE	(menstruat* OR incontinen* OR endometriosis OR fibroid* OR menopause OR "pelvic organ prolapse" OR menopause OR "heavy period" OR "period pain" OR menorrhagia OR "pelvic pain").ti,ab	174111
18	EMBASE	(7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 14 OR 15 OR 16 OR 17)	303064
19	EMBASE	exp *PREJUDICE/	675
20	EMBASE	exp *STIGMA/	2553
21	EMBASE	(descriminat* OR prejudice* OR stigma* OR attitude*	303512



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		OR judge* OR non-judgemental).ti,ab	
22	EMBASE	exp *SHAME/	1254
23	EMBASE	(embarass* OR ashamed OR shame).ti,ab	6166
24	EMBASE	(barrier* OR challenge*).ti,ab	995277
25	EMBASE	(awkward OR self?conscious).ti,ab	1821
26	EMBASE	("informed consent").ti,ab	68800
27	EMBASE	exp *"INFORMED CONSENT"/	17528
28	EMBASE	(26 OR 27)	78404
29	EMBASE	(experience* OR perception*).ti,ab	1544673
30	EMBASE	("women's experience").ti,ab	3564
31	EMBASE	(19 OR 20 OR 21 OR 22 OR OR 23 OR 28 OR 29 or 30)	
32	EMBASE	(6 AND 37)	11374
33	EMBASE	(18 AND 36)	10740
41	EMBASE	exp "UNITED KINGDOM"/	396786

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42	EMBASE	("national health service*" OR nhs*).ti,ab	55315
43	EMBASE	gb OR "g.b." OR britain* OR (british* NOT "british columbia") OR uk OR "u.k." OR united kingdom* OR (england* NOT "new england") OR northern ireland* OR northern irish* OR scotland* OR scottish* OR ((wales OR "south wales") NOT "new south wales") OR welsh*	746233
44	EMBASE	(39 OR 40 OR 41)	769872
45	EMBASE	(32 AND 44)	502
46	EMBASE	(33 AND 44)	501
47	EMBASE	(32 AND 44) [DT 2008-2019] [Female]	253
75	EMBASE	(diagnos* test*).ti,ab	58864
76	EMBASE	(hysteroscop*).ti,ab	10959
77	EMBASE	(hysteroscopy).ti,ab	7690
78	EMBASE	exp "UROGENITAL ENDOSCOPY"/	49952
79	EMBASE	exp "GYNECOLOGICAL EXAMINATION"/	86800

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80	EMBASE	exp HYSTEROSCOPY/	11117
81	EMBASE	(pain* OR discomfort OR uncomfortable).ti,ab	951396
82	EMBASE	exp PAIN/	1188941
83	EMBASE	(30 OR 81 OR 82)	1536226
84	EMBASE	(18 AND 75)	109
85	EMBASE	(76 OR 77 OR 78 or 79 OR 80)	115803
86	EMBASE	(83 AND 84)	36
87	EMBASE	(77 AND 81)	1704
88	EMBASE	(30 AND 87)	4
89	EMBASE	(42 AND 85)	17
90	EMBASE	(42 AND 85)	98
91	EMBASE	(81 AND 83)	15470
92	EMBASE	(44 AND 83)	434
93	EMBASE	(Laparoscop*).ti,ab	182761
94	EMBASE	exp LAPAROSCOPY/	145328
95	EMBASE	(93 OR 94)	212773
94	EMBASE	(81 OR 82)	1539309
95	EMBASE	(18 AND 30 AND 93 AND 94)	7

**CINAHL Strategy**

#	Database	Search term	Results
1	CINAHL	("urogyn?colog* service*" OR "gyn?colog* service*").ti,ab	70
2	CINAHL	("women's health service*").ti,ab	89
3	CINAHL	exp "WOMEN'S HEALTH SERVICES"/	2249
4	CINAHL	(1 OR 2 OR 3)	2362
5	CINAHL	("women's experience*").ti,ab	2898
6	CINAHL	(4 AND 5)	26
14	CINAHL	exp "GYNECOLOGIC CARE"/	1034
7	CINAHL	exp "PELVIC ORGAN PROLAPSE"/	2538
8	CINAHL	exp "MENSTRUATION DISORDERS"/	6333
9	CINAHL	exp MENORRHAGIA/	1054
10	CINAHL	exp "GENITAL DISEASES, FEMALE"/	86180
11	CINAHL	exp ENDOMETRIOSIS/	3659
12	CINAHL	exp "GYNECOLOGIC EXAMINATION"/	1166
13	CINAHL	exp "PELVIC PAIN"/	3599

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15	CINAHL	exp "STRESS INCONTINENCE"/	2535
25	CINAHL	("stress urinary incontinence").ti,ab	1340
26	CINAHL	(endometriosis).ti,ab	4188
27	CINAHL	(fibroids).ti,ab	1582
28	CINAHL	(fibroid*).ti,ab	1855
29	CINAHL	("pelvic organ prolapse").ti,ab	1372
30	CINAHL	(menopause).ti,ab	7442
31	CINAHL	("heavy period*").ti,ab	35
32	CINAHL	(pain* period*).ti,ab	17238
33	CINAHL	(menorrhagia).ti,ab	560
34	CINAHL	(5 AND 14)	3
35	CINAHL	(7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 15 OR 25 OR 26 OR 27 OR 28 OR 29 OR 30 OR 31 OR 32 OR 33)	118059
36	CINAHL	(5 AND 35)	356
37	CINAHL	36 [DT 2008-2019]	222
38	CINAHL	exp "DIAGNOSIS, DELAYED"/	3378
39	CINAHL	("informed consent").ti,ab	11282
40	CINAHL	(35 AND 38)	166
41	CINAHL	(35 AND 39)	347

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42	CINAHL	(4 AND 38)	1
43	CINAHL	(4 AND 39)	3
44	CINAHL	41 [DT 2009-2019]	259
45	CINAHL	(hysteroscop*).ti,ab	1681
46	CINAHL	(pain* OR discomfort OR uncomfortable).ti,ab	224902
47	CINAHL	exp PAIN/	177627
48	CINAHL	exp HYSTEROSCOPY/	1324
49	CINAHL	(45 OR 48)	2057
50	CINAHL	(46 OR 47)	288722
51	CINAHL	(49 AND 50)	312
52	CINAHL	(4 AND 35 AND 46)	12
54	CINAHL	(5 AND 49)	1
55	CINAHL	(5 AND 51)	0
56	CINAHL	(qualitative).ti,ab	98741
57	CINAHL	(51 AND 56)	2
58	CINAHL	exp "DIAGNOSTIC TESTS, ROUTINE"/	3083
59	CINAHL	("diagnostic test*").ti,ab	8863
60	CINAHL	(58 OR 59)	11405
61	CINAHL	(4 AND 60)	6

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62	CINAHL	(35 AND 60)	565
63	CINAHL	(5 AND 62)	1

### ***The King's Fund database***

su: Women's Health Services	107
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su: women and su: patient views	55
su: access to health services and su: women	96

## Appendix 2: gynaecological and urological issues in focus in this review

**Endometriosis** – tissue similar to the womb lining begins to grow in the ovaries and fallopian tubes. It is estimated to affect 5–10 per cent of women of reproductive age but is most commonly seen in women in their 30s or 40s. Endometriosis may appear asymptomatic in some women; however, in others it is a long-term condition that can significantly impact their quality of life (Irungu *et al* 2019).

- **Diagnosis:** a conclusive diagnosis can only be achieved through laparoscopy, which is an operation where a camera is inserted into the pelvis to look for signs of endometriosis.
- **Treatment:** can either involve medication or surgery, with doctors typically recommending conservative treatment approaches first before opting for surgery.

**Fibroids** are the most common form of benign tumours in women; they are made up of muscle and fibrous tissue and can vary in number and size, developing in or around the uterus. Fibroids occur in 20–50 per cent of women older than 30, rising to 70 per cent of women by the onset of menopause (NICE 2018) (Stewart *et al* 2017).

- **Diagnosis:** usually occurs during routine pelvic examinations, and further testing may be undertaken to confirm the presence of fibroids via ultrasound, hysteroscopy or laparoscopy.
- **Treatment:** asymptomatic fibroids do not require treatment; however, medication is available that targets the heavy menstrual bleeding and pelvic discomfort usually associated with the condition.

**Heavy menstrual bleeding** (or '**menorrhagia**' in clinical terminology) is described as abnormally heavy or prolonged bleeding. It impacts quality of life



greatly, as the major blood loss and cramping can disrupt daily activities. Around 30 per cent of women report experiencing heavy periods, with a prevalence of 9–14 per cent of women diagnosed in the UK (NICE 2018).

- **Diagnosis:** a gynaecological history and physical examination are required for diagnosis, with other clinical testing available for further assessment.
- **Treatment:** treatments can be classified under three categories – medical, surgical or radiological. The use of intra-uterine hormonal contraceptives is common as first-line treatment.

**Menopause** is described as a biological stage of a woman's life, marking the end of menstruation and reproductive capacity. The average onset of menopause is between the ages of 49 and 51 years; however, this can differ depending on lifestyle.

- **Diagnosis:** the appearance of menopausal symptoms and the absence of menses for 12 months are a diagnostic hallmark of menopause.
- **Treatment:** many women manage their menopausal symptoms without medical intervention, while others may seek symptomatic treatment using hormone-replacement therapy, herbal remedies, vaginal lubricants, clonidine, and anti-depressants.

**Polycystic ovary syndrome** is an endocrine disorder associated with a wide range of reproductive and metabolic abnormalities. It is one of the most common hormonal disturbances affecting 10 per cent of women of reproductive age. It is characterised by the appearance of polycystic ovaries, causing symptoms of menstrual irregularity, infertility, hirsutism and alopecia due to excess androgenic hormones.

- **Diagnosis:** can be made based on the clinical features of the condition, and further investigations involve a blood test and ultrasound.
- **Treatment:** can be managed with a combination of lifestyle change and medication to treat the symptoms.

**Pelvic organ prolapse** occurs when the muscles and tissues supporting the pelvic organs become weakened, causing one or more of the organs to bulge into the vagina; 8.4 per cent of women have reported a vaginal bulge or lump in primary care settings (NICE 2019).

- **Diagnosis:** a gynaecological history and an internal pelvic examination are required for diagnosis.

- Treatment: may not always be necessary if the prolapse does not interfere with daily life; however, lifestyle changes such as weight loss and pelvic floor training may be helpful. In women requiring treatment, the use of vaginal pessaries help to hold the organs in place. In severe cases, surgery may be necessary.

**Stress urinary incontinence** is the involuntary passage of urine when intra-abdominal pressure is raised – for instance, when coughing or sneezing – due to a weakness of the pelvic floor and urethral sphincter. Recent studies estimate the prevalence for women in the UK at 34 per cent (NHS Choices 2016).

- Diagnosis: a pelvic examination is required to determine whether incontinence is caused by weakened pelvic floor muscles or partial prolapse of the bladder into the vagina.
- Treatment: current management involves lifestyle changes, such as weight loss and pelvic floor muscle training. When this fails, surgery may also be considered.