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Published in:
BMJ Open

DOI:
10.1136/bmjopen-2023-075316

Publication date:
2024

BMJ Open

Women's experiences of the diagnostic journey in uterine adenomyosis: a scoping review protocol

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To cite: Taylor MA, Croudace TJ, McBride M, *et al*. Women's experiences of the diagnostic journey in uterine adenomyosis: a scoping review protocol. *BMJ Open* 2024;**14**:e075316. doi:10.1136/bmjopen-2023-075316

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2023-075316).

Received 04 May 2023
Accepted 21 December 2023

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ABSTRACT

Introduction Uterine adenomyosis is a benign gynaecological disease that causes physical and psychological problems, impacting on relationships. It is poorly understood and consequently may be diagnosed late. This protocol describes the process of conducting a systematic scoping review to retrieve and describe literature examining the daily experience and impact of living with uterine adenomyosis. It will explore the journey to diagnosis (and perceptions of what this process is like); identify the main concepts currently used in the literature and highlight gaps in knowledge for future research in relevant populations.

Methods and analysis Using the Joanna Briggs Institute methodology, the population–concept–context approach is used to form clear review questions. A three-phase search strategy will locate published and unpublished evidence from multiple sources. All articles reporting on the personal experiences of women diagnosed with uterine adenomyosis will be considered. Findings from qualitative, quantitative and mixed-method study designs from all settings will be included, not limited by geography but restricted to English. Documents will be screened by the primary researcher, supported by university supervisors. Search outputs will be presented using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 flow diagram. No formal quality appraisal will be conducted. Review findings will be descriptively collated and reported consistent with the Scoping Review Extension of the PRISMA checklist. Patient and public involvement engagement reflected a positive response for the project that this protocol supports.

Ethics and dissemination As primary data will not be collected, formal ethical approval is not required. Prepared as part of a professional doctorate thesis, the findings of this study will be disseminated via peer-reviewed publications, conference presentations, support groups and social media networks.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This review protocol is the first to focus on studies of the lived experience of being diagnosed with uterine adenomyosis, embracing both disease burden and women's perceptions of the diagnostic journey.
⇒ Joanna Briggs Institute recommended methodology for scoping reviews has been adopted, using a population–concept–context approach to formulate research questions and perform the review systematically, with transparency.
⇒ The review findings will add to the body of knowledge and understanding surrounding this poorly understood condition and are intended to provide valuable information for future qualitative (and potentially, intervention) research.
⇒ Understanding adenomyosis is a global challenge and a limitation of this review is the English language restriction that may exclude valuable evidence.
⇒ The term 'lived experience' is only one of several dimensions that capture 'patient experience'. Poor definitional clarity may be a limitation of this study, due to differing terms and interpretations used within sources. Understanding these differing definitions may be difficult and introduce ambiguity to some of the findings of the review.

INTRODUCTION

Background

The term 'women' will be used throughout this protocol and is defined as persons assigned female at birth but includes any person who lives with uterine adenomyosis (UA), regardless of gender identity.

UA is a benign, enigmatic, gynaecological disease defined by the ectopic infiltration of uterine cavity lining (endometrium) into the uterine muscle (myometrium) and is of indeterminate aetiology. Chronic pain and abnormal, often very heavy bleeding patterns are common. Uterine enlargement can cause adjacent urinary and bowel symptoms. Infertility and poor pregnancy outcomes are possible clinical manifestations, and the chronic nature of symptoms can impact quality of life (QoL) in terms of medical, psychological and wider sociological issues.[1–3] Broad symptomatology makes diagnosis challenging and as a process this can often occur over multiple years. Delays in the establishment of a diagnosis, result in missed potential opportunities to intervene (earlier). Despite recent diagnostic advances using ultrasound imaging[4–6] that have created possibilities to identify UA earlier, diagnosis is often still only made following the symptomatic cure of

a hysterectomy.[7–9] This is especially unhelpful for those wishing to retain their uterus and with the inherent access limitations and risks of surgery, subsequent time delays can lengthen diagnostic processes.

Further compounding these delays are existing societal and cultural conventions and the universal stigma associated with menstruation and period-related health issues, which perpetuates the ongoing lack of research in this field and contribute to the diminished seriousness of women's health problems.[10 11] Breaking down this discourse averseness is vital to encourage open discussion of what diversity of experience is normal and what menstrual variations may be considered abnormal.[12 13] A cultural shift is required to not only support improved knowledge and understanding of UA, thus encouraging a more advice-seeking population, but to raise awareness of such conditions within healthcare professional (HCP) communities and avoid women 'developing more serious and potentially avoidable ill health'.[12] Furthermore, inclusive cultural shifts must be acknowledged to address the challenges faced by all populations who menstruate. Only then will we start to progress with constructive discourse, equitable healthcare access and improved HCP knowledge, understanding and engagement.[11]

Another significant factor that contributes to diagnostic delays is the gender inequalities and distorted societal perception of women's pain. It is widely recognised that women often face dismissive attitudes when they report pain or discomfort, with their symptoms being attributed to emotional or psychological factors rather than physical ailments. This dismissal of women's pain stems from deeply ingrained gender stereotypes that portray women as overly emotional and less credible when it comes to their health concerns. As a result, women often experience significant delays in receiving appropriate medical attention, which ultimately leads to worsened health outcomes.[14 15]

Reassuringly, in the UK, focused policy regarding women's health is being prioritised more in recent years.[13 16] In 2021, with a responsibility to setting direction and leading debate in global and domestic health, the UK Department for Health and Social Care initiated a comprehensive survey aimed at gathering insights into women's health.[17] The response from nearly 100 000 individuals in England has played a pivotal role in shaping the UK government's inaugural Women's Health Strategy for England. This strategy incorporates personal perspectives and experiences shared by women, as well as insights from their family members, friends, partners, as well as from HCP communities.

The results of this survey have shed light on crucial areas that require further investigation, with the top five topics being gynaecological conditions (63%), fertility, pregnancy, pregnancy loss, and postnatal support (55%), the menopause (48%), menstrual health (47%), and mental health (39%). One disheartening revelation from the findings is that over 84% of women expressed feeling unheard by HCPs. Their symptoms were often disregarded or not taken seriously during initial consultations with general practitioners and other healthcare providers. Consequently, women frequently found themselves in the position of having to persistently advocate for themselves, enduring multiple visits, months and even years before securing a diagnosis. Moreover, even after receiving a diagnosis, women reported limited opportunities to discuss treatment options and felt that their preferences were frequently disregarded.[17]

The consequences of not taking women's health problems seriously are far-reaching. Women may endure prolonged ill health, delayed diagnosis and inadequate treatment, all of which lead to worsened health outcomes and a reduced QoL.[18] Moreover, the lack of attention and research on women's health issues hinders medical advancements and the development of effective treatments specifically tailored to meet the unique needs of women.

Lived experience and burden of disease

Lived experience is a poorly understood concept with varied definitions that can be confused with related experiential constructs. Indeed, the wider concept of patient experience is a complex phenomenon often understood to emerge solely from healthcare interactions.[19 20] This emphasis on 'healthcare systems related' elements only (quality and responsiveness of services, and health-related political influences), may fail to appreciate 'patient-related' elements (lived experience and more subjective influences such as perceptions and expectations). Zakkar presents both elements, combining all 'determinants' to construct patient experience and its subsequent 'manifestations'; patient satisfaction and engagement levels.[20] Similarly, it is noted that experience has been extensively debated for many decades in the conceptual discourse around the determinants that may shape an individual's QoL.[21] In the broadest sense, QoL encompasses all facets of living that shape subjective well-being and contentment with life overall,[22] within the unique context of an individual's culture, goals, beliefs, values and anxieties.[23] More recently, researchers have focused on health as a single element of that complex, enigmatic process. How an individual functions in life relative to the effects of illness, within their personal perceived health-related QoL (HRQoL), is just as multidimensional and includes physical, psychological, financial and social elements.[24 25] HRQoL and how disease may impact overall well-being, has been extensively debated.[21] However, in comparison to a simple count of mortality rates, there is no doubt that HRQoL instruments as outcome measures of the diagnostic and treatment journey, provide a more sophisticated and useful gauge of disease status, diagnostic and therapeutic intervention success, and prevention planning.[26–28] Scrutinising the expansive and converging experiential concepts further, the theoretical parallels of lived experience and HRQoL are conspicuous. Although focused to cancer specifically, Sitlinger and Zafar's review of disease burdens (physical, psychosocial and financial)

as components of HRQoL that affect 'well-being and survival'[24] draw clear similarities with Zakkar's wider work into modelling the determinants of lived experience (beliefs, financial burden, social burden and emotional burden).[20]

This work is motivated from the premise that understanding the presentation of UA, patients' journeys and the burden that the onset of the condition has on them and their lives, is key to achieving the goal to improve the healthcare experience of women living with UA. Better understanding of the lived experience could strengthen healthcare provision pathways, influence policy decisions, secure funding allocations and raise awareness.

Additionally, Brand and Timmons's[29] exploration into knowledge sharing in healthcare, highlights the value of direct experiential knowledge ensuring that adequate person-centred care is achieved. Indeed, compared with the worth assigned to HCPs' clinical expertise, the authors expose the missed opportunities and significant undervalue ascribed to knowledge learnt through the direct lived experience and impact of a disease.[29] Paradoxically, this is despite increasing recognition of using patient experience to drive healthcare policy improvements and optimise healthcare responses: championing the benefits of appreciating the knowledge from patients as well as from HCPs.[30–32]

Preliminary search

On 20 September 2022, a preliminary search was conducted in PubMed to estimate the extent and nature of current literature. The search terms used are as described in the search strategy section below. PubMed was chosen because it is a large database that includes MEDLINE and provides wide coverage for this limited exploratory search. The same inclusion criteria used for the formal review were applied to this preliminary search (Methods and analysis section provides more details). This preliminary search identified two papers describing the lived experience of patients with UA, but no literature was identified specifically dealing with perceptions of diagnostic pathways.

Using a grounded theory approach and a sample of 31 semistructured interviews, Nelsen *et al*[33] provide the most significant contribution to date in this field, proposing their study as a first step to understanding the lived experience of UA and its specific symptoms, and acknowledging the need for further similar research. Onward citation counts via CrossRef were examined and did not identify further relevant papers.

Using a content analysis approach (Colaizzi's 7 steps) and a sample of 18 in-depth interviews, Huang *et al's*[34] subsequent research into how patients manage their disease and the barriers to doing so effectively, echo some of Nelsen *et al's* earlier findings. They identify HCPs' lack of knowledge directly impacting unfavourably on patients' QoL.

Additionally, in narrative articles by clinical groups, there is a plea for urgent research into all aspects of this 'under-recognised, undertreated and understudied' condition[35] and acknowledgement of an urgent need for validated, quality-of-life instruments.[36] No systematic reviews (SRs), scoping or otherwise, detailing this phenomenon have been found to date and the apparent limited understanding across the subject area, suggests a research gap warranting this scoping review (ScR) as the first attempt at assessing the current knowledge base.

Adenomyosis and endometriosis

UA is often considered to be the same as endometriosis and indeed, for many years, UA was referred to as endometriosis interna.[7 37] Unlike UA, which is confined to the uterus, endometriosis is defined as endometrial tissue found outside the uterus. This close relationship involving ectopic endometrial tissue often gives rise to the assumption of similar symptoms, impact and healthcare needs. Certainly, in Omtvedt *et al*'s[38] survey research exploring what components are needed to develop a multidisciplinary centre for endometriosis and adenomyosis, the authors acknowledge as a limitation of their work the possibility that 'people with adenomyosis have other, unmet needs'. Undeniably, these conditions may coexist[39] but although the pathogenic mechanism of neither condition is fully appreciated, there is an increasing acceptance that they are different entities requiring different care needs.[7 37]

However, there remains a notable strong association of UA with endometriosis, as historically 'they were considered—with the exception of ovarian endometriomas—as one disease'.[40] Subsequently, it is important to acknowledge the greater body of evidence into the lived experience of endometriosis.[41 42] Furthermore, excluding evidence that includes both adenomyosis and endometriosis within the same study, may exclude significant background and contextual information that is considered important to this review. A preliminary search for this protocol initially excluded literature investigating UA within a population with a coexisting diagnosis of another gynaecological pelvic disease. Modifying this stance, a wider search strategy is now proposed to include literature investigating the combined diseases of endometriosis and UA within the same study population, more fully capturing and quantifying work that has been conducted to date.

ScR rationale

The ScR is becoming an established evidence synthesis methodology[43] and while necessarily sharing important similarities in terms of trust and transparency, they differ from the traditional SR.[43] Indeed, there are accepted and differing indications for choosing to conduct an ScR.[44 45] Although not often the case,[46] an ScR may be used to explore the feasibility of subsequently progressing onto an SR by assessing the size and scope of evidence available and if the evidence even exists. An ScR aims to identify the key concepts and characteristics of evidence within a

much broader topic area, both in question and exploration; mapping the main concepts of the topic and identifying the main sources and nature of evidence that exists. In doing so, the most common reasons cited for conducting ScRs are to identify and assess research gaps within a field of study and influence future research projects.[46] Such reviews are commonly adopted when a field of study is emerging or there is not enough homogeneity to enable fair comparisons within available evidence and differing methodological approaches.[47] Subsequently, with less attention towards assessing the quality of evidence found and synthesising results to answer a focused narrow question, attention is more to gathering and producing a descriptive output of everything that exists.

A preliminary review of the literature found no SRs and a dearth of peer-reviewed studies in general. This apparent paucity of current evidence suggests the usefulness of a broad ScR to map existing knowledge; define concepts, explore methods used and tabulate study findings in terms of themes and conclusions. This will establish the extent of the research gap to guide future projects, all of which will specifically direct this postgraduate researcher's dissertation project. As the objective of this ScR is to scope all accessible evidence, it is confidently asserted that this methodological approach is appropriate to the objective of this review.

METHODS AND ANALYSIS

Protocol registration

This protocol has been registered on Open Science Framework registries.[48]

Research study

This protocol outlines the ScR that will support a primary research project into the lived experience of UA. To meet academic targets for this doctorate project, the review searches are run between May and July 2023, with a target for the ScR to be completed by 15 December 2023.

Patient and public involvement

Although not directly involved in the development of this literature review protocol, patient and public involvement (PPI) engagement with endometriosis UK reflected a positive and supportive response for the project design that this protocol and ScR will support.

Framework of objectives

Figure 1 presents an overview of the review strategy and has been developed following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR)[49] and the Joanna Briggs Institute (JBI) guidelines for ScR.[50] This illustration outlines not only the framework of how this protocol was developed, but also provides the reader with a clear visual representation that dependable techniques and processes have been followed, supporting overall trustworthiness of the research.

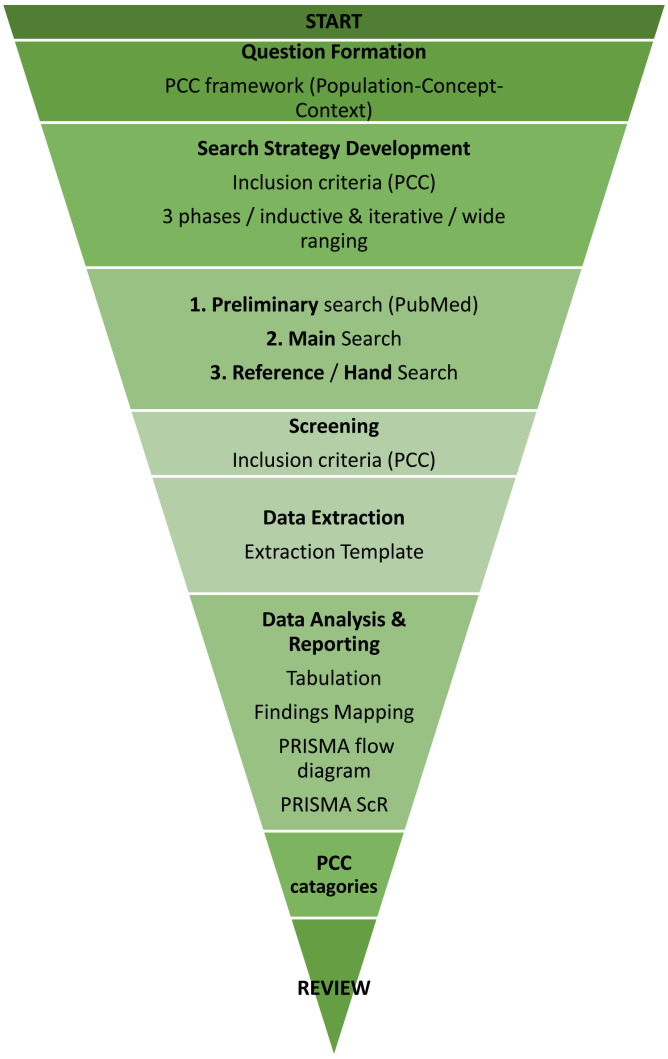

Figure 1 Strategy overview. PRISMA-ScR, Scoping Review Extension of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

Question formation and boundaries

Explicit review questions provide a foundational structure to achieve the objective and shape the inclusion criteria, thus understanding boundaries of the search.[50 51] The questions were developed using the population–concept–context (PCC) framework (see box 1), linked directly to achieving the primary review objective to explore two concepts within current literature, in the form of two questions (Q1 and Q2).

For this protocol, the concept of a 'journey' includes any research on the experience of factors that result in a diagnosis such as primary or secondary care consultations and diagnostic interventions.

Box 1 PCC framework

Population
All peer-reviewed and grey literature that includes all people diagnosed with adenomyosis across all age groups.

Concept
Q1 All literature reporting research on the daily living experience of impact of the disease uterine adenomyosis will be included in this review.
Q2 All literature reporting research on the perceptions of the diagnostic journey that leads to a diagnosis of uterine adenomyosis will be included in the review.

Context
The context is international. The location and environment will not be limited. The search is intended to be broad, and given the apparent limited research, no time frame/date filtering will be set during searches.

ScR questions

Q1: What research exists internationally, exploring the lived experience of disease impact of UA, for all women across all age groups?

- What approaches have researchers used to investigate lived experience of disease impact?
- How has the concept of 'lived experience' been defined?
- What are the characteristics of the samples studied?
- What methods have been used to measure lived experience related to disease impact and/or QoL and/or HRQoL?
- What factors were investigated or identified in relation to lived experience and disease impact?
- What themes were identified?

Q2: What research exists internationally, exploring perceptions of the diagnostic journey that leads to a diagnosis of UA for all women across all age groups?

- What approaches have researchers used to evaluate perceptions of the diagnostic journey?
- How has the concept of 'diagnostic journey' been defined?
- What are the characteristics of the samples studied?
- What methods have been used to measure perceptions of the diagnostic journey?
- What factors were investigated or identified in relation to perceptions of the diagnostic journey?
- What themes were identified?

Inclusion criteria

Population

This review will consider documents researching humans diagnosed with UA.

Concept

This review will consider descriptive and or interpretive evidence that draws on the experiences of persons diagnosed with UA including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research.

Context

The context will include all settings and will not be limited by geography. All languages, recognising the nature of the search, may fail to find non-English papers, as limiting may result in important contextual evidence being missed. Any English abstracts of non-English research will be case-by-case screened for inclusion dependent on the ability to understand the research process and findings and may be included at least as background information. This will support transparency in the process. There will be no time frame filtering during searches, as it is important to understand the full extent of evidence available. Therefore, the search time frame will be determined by the earliest documents available in the database being interrogated (eg, Medline 1960s).

Sources

Qualitative studies will be included as well as mixed-methods studies that have included qualitative outcomes. Although not included in the preliminary search, quantitative studies may be considered in this ScR if lived experience or QoL is included as an outcome (as defined in the Introduction section). Examples include those that have used surveys or questionnaires. Primary evidence and secondary reviews will be included.

Exclusions

- No clear focus to adenomyosis with significant coexiting diagnosis of another gynaecological pelvic disease. As noted, endometriosis is not an exclusion criterion (see rationale within the Introduction section).
- If the focus is solely on medical, surgical or pharmacological interventions.
- If lived experience, symptom impact, QoL or diagnosis is not included as an outcome (as defined in the Introduction section).
- If the participants are the same as in a previous related study, unless there is separate qualitative analysis.

Search strategy

The search strategy adopts the JBI three-phase process.[52]

1. An initial limited pilot search using PubMed was completed on 20 September 2022. This was based on personal knowledge of the field and iteratively developed through an analysis of the terminology used in the titles and abstracts of papers found, followed by scrutiny of reference lists and the text words and index terms used. Boolean operators search terms and parenthesis were employed (see table 1). Due to the extensive number of sources being searched, Medical Subject Headings were not used as are not available to all sources and therefore cannot be applied systematically to ensure quality of conduct and reporting.[53]
2. Using the pilot phase identified terms and adapting them inductively and iteratively, the search protocol will be further constructed. This will be tailored to each database and source that is found, re-running

Table 1 Preliminary search strings

Q1	Title/abstract	adenomyosis OR "adenomyosis uteri"
AND	Title/abstract	Impact* OR experienc* OR life OR living OR (QOL OR "quality of life") OR coping OR outcome OR wellbeing
AND	All fields	focus group* OR grounded theory OR interview* OR life histor* OR narrative* OR qualitative OR phenomenolog* OR story
		(Filter to Human)
Q2	**Title/abstract**	**adenomyosis OR "adenomyosis uteri"**
AND	Title/abstract	Diagnos*
AND	Title/abstract	journ* OR pathway* OR perception*
AND	All fields	experienc* OR life OR living
		(Filter to Human)

previous searches if required on identification of relevant additional terms. This process will be explicitly detailed in the review.

3. Manual handsearching reference lists from relevant studies found and onwards citations, to retrieve potential additional papers.

The process will be inductively iterative and as familiarity of terminology grows, adapted to achieving comprehensiveness, within the time and resource constraints of a single researcher. Any limitations to the breadth of the search process will be explicitly detailed and justified in the review. The aim is to be wide-ranging and find both published and unpublished literature including grey literature.

Sources

- EBSCOHost—Medline and CINAHL Plus (Medicine and Nursing and Allied Health Literature).
- Web of Science (multidisciplinary database including social sciences).
- Google Scholar (articles, theses, books, abstracts from academic publishers, professional societies, online repositories, universities and other web sites).
- Cochrane library databases.
- PROSPERO data base of systematic reviews (review completed and published/double checked via Google).
- JBI database of systematic reviews.
- EThOS (British Library e-thesis online).
- Web search engines, for example, Google (grey literature).

A research librarian will be consulted as recommended when searching for grey literature.[54]

Due to the time constraints of a doctoral thesis by a single researcher, the searches will not be formally re-run at the ScR conclusion.

Study selection

References will be stored and managed by uploading to the RefWorks web-based bibliography and database manager, where duplicates can be removed.

Titles and/or abstracts retrieved through the search strategy will be screened by the primary researcher. This will identify studies that meet the inclusion criteria. The full text of any potentially eligible evidence sources will be retrieved and assessed more fully by the primary researcher. If there is any dubiety with eligibility, then these will be resolved in consultation with a university supervisor. Any disagreements concerning eligibility will be further explored through discussion and reflection with a second university supervisor.

Data extraction

A draft extraction template as adapted from that described by Peters, *et al*[50] has been piloted (see online supplemental file 1). However, the process will be inductive with any emerging categories added as required. This will be explicitly detailed and justified in the review.

The following information will be collected for each item: author, publication year, evidence type, source, title, aim(s), findings, disease(s), definitions and conclusions. Additional information will be collated based on the PCC framework (see box 1) detailing; sample size, demographics, means of diagnosis, race/ethnicity (population); methodology and methods used to understand the phenomenon (concept); study setting/origin, recruitment means, means of data collection and data collection setting (context). Any missing data will be retrieved, if possible, from authors.

References will be collated into an electronic folder, to be systematically managed for grouping and analysis. This will be within a self-created Excel spreadsheet.

Quality assessment

ScRs are deliberately seeking to find a wide-ranging amount of evidence often with considerable methodological heterogeneity. This makes a formal quality assessment difficult.[55 56] Indeed, as the objective of an ScR is descriptive rather than analytic then quality appraisal is not deemed mandatory.[49] Additionally, it may be counterproductive and risks omitting valuable evidence. However, Dixon-Woods *et al*[57] present some 'prompts' as reminders of the quality elements that may require some appraiser scrutiny. Greenhalgh[58] supports this guidance as it provides a less-prescriptive, more pragmatic approach that can be useful when quality assessing. Such quality appraisal prompts, rather than strict mandatory criteria, will provide good baseline quality insights for this ScR and can also be used for quantitative papers identified. Nevertheless, the need for formal quality appraisal is out with the objective of this ScR, and all identified evidence will be included.

Data analysis

Results from each item of evidence will be analysed using an inductive approach and basic content analysis as described in the JBI endorsed recommendations by Pollock *et al*.[59] Categories will be identified, as described by the paper's cited author. Due to the likely heterogeneity of evidence found, a descriptive tabular and/or diagrammatic mapping of findings with some overview narrative will be produced. Any more in-depth synthesis is more appropriate for an SR (qualitative evidence synthesis) and out with the objective of an ScR.[50] This process will provide a clear and transparent, auditable process that will allow the reader to understand how the findings and conclusions of the review, were achieved.

Presentation of results

Search outputs will be presented using the 'PRISMA 2020 flow diagram for new SRs.[60]

Review results will be reported consistent with the Scoping Review Extension of the PRISMA-ScR checklist and explanation notes.[49] It is also noted that the updated PRISMA statement in 2021[61] has additional guidance that the JBI suggests as pertinent to ScR researchers. The results will be reported to answer the primary objective and research question using the data from the extraction tool for the PCC framework categories.

It is recognised that ScRs can be table-heavy, which is difficult to process easily for readers. In this regard, attempts will be made to 'convey results to the reader in an understandable way'[59] with use of visual representations such as tree graphs and/or pie charts.

ETHICS AND DISSEMINATION

Central to understanding modern healthcare excellence in stimulating innovation, encouraging shared decision-making and promoting evidence-based practice, is the patient.[58 62] However, due to this researcher's limited student resources, this protocol and review will not have PPI and they were not involved in the design, conduct or planning. In this regard, approval from the ethics boards of this researcher's university and health board is not required for this review. However, the wider project has been discussed with local clinical gynaecology colleagues as well as a PPI forum, and it is anticipated the results will be of interest to them specifically. The review may also be of interest to journal editors, HCPs, government authorities and policy-makers, researchers conducting ScRs and patient support groups. The primary purpose of this review is to guide a doctoral thesis into exploring lived experience; to understand symptom impact, journey to diagnosis and ultimately, to improve patient care. This ScR will quantify current literature, identify gaps, define concepts and prevent research duplication. The intention is to prepare this protocol and the final review results for dissemination via publication, allowing distribution and engagement with interested parties via social media. This will also be beneficial to the progress and value of this researcher's final thesis.

Contributors This protocol has been developed as part of a professional doctorate thesis. MAT is the postgraduate student researcher and corresponding author. TJC, MM and FEM are university supervisors for this thesis. MAT, TJC and MM have been involved with the study's conception and design. MAT drafted the manuscript. FEM came onto the supervision team slightly later in Autumn 2023. MAT, TJC, MM and FEM have been involved in revisions. All authors have critically revised the manuscript for important intellectual content. All authors have read and approved the final manuscript.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

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