

Exploring the knowledge, attitudes, and perceptions towards endometriosis among both patients and healthcare providers: a scoping review protocol

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Abstract	. 3
1.Scoping review	. 4
1.1Protocol for scoping review	. 4
1.1.1Title	. 4
1.1.2Authors	. 4
1.1.3Introduction	. 4
1.1.4Rationale for scoping review	. 5
1.1.5Review question	. 7
1.1.6Inclusion criteria	. 7
1.1.6.1Participants	. 7
1.1.6.2Concept	. 8
1.1.6.3Context	. 9
1.1.7Types of sources	10
1.1.8Methods	12
1.1.8.1Search strategy	12
1.1.8.2Study/Source of evidence selection	14
1.1.8.3Data extraction	14
1.1.8.4Data analysis and presentation	15
1.1.9Acknowledgements	15
1.1.10Funding.	16
1.1.11Conflicts of interest	16
2.References	17
3.Appendices	19
Appendix I: Search strategy	19
Appendix II Grey literature	28
Appendix III: Data extraction form	29
Data extraction form	29

Abstract

Objective:

This scoping review aims to systematically map the existing literature on the knowledge, attitudes, and perceptions (KAP) of endometriosis among both patients and healthcare providers.

Introduction:

Endometriosis is a chronic and often debilitating condition affecting an estimated 10% of reproductive-aged individuals globally. Despite its significant impact, diagnosis is frequently delayed by years due to a combination of patient, provider, and systemic factors. Previous research suggests that gaps in knowledge, negative attitudes, and misconceptions among both patients and healthcare professionals contribute to these delays and to suboptimal care. However, the evidence base remains fragmented, with studies varying in scope, methodology, and focus. There is currently no comprehensive synthesis that explores how KAP influences the endometriosis care pathway across different populations and health systems.

Inclusion Criteria:

This review will consider all primary research studies (qualitative, quantitative, and mixed methods) exploring knowledge, attitudes, or perceptions of endometriosis among patients diagnosed with the condition and healthcare providers directly involved in their care. Studies will be included if they report on KAP regarding symptoms, diagnosis, treatment, or support, and are published in English. Excluded are studies focusing on non-diagnosed individuals, healthcare professionals outside endometriosis care, and publications not presenting original data.

Methods:

The review will follow the JBI methodology for scoping reviews and the PRISMA-ScR reporting framework. A comprehensive search will be conducted across multiple databases including PubMed, Ovid MEDLINE, EMBASE, CINAHL, APA PsycINFO, Scopus, and Web of Science. Grey literature and reference list screening will be incorporated to ensure thorough coverage. Study selection and data extraction will be performed independently by two reviewers. Extracted data will be presented narratively and in tabular form, thematically categorized by participant type (patients, providers) and KAP domains (knowledge, attitudes, perceptions).

Keywords:

Endometriosis; Knowledge; Attitudes; Perceptions; Healthcare providers; Patients; Diagnostic delay; Scoping review

1.Scoping review

1.1Protocol for scoping review

1.1.1Title

Exploring the knowledge, attitudes, and perceptions towards endometriosis among both patients and healthcare providers: a scoping review protocol

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1.1.3Introduction

Endometriosis is a chronic gynaecological condition affecting approximately 10% of reproductive-aged individuals worldwide. It is characterized by the presence of endometrial-like tissue outside the uterus, leading to symptoms such as dysmenorrhea, chronic pelvic pain, dyspareunia, and infertility. Despite its significant impact on quality of life, diagnosis is often delayed by several years due to a combination of medical, social, and systemic factors[1, 2]. Among the key barriers to timely diagnosis and effective management is the level of **knowledge**, **attitudes**, **and perceptions** (KAP) held by both patients and healthcare providers (HCPs).

Evidence from a range of international studies suggests that diagnostic delay and inadequate endometriosis care are global issues, although the extent and nature of these challenges vary across countries. In high-income countries such as **the United Kingdom**, **Australia**, **and the United States**, studies often highlight provider dismissal, limited diagnostic tools, and fragmented care pathways[3-8]. Conversely, research from middle- and low-income countries (**including Lebanon**, **Pakistan**, **and Brazil**) tends to emphasize low public awareness, limited access to specialist services, and cultural stigma surrounding menstruation and reproductive health[9-11]. These differences indicate that while delayed diagnosis is a widespread phenomenon, the underlying causes and healthcare responses differ considerably across sociocultural and healthcare contexts.

The existing body of literature on knowledge, attitudes, and perceptions (KAP) toward endometriosis presents a diverse yet fragmented landscape, both geographically and thematically. Studies extend over a wide range of countries (including Australia, the UK, Italy, Poland, Lebanon, Pakistan, Finland, Israel, and the United States) reflecting global concern but also revealing notable disparities in research emphasis and depth[3-8, 12-15]. For instance, while Western European nations and Australia contribute richly to qualitative insights around lived experiences and healthcare interactions, studies from the Middle East and South Asia (e.g., Lebanon, Pakistan) tend to focus on public awareness and the impact of brief educational interventions. Despite this geographical breadth, there is limited crosscultural comparison, and certain regions (particularly low- and middle-income countries) remain underrepresented. Thematically, the literature includes studies focused on patients, healthcare providers, and the general public, yet these efforts are largely siloed, lacking a unified synthesis. This fragmented evidence base highlights a pressing need to integrate and contextualize diverse perspectives to inform global approaches to endometriosis care.

A growing body of literature highlights that patients with endometriosis frequently encounter misdiagnosis, delays in care, and inadequate support due to gaps in knowledge among both the general public and medical professionals [5, 16]. Studies suggest that many healthcare providers lack sufficient training on recognizing endometriosis symptoms, leading to dismissive attitudes and ineffective treatment strategies[2, 17]. Simultaneously, many patients experience difficulty articulating their symptoms, which, coupled with societal normalization of menstrual pain, further contributes to diagnostic delays[18, 19]. These barriers create a significant unmet need for improving both awareness and the quality of patient-provider interactions in endometriosis care.

1.1.4Rationale for scoping review

While there have been numerous studies on specific aspects of KAP regarding endometriosis, a preliminary search of MEDLINE, the Cochrane Database of Systematic Reviews and JBI Evidence Synthesis was conducted and no current or underway systematic reviews or scoping reviews on the topic were identified. There is currently no comprehensive synthesis of what is known about the subject across different populations and healthcare settings. Existing research varies in focus, methodology, and scope, making it difficult to identify key areas where interventions are most needed.

Some recent reviews have explored related but distinct aspects of endometriosis care. For example, Cromeens et al. (2021) proposed a scoping review protocol to examine pathways, timing, and delays in diagnosis[20]. While valuable in highlighting the consequences of diagnostic delay and its

association with patient outcomes, the review did not investigate the attitudinal or perceptual factors that influence these delays. Fryer et al. (2024) provided the first synthesis of evidence explicitly examining where and why diagnostic delays occur, revealing system-level issues such as healthcare provider knowledge gaps and the frequent dismissal of patients' symptoms[2]. However, their review focused primarily on structural and process-related barriers rather than exploring the deeper cognitive and behavioural mechanisms that shape clinician responses and patient experiences.

Similarly, Westwood et al. (2023) conducted a scoping review on disparities in endometriosis diagnosis and surgical management within the United States (U.S.), demonstrating that racial and ethnic minority women face increased risks of surgical complications and reduced access to minimally invasive procedures[21]. This review underscored the presence of systemic inequities but did not address how healthcare providers' knowledge and perceptions may contribute to such disparities.

Together, these reviews underscore the importance of understanding diagnostic delay and inequities in care, but none offer a holistic synthesis of how knowledge, attitudes, and perceptions shape the diagnosis, treatment, and support experiences of people with endometriosis. This scoping review builds upon the work of Fryer et al. (2024) by investigating the broader contextual and systemic KAP factors (particularly among healthcare providers) that underpin diagnostic delays and fragmented care. It directly addresses the research priorities outlined by the James Lind Alliance Priority Setting Partnership, as reported by Graham et al. (2020) and Horne et al. (2017), which identified reducing diagnostic delay and improving education and awareness among healthcare professionals as top research priorities[22, 23].

A scoping review is therefore necessary to systematically map the available evidence, identify recurring themes, and highlight areas where further research or educational initiatives are needed. By synthesizing findings from diverse studies, this review will provide a clearer understanding of how knowledge, attitudes, and perceptions shape the experiences of both patients and healthcare providers, ultimately guiding future strategies for improving endometriosis management and support. This scoping review aims to map the existing literature on the knowledge, attitudes, and perceptions (KAP) of endometriosis among both patients and healthcare providers, highlighting trends, gaps, and areas for improvement. By synthesizing existing research, the review will provide insights into the knowledge levels among different stakeholders, identify misconceptions, and suggest future research area. The findings will help inform interventions to enhance early recognition, improve patient-provider communication, and probably lead to better healthcare outcomes for individuals affected by endometriosis.

The objectives of this scoping review are:

- 1. To identify the current level of knowledge, attitudes, and perceptions about endometriosis among patients and healthcare providers.
- 2. To identify patients' **attitudes** toward the disease, medical management and support, and gauges feelings, beliefs, or predispositions healthcare system
- 3. To identify Healthcare providers' **attitudes** toward the disease, medical support, and available treatments
- 4. To explore how patients and healthcare providers perceive the symptoms, diagnosis, and treatment of endometriosis.
- 5. To explore existing barriers related to endometriosis care from both patient and provider perspectives.
- 6. To identify gaps in research and suggest areas for future studies or interventions aimed at improving knowledge and support for endometriosis management.

1.1.5Review question

What is known about the knowledge, attitudes, and perceptions (KAP) of endometriosis among patients and healthcare providers?

1.1.6Inclusion criteria

This scoping review will be conducted in accordance with the Joanna Briggs Institute (JBI) methodology for scoping reviews. The inclusion criteria have been developed based on the PCC framework (Participants, Concept, Context), which provides a structured approach for determining eligibility and developing an effective search strategy.

1.1.6.1Participants

This review will include peer-reviewed and grey literature that involve the following participant groups:

Patients diagnosed with endometriosis, across all age groups and demographics. This
includes adolescents, reproductive-age individuals, and those diagnosed later in life,
regardless of the disease stage or severity. Moreover, in recognition of the significant
diagnostic delay often experienced in endometriosis, the review will also consider studies

involving individuals who self-identify or self-diagnose with the condition, acknowledging that many may experience symptoms for years before receiving a formal diagnosis.

- Healthcare providers (HCPs) who interact with and manage endometriosis patients, including:
 - General practitioners
 - Gynaecologists
 - Nurses
 - Psychotherapists
 - Nutritionists
 - Pharmacists

These groups are selected due to their direct involvement in the experience, diagnosis, and management of endometriosis.

Exclusion Criteria:

- Studies focusing on **non-diagnosed individuals** (e.g., general population or those with self-reported symptoms but no formal diagnosis).
- **Healthcare professionals not involved in endometriosis care**, such as administrative staff or those in unrelated specialties (e.g., dermatologists, radiologists, etc.).
- Family members, partners, or the general public unless they are the primary participants providing data on the KAP of diagnosed individuals or relevant healthcare professionals.

1.1.6.2Concept

The central concept of this review is the knowledge, attitudes, and perceptions (KAP) of endometriosis among the included participant groups. The review will include literature that discusses any of the following:

- Knowledge: Refers to factual, cognitive understanding of endometriosis. For healthcare
 providers, this includes knowledge of clinical features (e.g., symptoms, diagnosis criteria, and
 treatment options). For patients, it includes awareness and understanding of the condition,
 its management, and its implications on health and daily life.
- Attitudes: Refers to feelings, beliefs, and values toward endometriosis. This may include stigmas, perceived severity, or perceived legitimacy of the condition by patients or healthcare providers.

 Perceptions: Refers to how individuals interpret or make sense of endometriosis based on personal experience, clinical exposure, societal influence, or cultural norms. This may include perceived barriers to care, treatment expectations, and perceived quality of life impacts.

Exclusion Criteria:

- Studies that do not address any aspect of knowledge, attitudes, or perceptions of endometriosis.
- Literature focusing solely on **clinical, biochemical, or molecular aspects** of endometriosis without exploring the subjective or experiential dimensions related to KAP.
- Studies that focus on awareness campaigns or education programs without assessing the actual perceptions, attitudes, or knowledge among patients or providers.

1.1.6.3Context

The review will focus on literature discussing the **symptoms**, **diagnosis**, **management**, **and support systems** for endometriosis within the context of KAP.

- Geographical Scope: International. Studies from all countries and healthcare systems will be considered to capture global perspectives.
- **Settings**: No restriction will be placed on the healthcare setting (e.g., hospitals, clinics, community health centres), as long as the study addresses relevant KAP components.
- **Cultural and Social Contexts**: Studies across all cultures, ethnicities, and socio-demographic settings will be included to reflect diverse interpretations and experiences of endometriosis.
- Language: Only studies published in English will be considered. While this may limit the breadth of international perspectives, the decision is methodologically justified. Many of the included studies are qualitative in nature and contain conceptually rich data, including nuanced themes and participant expressions that are deeply embedded in specific cultural and linguistic contexts. Widely available translation tools and services may not adequately capture the subtleties of such data, potentially leading to misinterpretation or loss of meaning. Therefore, restricting the review to English language publications ensures greater reliability in understanding and interpreting the findings, particularly in studies involving complex qualitative themes.

Exclusion Criteria:

Studies published in languages other than English.

• Studies that do not provide adequate contextual information regarding endometriosis diagnosis, symptom experience, management, or support in relation to KAP.

Table 1. Inclusion and exclusion criteria

Category	Inclusion	Exclusion		
Participants	- Patients diagnosed with	- Public, family members, or		
	endometriosis across all age	HCPs not directly involved with		
	groups	diagnosed patients		
	- Healthcare providers (GPs,	- Non-diagnosed individuals		
	gynaecologists, nurses,			
	psychotherapists, etc.)			
Type of Study	Studies assessing knowledge,	Studies assessing KAP		
	attitudes, or perceptions about	unrelated to endometriosis		
	endometriosis			
Type of Publication /	Primary research studies	Reviews, case studies, posters,		
Methodology	including qualitative,	conference abstracts,		
	quantitative, and mixed	abstracts without full text,		
	methods designs	reports, study protocols		
Language	English	Any language other than		
		English		
Context	Focus on diagnosis, symptoms,	Studies unrelated to these		
	management, or support	aspects or lacking context in		
	systems related to	relation to endometriosis and		
	endometriosis in any	КАР		
	international context			

1.1.7Types of sources

This scoping review will include a broad range of **original primary research studies** to comprehensively map the existing literature related to the KAP of endometriosis among patients and healthcare providers. The selection of sources will adhere to the JBI methodology for scoping reviews, which emphasizes inclusivity in order to capture the breadth and depth of existing evidence.

Included Source Types

The review will consider **all original primary research studies**, regardless of methodological orientation. This includes:

- Qualitative studies (e.g., interviews, focus groups, ethnographic studies): These provide indepth understanding of personal experiences, beliefs, and interpretations relating to endometriosis.
- Quantitative studies (e.g., cross-sectional surveys, cohort studies): These measure and describe levels of knowledge, attitudes, or perceptions in various populations and can offer comparative insights.
- Mixed methods studies: These combine qualitative and quantitative approaches to provide a more comprehensive perspective on the research question.
- Grey literature, including theses, dissertations, and reports from reputable organizations, will
 be included where they report relevant primary research findings. These sources are valuable
 for capturing emerging or less formally published data.

Only studies presenting **empirical data** related to KAP will be included. This ensures the review is grounded in documented experiences and measurable findings relevant to the research question.

Excluded Source Types

The following types of sources will be excluded from the review:

- Opinion papers, editorials, or commentary articles: These are typically based on anecdotal evidence or author viewpoints and do not present systematically collected data.
- Narrative reviews, systematic reviews, meta-analyses: While valuable for broader evidence synthesis, these are not considered original sources of primary data and will be excluded to avoid duplication.
- Case reports or case series: These often provide isolated clinical observations without generalizable data on KAP.
- Conference abstracts, posters, and presentations: These will be excluded unless accompanied by a full-text version of the study due to the limited detail they offer.
- **Study protocols**: These outlines intended research but do not contain data or findings and are therefore outside the scope of this review.

This selective inclusion of source types is intended to ensure that the evidence synthesized is grounded in **empirical research**, relevant to the **PCC framework**, and useful for identifying gaps and informing future studies or interventions aimed at improving endometriosis care.

1.1.8Methods

The proposed scoping review will be conducted in accordance with the Joanna Briggs Institute (JBI) methodology for scoping reviews with the guidance of the Preferred Reporting Item for Systematic Review and Meta-Analysis extension for scoping review (PRISMA-ScR) checklist.

1.1.8.1Search strategy

Specific search strategy was developed through initial limited search of one database to identify articles on the topic. The text words contained in the titles and abstract of the relevant retrieved articles and the index terms in each article were used to develop a full search strategy for this review (see Appendix 1). Published studies on this topic will be identified using the agreed search strategy on multiple databases including PubMed, Ovid MEDLINE, EMBASE, CINAHL, APA PsycInfo, Scopus, and Web of science. Each database contributes unique strengths and perspectives, allowing for a multidisciplinary understanding of the topic. PubMed and Ovid MEDLINE serve as foundational sources for biomedical and clinical research, offering extensive coverage of peer-reviewed literature in medicine, epidemiology, and healthcare delivery. These databases are particularly well-suited for identifying studies focused on healthcare providers' clinical knowledge and patient care experiences related to endometriosis. In contrast, EMBASE complements MEDLINE by including a broader range of international and European journals, as well as conference abstracts and grey literature. EMBASE also offers more detailed indexing, which supports the identification of studies involving nuanced healthcare practices and patient perspectives that may not be captured in MEDLINE alone. While PubMed, MEDLINE, and EMBASE focus primarily on clinical and biomedical literature, CINAHL (Cumulative Index to Nursing and Allied Health Literature) brings a valuable focus on nursing and allied health professions. Given that this review includes perspectives from nurses, psychotherapists, and nutritionists, CINAHL ensures representation of literature that addresses their roles and experiences in endometriosis care—areas that are less emphasized in the biomedical databases. To further capture the psychosocial dimensions of endometriosis, APA PsycINFO is included for its strength in indexing psychological and mental health literature. This database is particularly important for exploring patients' attitudes, beliefs, stigma, and emotional well-being, as well as healthcare providers' perceptions from a psychological standpoint dimension often underrepresented in strictly medical databases. In addition to subject-specific databases, Scopus and Web of Science provide broad

multidisciplinary coverage and strong citation tracking capabilities. Both databases include literature from the health sciences, social sciences, and humanities, supporting the identification of research that spans public health, health communication, and systemic healthcare issues. While **Scopus** is known for its wide journal coverage and advanced search features, **Web of Science** enhances the review's ability to trace citation networks and uncover high-impact studies that may influence how endometriosis is perceived and managed across different contexts. Together, they ensure the inclusion of cross-cutting perspectives essential to understanding the sociocultural and systemic factors that shape endometriosis-related knowledge and care. By combining these databases, the review is positioned to capture a comprehensive and diverse range of evidence, reflecting the complexity of endometriosis from clinical, psychological, allied health, and sociocultural perspectives.

Grey literature will be included in this scoping review to ensure a comprehensive and balanced understanding of the existing KAP toward endometriosis among patients and healthcare providers. Given the evolving nature of endometriosis research and the potential for delayed or selective publication of studies in peer-reviewed journals, grey literature sources (such as government reports, policy documents, organizational guidelines, conference proceedings, and unpublished theses) can offer timely, relevant, and often practice-oriented insights. Moreover, grey literature helps reduce publication bias and captures data from a wider range of stakeholders, including professional bodies and patient advocacy groups. This is particularly important in the context of endometriosis, where gaps in care and policy are often highlighted outside traditional academic channels. Including grey literature therefore enriches the review by integrating diverse perspectives and ensuring that less visible but highly relevant information is not overlooked. To identify relevant grey literature, the agreed search strategy was applied across multiple platforms, including the Networked Digital Library Theses and Dissertations (http://search.ndltd.org/ Policy Commons (https://policycommons.net/modules/global-think-tanks), medRxiv (https://www.medrxiv.org/), Research Square (https://www.researchsquare.com/), SSRN (https://papers.ssrn.com/), and the Open Science Framework (https://osf.io). The keywords will be (endometriosis, knowledge, believe, belief, attitude, and perception).

Furthermore, the reference lists of all included articles will be screened to identify additional relevant publications that may not have been captured through the initial database search. This process, often referred to as 'citation chasing' or 'snowballing', helps ensure a comprehensive review by including studies that are pertinent but may be indexed differently or published in journals not included in the searched databases. It increases the likelihood of identifying key or foundational literature, as well as more recent or region-specific studies that are crucial for mapping the breadth and depth of the topic.

The search will not be limited by geographic region in order to provide a comprehensive overview of knowledge, attitudes, and perceptions (KAP) related to endometriosis across diverse healthcare systems, cultures, and populations. This global scope is essential for identifying common challenges, variations in care, and potential areas for improvement in the management of endometriosis worldwide. Databases will be searched from inception up to the date of the final search. No lower date limit will be applied to ensure a comprehensive and inclusive overview of the literature on endometriosis. This approach allows the identification of foundational studies, the evolution of knowledge, and shifts in diagnostic criteria, clinical management, and healthcare provider awareness over time. Including older research also helps contextualize current understandings within their historical development and may reveal long-standing gaps or persistent misconceptions in the field.

1.1.8.2Study/Source of evidence selection

Following the searching step, all retrieved studies will be imported into **EndNote** reference manager software and **Covidence** software to manage the processes of this review, and the duplicates will be removed by the primary reviewer Khalid Alzahrani (KA) before being assessed for eligibility. After deduplication, the remaining studies will be screened by the primary reviewer (KA) and another independent reviewer Hisham Alshammari (HA) first, by title and by abstract, then the full text screening will be performed to be assessed for eligibility and to exclude studies that cannot satisfy the inclusion criteria. Reasons for excluding any study after the full-text assessment will be reported in the scoping review report. The selection process will be undertaken also by the primary and secondary independent reviewers (KA and HA) and supported by experienced reviewers Tanja Mueller (TM), and Natalie Weir (NW) to resolve any conflict that arises. A Preferred Reporting Item for Systematic Review and Meta-Analysis extension for scoping review (PRISMA-ScR) flow diagram will be used to report the number of studies identified and screened at each stage and illustrate the inclusion and exclusion process[24].

1.1.8.3Data extraction

Data will be extracted by two independent reviewers (KA and HA) using a data extraction form generated and piloted by the primary reviewer (KA) (see Appendix 2). The form was designed to extract a comprehensive and detailed information including author name, year of publication, purpose of the study, study design, Country, Participants' type and number of participants, KAP Focus, detailed information about the concept, and context of the study, the study findings, conclusion, and recommendations relevant to the review. The drafted data extraction form will be revised and

modified throughout the extraction process as necessary. Any modification will be clarified in the final scoping review.

Participants	Concept	Context		
Population	KAP Focus	Geographical Scope		
-Participants' type: patients,	-knowledge, attitudes,	-Studies across all cultures		
HCPs, or both	perceptions	- Settings: No restriction will be		
-Number of participants	Key Findings	placed on the healthcare		
	- symptoms	setting/ worldwide		
	- diagnosis			
	- treatment			
	- Conclusion			

1.1.8.4Data analysis and presentation

The extracted data will be presented in a tabular form accompanied by a narrative descriptive summary of the evidence that align with the review question and objectives. The followed framework to organise and present the data will be decided on the final review, depending on the content of the extracted data. For example, the data might be grouped according to the Participants' type or to the KAP Focus such as study's focus on knowledge, attitude, and perception.

	knowledge	knowledge	knowledge	attitudes	attitudes	attitudes	perceptions	perceptions	perceptions
	symptoms	diagnosis	treatment	symptoms	diagnosis	treatment	symptoms	diagnosis	treatment
Patients									
HCPs									

1.1.9Acknowledgements

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1.1.11Conflicts of interest

The authors declare no conflict of interest.

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3.Appendices

Appendix I: Search strategy

PubMed <mark>2,443</mark>

Search	Query	Sort	Filters	Search Details	Results	Time
number		Ву				
11	(("endometriosis"[MeSH Terms] OR "endometriosis"[Title/Abstract]) AND ((((("awareness"[MeSH Terms] OR "aware*"[Title/Abstract]) OR ("knowledge"[Title/Abstract] OR "knowledge"[MeSH Terms])) OR ("attitude"[MeSH Terms] OR "attitude*"[Title/Abstract])) OR ("belie*"[Title/Abstract])) OR ("perception*"[Title/Abstract] OR "perception"[MeSH Terms]))) NOT ("scoping review"[Title/Abstract] OR "systematic review"[Title/Abstract])		Recent	(("endometriosis"[MeSH Terms] OR "endometriosis"[Title/Abstract]) AND ("awareness"[MeSH Terms] OR "aware*"[Title/Abstract] OR ("knowledge"[Title/Abstract] OR "knowledge"[MeSH Terms]) OR ("attitude"[MeSH Terms] OR "attitude*"[Title/Abstract]) OR "belie*"[Title/Abstract] OR ("perception*"[Title/Abstract] OR "perception"[MeSH Terms]))) NOT ("scoping review"[Title/Abstract] OR "systematic review"[Title/Abstract])	2,443	11:06:19
10	"scoping review"[Title/Abstract] OR "systematic review"[Title/Abstract]	Most	Recent	"scoping review"[Title/Abstract] OR "systematic review"[Title/Abstract]	377,668	11:06:01
0	("endometriosis"[MeSH Terms] OR "endometriosis"[Title/Abstract]) AND ((((("awareness"[MeSH Terms] OR "aware*"[Title/Abstract]) OR ("knowledge"[Title/Abstract] OR "knowledge"[MeSH Terms])) OR ("attitude"[MeSH Terms] OR "attitude*"[Title/Abstract])) OR ("belie*"[Title/Abstract])) OR ("perception*"[Title/Abstract] OR "perception"[MeSH Terms]))	Most	Recent	("endometriosis"[MeSH Terms] OR "endometriosis"[Title/Abstract]) AND ("awareness"[MeSH Terms] OR "aware*"[Title/Abstract] OR ("knowledge"[Title/Abstract] OR "knowledge"[MeSH Terms]) OR ("attitude"[MeSH Terms] OR "attitude*"[Title/Abstract]) OR "belie*"[Title/Abstract] OR ("perception*"[Title/Abstract] OR "perception"[MeSH Terms]))	2,550	11:05:28
8	(((("awareness"[MeSH Terms] OR "aware*"[Title/Abstract]) OR ("knowledge"[Title/Abstract] OR "knowledge"[MeSH Terms])) OR ("attitude"[MeSH Terms] OR "attitude*"[Title/Abstract])) OR ("belie*"[Title/Abstract])) OR ("perception*"[Title/Abstract] OR "perception"[MeSH Terms])	Most	Recent	"awareness"[MeSH Terms] OR "aware*"[Title/Abstract] OR "knowledge"[Title/Abstract] OR "knowledge"[MeSH Terms] OR "attitude"[MeSH Terms] OR "attitude*"[Title/Abstract] OR "belie*"[Title/Abstract] OR "perception*"[Title/Abstract] OR "perception"[MeSH Terms]	2,893,520	11:05:18
7	"perception*"[Title/Abstract] OR "perception"[MeSH Terms]	Most	Recent	"perception*"[Title/Abstract] OR "perception"[MeSH Terms]	784,802	11:05:01
6	"belie*"[Title/Abstract]	Most	Recent	"belie*"[Title/Abstract]	386,022	11:04:43
5	"attitude"[MeSH Terms] OR "attitude*"[Title/Abstract]	Most	Recent	"attitude"[MeSH Terms] OR "attitude*"[Title/Abstract]	827,744	11:04:26
4	"knowledge"[Title/Abstract] OR "knowledge"[MeSH Terms]	Most	Recent	"knowledge"[Title/Abstract] OR "knowledge"[MeSH Terms]	1,043,398	11:04:13
3	"awareness"[MeSH Terms] OR "aware*"[Title/Abstract]	Most	Recent	"awareness"[MeSH Terms] OR "aware*"[Title/Abstract]	358,269	11:04:00
2	"endometriosis"[MeSH Terms] OR "endometriosis"[Title/Abstract]	Most	Recent	"endometriosis"[MeSH Terms] OR "endometriosis"[Title/Abstract]	36,650	11:03:30

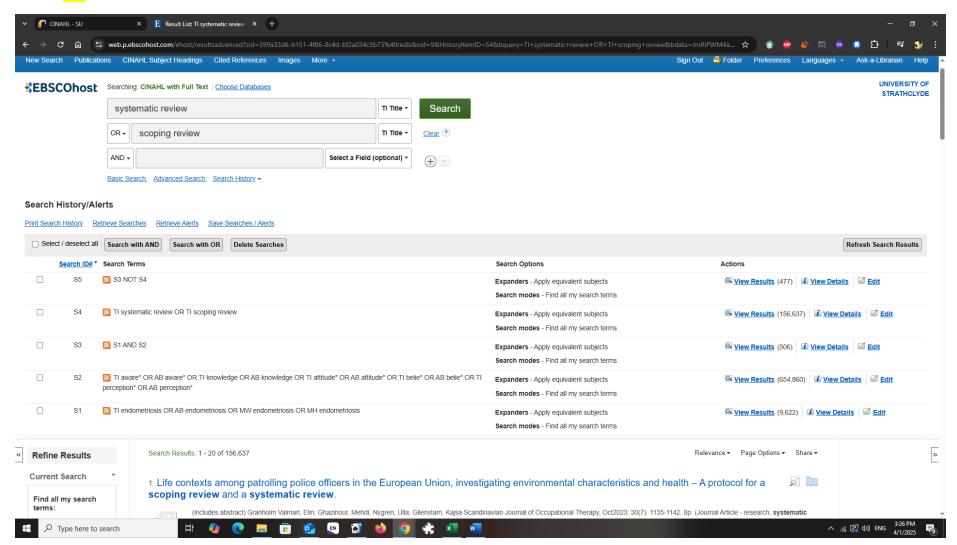
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- 1 aware*.ti,ab. 495065
- 2 knowledge.ti,ab. 1303518
- 3 attitude*.ti,ab. 270948
- 4 belie*.ti,ab. 516447
- 5 perception*.ti,ab. 452805
- 6 1 or 2 or 3 or 4 or 5 2627062
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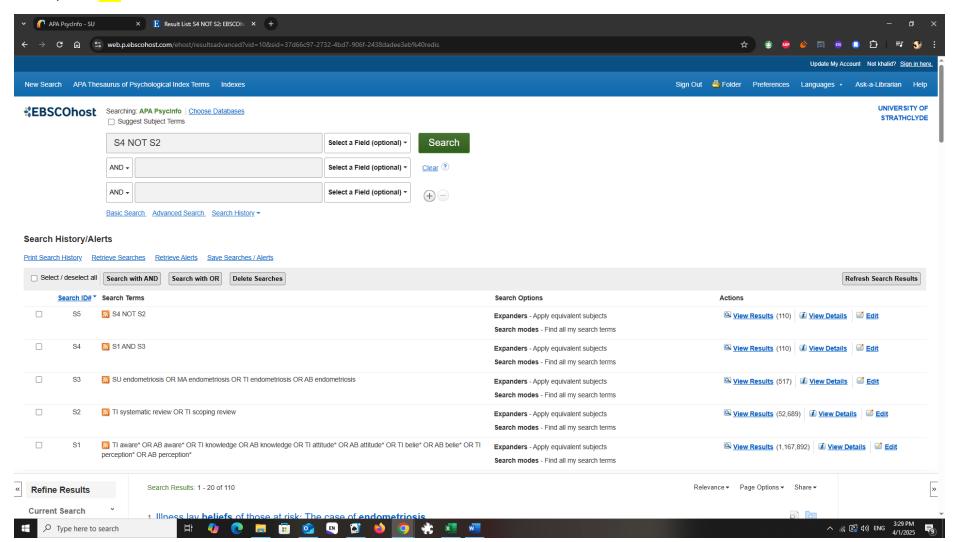
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- 1 aware*.ti,ab. 348043
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- 5 perception*.ti,ab. 369945
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- 7 endometriosis.ti,ab. 31127
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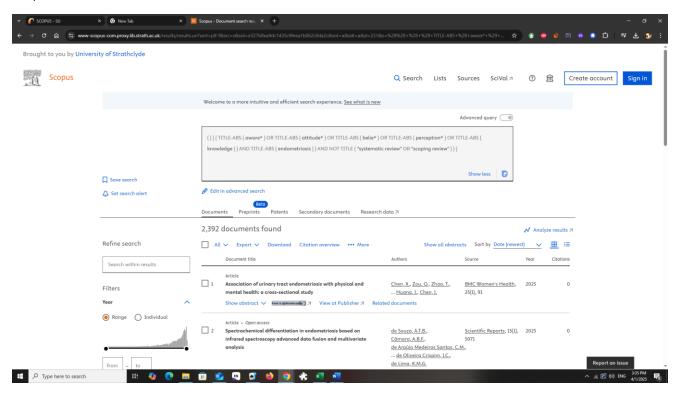
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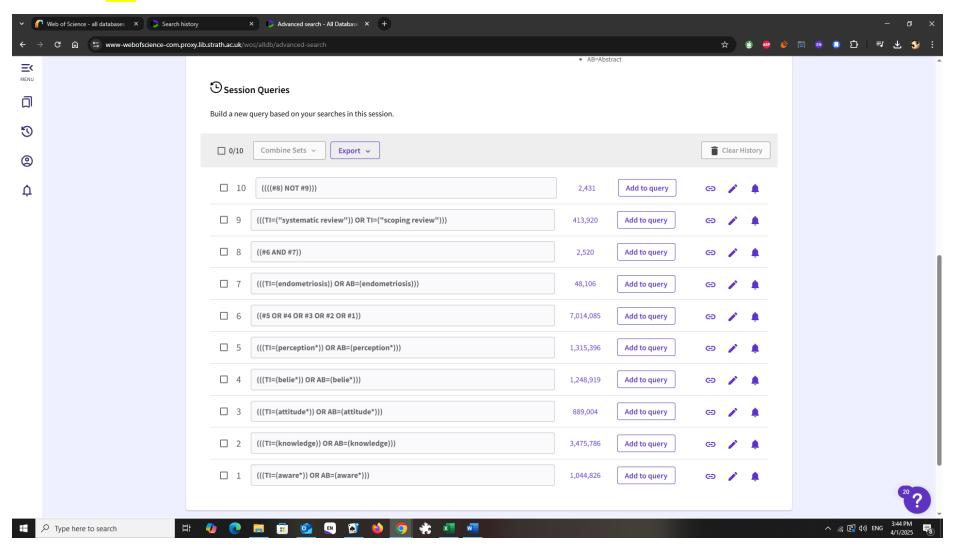
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((((TITLE-ABS (aware*) OR TITLE-ABS (attitude*) OR TITLE-ABS (belie*) OR TITLE-ABS (perception*) OR TITLE-ABS (knowledge)) AND TITLE-ABS (endometriosis)) AND NOT TITLE ("systematic review" OR "scoping review")))

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Appendix II Grey literature

Example for grey literature

https://www.medrxiv.org/

The ELEMI healthcare professional Study

https://www.medrxiv.org/content/10.1101/2023.03.18.23287312v1

Endometriosis Online Communities: A Quantitative Analysis

https://www.medrxiv.org/content/10.1101/2024.02.27.24303445v1

https://www.researchsquare.com/

Bridging the gap: Can a patient questionnaire together with staff education increase diagnostics of endometriosis in primary care? -A pilot study

https://www.researchsquare.com/article/rs-2258804/v1

Fertility Preservation Counselling for Women With Endometriosis: A European Online Survey

https://www.researchsquare.com/article/rs-966804/v1

Trends among patients with endometriosis over a 7-year period and the impact of the COVID-19 pandemic. Experience from an academic high level endometriosis centre in Germany.

https://www.researchsquare.com/article/rs-1784980/v1

'A day to day struggle': A comparative qualitative study on experiences of women with endometriosis and chronic pelvic pain

https://www.researchsquare.com/article/rs-289745/v1

Sex, Pain & Endometriosis: The development of a patient-centred e-health resource for those affected by endometriosis-associated dyspareunia

https://www.researchsquare.com/article/rs-1946310/v1

https://papers.ssrn.com/

Perceived Effectiveness and Use of Naturopathic Treatments for Endometriosis: A Cross-Sectional Survey of Australian Naturopaths Experienced in Endometriosis Management

https://papers.ssrn.com/sol3/papers.cfm?abstract_id=4102851

Endometriosis is More than a Painful Period. Period

https://papers.ssrn.com/sol3/papers.cfm?abstract_id=4907532

https://osf.io

"My body is out to wreck everything I have": A qualitative study of how women with endometriosis feel about their bodies

https://osf.io/preprints/psyarxiv/awrgx_v1

Are people with chronic pain more diverse than we think? An investigation of ergodicity

https://osf.io/preprints/psyarxiv/5nrje v1

Appendix III: Data extraction form

Data extraction form

Study	Purpose of	Study	Country	Population	KAP	Assessment tool/s	Key Findings	Future	Limitations
-Author name (year of publication)	study Aim/objectives	design		-Participants' type: patients, HCPs, or both -Number of participants	Focus	(+ validated Y/N)	-related to: *Symptoms *Diagnosis *Treatment -Conclusion	recommendation	