

## REVIEW



# Challenges experienced by those with polycystic ovary syndrome in healthcare interactions: a qualitative evidence synthesis



## BIOGRAPHY

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## KEY MESSAGE

Interactions with healthcare professionals for patients with polycystic ovary syndrome were identified as challenging when medical news was not shared in the best way, information and deliberation opportunities were insufficient, patient activation was not supported and system-level barriers were present. The challenges identified could be addressed using evidence-based frameworks.

## ABSTRACT

Studies report interaction difficulties between patients with polycystic ovary syndrome (PCOS) and healthcare professionals (HCP). This systematic review and qualitative evidence synthesis aimed to collate and synthesize the existing peer-reviewed literature investigating challenges for people with PCOS when interacting with HCP. Medline, PsycInfo, EMBASE, All EBM and CINAHL were searched from 1990 to September 2022. Study risk of bias (RoB) was performed and all textual data relevant to challenging interactions between patients with PCOS and HCP were extracted and analysed using thematic synthesis. Of the 6353 studies identified, 28 were included. Two were appraised as high, four as moderate and 22 as low RoB. Four analytic themes were derived illustrating that interactions were challenging when: (i) medical information (PCOS, its management) was not shared in the best way; (ii) information provision and deliberation opportunities were insufficient to achieve outcomes that mattered to patients; (iii) interactions prompted but did not support patient activation; and (iv) health system-level barriers (e.g. policies and guidelines) were present or made worse by HCP behaviour. Future research should examine methods for the implementation and evaluation of established frameworks for sharing medical information and supporting patient agency in the context of PCOS care.

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## KEY WORDS

Decision support  
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## INTRODUCTION

**P**olycystic ovary syndrome (PCOS) is a polygenic endocrine disorder characterized by hyperinsulinaemia and hyperandrogenism that affects about 12% of women globally (Bozdag et al., 2016; Skiba et al., 2018). According to the International Guideline criteria, the diagnosis in adults requires two of the following three features: (i) oligoanovulation, (ii) hyperandrogenism, and (iii) polycystic ovarian morphology (PCOM) on ultrasonography or an elevated concentration of anti-Müllerian hormone (Teede et al., 2023b). Diagnosis in adolescents requires both ovulatory disturbance and hyperandrogenism, but PCOM and anti-Müllerian hormone assessments are not indicated as they lack specificity for PCOS at this life stage (Kiconco et al., 2023).

PCOS results in diverse and significant health burdens that imply a high need for self-management, namely associated metabolic (type 2 diabetes, obesity, metabolic syndrome, cardiovascular disease), reproductive (irregular periods, infertility, pregnancy complications), psychological (depression, anxiety, disordered eating) and dermatological (hirsutism, acne, androgenic alopecia) features, across the lifespan. The impact of the diagnosis and experience of PCOS on quality of life has been shown to be marked, being similar to or greater than that of other chronic conditions such as diabetes (Rempert et al., 2023).

Interactions between patients, their doctors and the wider healthcare team related to PCOS (hereafter referred to as 'interactions') are important for patients to learn about their health, make informed decisions that are in line with their preferences and values, and be supported to achieve their desired outcomes (e.g. quality of life, metabolic, dermatological, etc). International research additionally suggests recurrent challenges in interactions between patients with PCOS and their HCP. Patients often report that HCP dismiss their concerns or do not take them seriously (Atkinson, 2021; Ismayilova and Yaya, 2022a), or do not address them in a sensitive or empathetic way (Soucie et al., 2021). Also reported is that the PCOS care pathway is often not explained with sufficient clarity (e.g. information about options, referral, treatment, next steps)

(Kaur et al., 2021). Individuals with PCOS and HCP perceive that challenging interactions undermine the positive diagnosis and treatment outcomes intended to be achieved from healthcare interactions (Copp et al., 2022). Namely, patients report feeling unable to make satisfying or quality decisions about their health or treatment (Weiss and Bulmer, 2011), to accept or adjust to their diagnosis (Holbrey, 2013) or to feel competent in the management of their condition after diagnosis (Ismayilova and Yaya, 2022a).

Major gaps in research, education and dedicated care pathways have been linked to delayed diagnosis and high dissatisfaction in patients with PCOS (Teede et al., 2023b). Healthcare in PCOS is fragmented, with few documented models of care (Melson et al., 2023). Challenges of PCOS management include variations in clinical presentation due to, for example, ethnicity (Sendur and Yildiz, 2021) or age (Witchel et al., 2019), the varied effectiveness of treatment directed at different symptoms (Hoyos et al., 2020) and differing patient priorities about the most bothersome symptoms (Martin et al., 2017). There are also health system and organizational factors (e.g. limited education about PCOS, limited access to secondary care) that hinder effective PCOS care (Briscoe et al., 2022). Such variability contributes to missed and delayed diagnosis and poor patient healthcare experiences (Teede et al., 2014).

The 2023 International PCOS Guideline has recognized that improving patient and HCP interactions related to PCOS is a priority to improve care. The aim of this review was to meet this priority via a systematic review and qualitative evidence synthesis (QES) of peer-reviewed literature investigating challenges for people with PCOS when interacting with HCP.

## MATERIALS AND METHODS

The review question, 'What are the key challenges for individuals with PCOS when interacting with healthcare professionals about PCOS?', was prioritized by multiple key stakeholders in the 2023 International Guideline, including individuals with PCOS lived experience and clinical and academic experts (Teede et al., 2023b). The protocol

of the review was developed a priori by experts of the PCOS Guideline Development Group (GDG; H.T., J.B., M.A.B.) and is publicly available online in the 2023 PCOS Guideline technical report (Mousa et al., 2023).

The review was reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Tricco et al., 2016) and Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ; Tong et al., 2012) guidelines.

### Information sources and search strategy

Five main bibliographic databases were searched – MEDLINE (Ovid), PsycINFO (Ovid), EMBASE (Ovid), All EBM (Ovid) and CINAHL (EBSCOhost) – from 1990 to 13 September 2022. The search criteria included predefined key words such as PCOS, patients, healthcare providers, health communications, etc. Reference lists of relevant reviews were manually examined to identify any additional studies that could be eligible. Details of the search strategy are available in [Supplemental Table 1](#).

### Eligibility (inclusion and exclusion criteria)

The eligibility criteria for the studies were developed according to the PICOS (i.e. Participants, Intervention/exposure, Comparison, Outcomes, Study type) framework ([Supplemental Table 2](#)). The population of interest was female patients with PCOS, exposures were any healthcare interactions in a healthcare setting, and outcomes were patients' perspectives on interacting with health professionals for PCOS diagnosis or treatment. Studies were excluded if they reported on women without PCOS, interactions with non-HCP, articles reporting the perspectives of HCP as participants, and those focusing solely on patients' experiences or feelings related to receiving a PCOS diagnosis rather than on their interactions with healthcare professionals during the diagnostic process. Unpublished studies, dissertations, theses, editorials or commentaries, conference abstracts, letters to editors, protocols and studies not written in English were excluded.

### Study selection

Search results were imported into Covidence ([www.covidence.org](http://www.covidence.org)) and

duplicates were removed. A single reviewer (C.T.T.) screened each title/abstract and full text article according to the predefined inclusion/exclusion criteria. Any uncertainty related to the study selection was discussed with the GDG 2 (members A.M., C.T.T., M.A.B., J.B. [deputy chair GDG2], H.T. [chair GDG]).

### Quality appraisal

The value of the primary studies to the review question was determined in two ways. A single reviewer (C.T.T.) performed the study quality appraisal using the Critical Appraisal Skills Programme (CASP) checklist for qualitative or mixed-methods studies and the Monash Centre for Health Research and Implementation (MCHRI) Evidence Synthesis Program Critical Appraisal Tool (MCHRI, 2013) for cross-sectional studies. Study quality was ranked as having a low, moderate or high risk of bias (RoB) based on overall judgement by a single reviewer (C.T.T.). Study quality did not determine study inclusion or weighting of the study results.

Additionally, the Confidence in the Evidence from Reviews of Qualitative Research (GRADE-CERQual) assessment was used to assess confidence in the findings of the QES by C.H. and J.B. (Lewin et al., 2015). The assessment is based on the limitations of the research, the relevance of studies to the review question, the coherence of the review findings and the adequacy of the data supporting the review findings.

### Data extraction and meta-synthesis

Data extraction included study characteristics (e.g. author, year, country, PICO characteristic, data collection and analysis method) and relevant research findings and implications related to challenging interactions with HCP. To avoid omitting findings of potential value to the synthesis (Noyes and Lewin, 2011), the authors were inclusive in the extraction of findings and included quotes from participants' speech or text, and authors' interpretations (i.e. results, themes, sub-themes as relevant) even when not corroborated by participant quotes (Noyes and Lewin, 2011). Data extraction was performed by J.B. and C.H. in parallel for all studies. Any disagreements were resolved by discussion. For data synthesis, the PDFs of included studies were uploaded to NVivo 20 (NVivo, 2023), where all data

relevant to the review were highlighted and directly coded.

QES was used to establish a deeper understanding of existing peer-reviewed studies (Flemming and Noyes, 2021). The most common method of synthesis, and the one used in the present QES, is thematic synthesis (Thomas and Harden, 2008). Thematic analysis is an adaption for the purpose of secondary data synthesis of thematic analysis. This realist-pluralist approach assumes that it is possible to uncover people's reality from their reported experiences and understandings (Braun and Clarke, 2006), possible to reconcile differences (concepts, methods, theories) between studies and possible to produce reproducible, meaningful and novel explanations (Johnson, 2017). The authors' knowledge of the field also suggested this approach because they expected significant diversity in the available research (e.g. international, cross-disciplinary, varied healthcare systems, sampling, lifespan, aims).

The three-stage thematic synthesis procedure (Thomas and Harden, 2008) was adopted to synthesize the data: (i) line by line coding; (ii) development of descriptive themes; and (iii) generation of analytic themes. First, C.H. and J.B. performed inductive coding of all relevant data pertaining to interactions between HCP and patients. A coding framework was developed comprising codes derived from the data. Coding was performed by C.H. and the coding framework was then checked by J.B. Any disparities or discrepancies in coding were resolved by discussion, and the coding framework was adjusted accordingly and applied to all the included literature.

In the second stage, JB and CH inductively grouped codes into descriptive themes reflecting or describing patterns of similarity among codes within and across studies. J.B. and C.H. compared the descriptive themes and discussed these until a consensus had been agreed. In practice although the process is described linearly, line by line coding and the development of descriptive themes occurred in parallel, in iterative fashion, and new concepts were identified when deemed necessary.

In the final stage, J.B. and C.H. generated analytic themes to propose meta-concepts that go beyond the primary reported data and explained the challenges in

interactions with health professionals for patients with PCOS. Analytic themes were deductive insofar as the interpretation of the aggregated descriptive themes was influenced by the literature included in the review and a knowledge of broader psychological and health theories.

This type of hybrid thematic analysis is used in mixed-methods research to provide a method by which participant voices can be heard (e.g. was not consulted about options: 'I didn't like that they would just prescribe birth control pills without talking to me about the options'; Weiss and Bulmer, 2011) yet is complemented by related theoretical concepts (e.g. shared decision making [SDM]). The analytic themes were used to underpin the set of recommendations for research, policy and training. A thematic map illustrating the proposed relationships among the analytic themes was generated. Analytic themes are presented with accompanying quotes from the included studies with sufficient information provided to ensure clarity about whether the quote is from a person with PCOS or from a researcher.

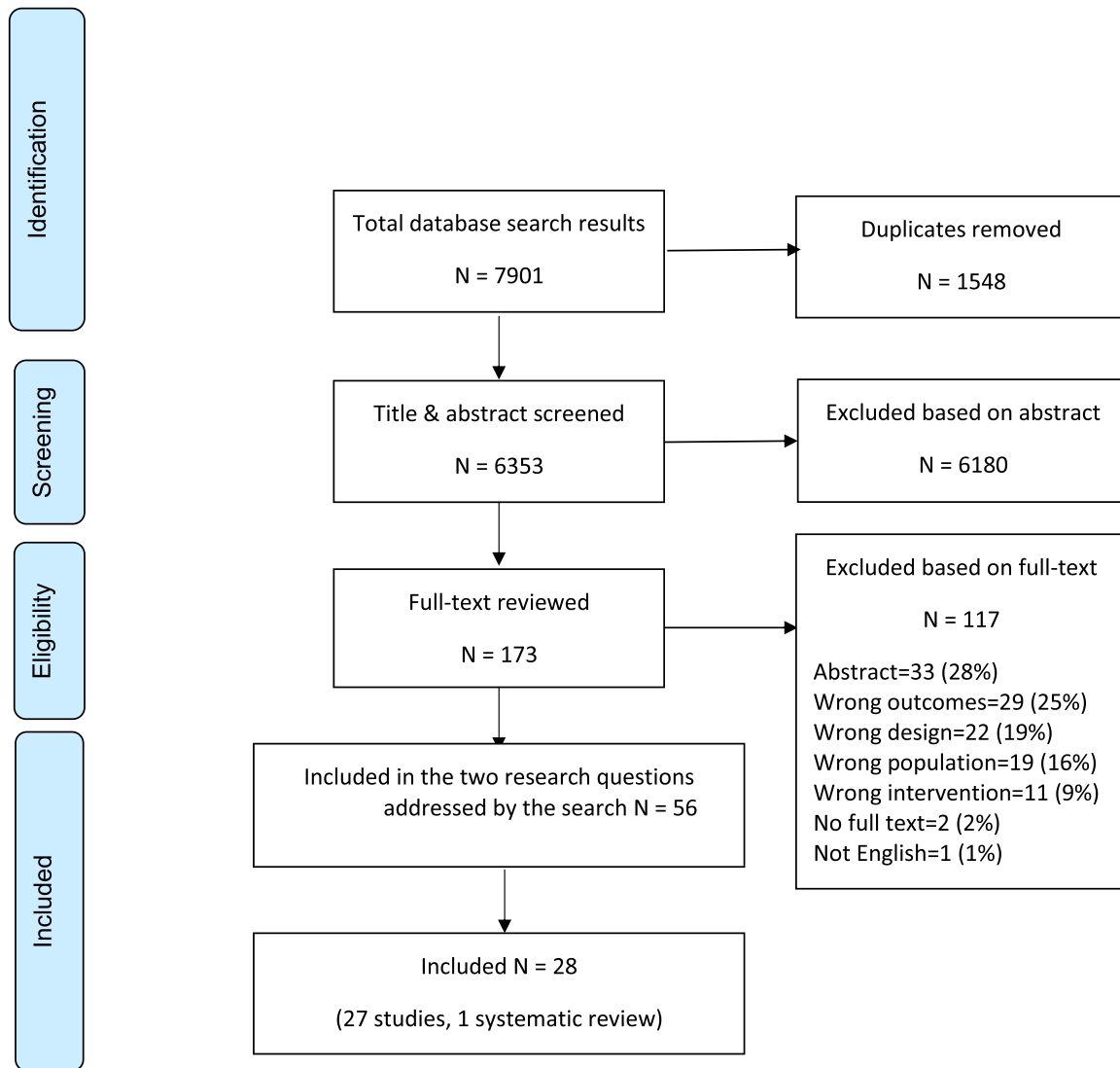
## RESULTS

### Study selection results

FIGURE 1 shows the PRISMA review flowchart. In total, 7901 records were retrieved, of which 1548 duplicates were removed. The remaining 6353 studies were screened by title and abstract, after which 173 full-text articles were retrieved and 117 were excluded (Supplemental Table 3 shows the study exclusions, with reasons). In total, 56 studies met the inclusion criteria for the two research questions addressed by the search, and 27 studies and 1 systematic review of women with PCOS met the inclusion criteria for this specific review. Supplemental Table 4 for a list of the included studies).

### Characteristics and topics of the included studies

TABLE 1 presents the characteristics of the included studies. Most studies had been published in the previous 5 years ( $n = 19$ ) and were primarily from high-income, anglophone, developed nations (UK,  $n = 8$ ; Australia,  $n = 7$ ; USA,  $n = 5$ ; Canada,  $n = 3$ ; France,  $n = 1$ ). Four studies were from either Iran ( $n = 2$ ) or India ( $n = 2$ ). The majority of studies ( $n = 16$ ) sampled women self-reporting a diagnosis of PCOS. Of 11 studies recruiting from health settings



**FIGURE 1** The PRISMA flowchart detailing the process of identification, screening and eligibility for the systematic review.

and with confirmed diagnoses, one study used National Institute of Health (NIH) criteria (Avery and Braunack-Mayer, 2007), five used Rotterdam criteria (Bazarganipour, 2017; Hadjiconstantinou et al., 2017; Kaur et al., 2021; Lim, Smith et al., 2021; Tomlinson et al., 2017) and five did not specify the criteria used (Crete, 2011; Hajivandi et al., 2022; Sharma and Mishra, 2018; Snyder, 2006; Tay et al., 2021).

Most studies recruited participants from social media or community posts to PCOS support groups. Nine studies recruited women via gynaecology or PCOS clinics (Bazarganipour, 2017; Crete, 2011; Hadjiconstantinou et al., 2017; Hajivandi et al., 2022; Lim, Wright et al., 2021; Sharma and Mishra, 2018; Snyder, 2006; Tay et al., 2021;

Tomlinson et al., 2017). All but two studies sampled across the lifespan (from 18 to 66 years, depending on the study). The other two studies specifically sampled adolescent or emerging adults aged 15–21 years (Hajivandi et al., 2022) or 18–23 years (Weiss and Bulmer, 2011).

Three studies were mixed methods (Hillman et al., 2020; Kaur et al., 2021; Pirota et al., 2021), one a systematic review (Gibson-Helm et al., 2018) and one cross-sectional study (Lin et al., 2018), with the remaining studies being qualitative. Among the latter, the predominant data collection method was interview alone or in combination with other methods (e.g. focus groups). The duration of the interviews ranged from 17 min (Lim, Smith et al., 2021) to 90 mins (Avery and Braunack-Mayer,

2007; Kitzinger, 2002; Tomlinson et al., 2017; Williams et al., 2015). One study using a citizen panel reported a 3 h duration (Lim, et al., 2021). All studies investigated and referred to experiences of having PCOS, but not all studies had the same domain of inquiry, with most studies investigating domains directly related to care (TABLE 1).

#### Study selection quality

The results of the study quality assessments are presented in TABLE 2. Two studies were assigned a high RoB rating (Atkinson et al., 2021; Williams et al., 2015) and four studies a moderate RoB (Kaur et al., 2021; Lim, Wright et al., 2021; Sharma and Mishra, 2018; Wright et al., 2020), with the remaining 22 studies (78.6%) assigned a low RoB. The low-RoB studies generally met the CASP criteria for

**TABLE 1 CHARACTERISTICS OF THE INCLUDED STUDIES**

Authors	Country	Population	Domain of inquiry for experiences	Data collection method and setting	Analysis method
<i>Atkinson et al. (2021)</i>	UK	<i>n</i> = 12 women self-reporting a diagnosis of PCOS; 2 Asian, 10 white; aged 24–42 years; time since diagnosis 8.69 years	Experiences of care during COVID-19	Recruitment nested in online survey Telephone interviews, 16–38 min, mean duration 24 min	Thematic analysis
<i>Authier et al. (2020)</i>	France	785 comments from women ( <i>n</i> = 211) self-reporting PCOS and infertility extracted from public forums on these topics; ethnicity, age, BMI, time since diagnosis not reported	Experiences reported on discussion forums	Comments made on 7 internet forums devoted to PCOS and infertility	Thematic content analysis
<i>Avery and Braunack-Mayer (2007)</i>	Australia	<i>n</i> = 10 women with PCOS; 7 diagnosed with NIH and 3 self-reporting a diagnosis; aged 28–38 years; ethnicity not reported; time since diagnosis 1–17 years	Information provision	Recruited nutritional study ( <i>n</i> = 7) or support group ( <i>n</i> = 3); in-depth, in-person interviews, 45–90 min	Framework content analysis
<i>Bazarganipour et al. (2017)</i>	Iran	<i>n</i> = 20 women with confirmed PCOS diagnosis (Rotterdam criteria); aged 21–34 years; ethnicity, BMI, time since diagnosis not reported	Inhibiting factors for adherence and non-adherence in management	Recruited from outpatient gynaecology clinic; semi-structured in-person interview before appointment in clinic/private setting, 20–89 min, mean 42 min	'Conventional content analysis' described as text coded and grouped into themes
<i>Copp et al. (2022)</i>	Australia	<i>n</i> = 26 women self-reporting a PCOS diagnosis by a medical doctor; aged 18–45 years, living in Australia; ethnicity, age, BMI, time since diagnosis not reported	Management across PCOS severity, reported by patients and clinicians	Recruited through social media targeting general users (not PCOS support groups); in-person or telephone semi-structured interviews, 25–80 min	Framework analysis with phenomenological approach
<i>Crete (2011)</i>	USA	<i>n</i> = 10 women with a confirmed diagnosis of PCOS; 1 American Indian, 2 Latino, 7 Caucasian; aged 20–50 years; time since diagnosis 7.5 years (2.5–16 years)	Management of PCOS, and importance of holistic approach	Recruited through hospital gynaecology clinics that invited eligible women managed within the past 5 years; in-person interviews carried out in hospital, duration of interviews not reported	Hermeneutic phenomenological reflection
<i>Gibson-Helm et al. (2018)<sup>a</sup></i>	Australia	35 studies; reporting perspectives of women or any healthcare providers that deal with PCOS; ethnicity, age, time since diagnosis not reported	Information, resource and education needs of women with PCOS and of their healthcare providers	Any setting; relevant themes for this review were women's experiences of PCOS	Narrative review
<i>Hadjiconstantinou et al. (2017)</i>	UK	<i>n</i> = 12 women with a clear PCOS diagnosis according to the Rotterdam criteria; 7 white British, 4 South Asian, 1 black African; aged 17–51 years; time since diagnosis not reported	Acceptability of group education	Recruited mostly from advertising in a local outpatient clinic ( <i>n</i> = 9) plus those approaching researchers ( <i>n</i> = 3); in-person semi-structured interviews at home or at local clinic; interview duration not reported	Framework analysis
<i>Hajivandi et al. (2022)</i>	Iran	<i>n</i> = 18 adolescent girls with a diagnosis of PCOS by a gynaecologist and overweight or obese; aged 15–21 years; ethnicity not reported; 14/18 participants were at more than 1 year since diagnosis	Health system needs to support healthy nutritional behaviours in adolescent girls	Recruited through gynaecology clinics and offices of gynaecologists and midwives; in-person, in-depth semi-structured interviews and focus groups (8 adolescents), and field notes of non-verbal behaviour, 30–85 min duration	Conventional content analysis

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TABLE 1 (Continued)

Authors	Country	Population	Domain of inquiry for experiences	Data collection method and setting	Analysis method
Hillman et al. (2020) <sup>b</sup>	UK	Online survey participants: <i>n</i> = 334 women self-reporting a diagnosis of PCOS by a medical doctor (69.3%), self (17.6%), family/friend (13.1%); 61.3% white British, 31.2% British Asian, 7.4% other; aged 19–51 years (mean age 35.4 years); time since diagnosis not reported Interview participants: <i>n</i> = 11 women from online survey; 6 white British, 5 British Asian; median age 36 years; time since diagnosis not reported	Diagnosis and diagnostic delay, associated comorbidities and impacts on fertility and mental health	Recruitment through social media and BBC radio Leicester to relevant groups and a radio, and nested in an online survey; telephone semi-structured interviews (average 15–45 min, average 21 min) and textual data in online survey	Framework analysis. Descriptive and regression analysis
Holbrey (2013)	UK	<i>n</i> = 50 women; 2 reporting symptoms of PCOS and 48 self-reporting an official PCOS diagnosis; aged 20–45 years (mean 33.6 years); time since diagnosis for 58% at least 5 years and 42% less than 5 years	Impact of participation in online support group	Recruited from UK online PCOS support group; online survey from which textual replies to open questions were extracted	Essentialist thematic analysis
Ismayilova and Yaya (2022a)	Canada	<i>n</i> = 25 women self-reporting a medical diagnosis of PCOS; aged 18–66 years (most were 25–30 years); 18 white, 4 Asian, 1 Black and 2 Middle Eastern; time since diagnosis not reported	Navigating the healthcare system and what could be improved	Recruitment nested in an online survey advertised to PCOS groups via social media and a support group; in-depth semi-structured telephone interviews, about 60 min in duration	Interpretive descriptive and thematic approach
Ismayilova and Yaya (2022b)	Canada	As per Ismayilova and Yaya (2002a)	Barriers and facilitators to manage PCOS condition	As per Ismayilova and Yaya (2022a) this paper reports on themes relating to women's experience of medical management	Thematic analysis and interpretive description methodology
Kaur et al. (2021) <sup>b</sup>	India	Women aged 20–45 years diagnosed with PCOS (Rotterdam criteria) in a survey ( <i>n</i> = 275) Nested interview sample ( <i>n</i> = 62). Interviews only with highly distressed or vocal patients All sample, 59.3% Hindu; mean age 24.0 years; 40.7% diagnosed in the previous year and 14.2% more than 5 years before	Perceptions of feeling 'freakish'	Recruited in outpatient department among eligible patients after diagnosis/prescription for survey and (nested) in-depth interviews; interviews in presence of family escorts; duration 25–40 min	EXCEL, SPSS framework analysis; results for survey and interviews integrated by triangulation
Kitzinger (2002)	UK	<i>n</i> = 30 women with PCOS (ascertainment not reported); 24 white and six non-white; aged 21–42 years (mean age 29 years); time since diagnosis not reported	Treatment-seeking pathways and perspectives on this	Recruited from a flyer mailed to members of a UK PCOS support group; in-person, in-depth semi-structured interviews, duration 45–90 min	Thematic analysis and discursive analysis, interpretive autobiography
Lim, Smith et al. (2021)	Australia	<i>n</i> = 10 women self-reporting a medical diagnosis of PCOS based on Rotterdam criteria; mean age 36 years; 5 European, 3 Asian, 1 Oceanic, 1 not reported; time since diagnosis not reported	Health literacy needs in PCOS	Recruitment through social media posted to relevant groups and telephone screening for study inclusion; focus groups ( <i>n</i> = 7), duration 104–117 min, mean 110.5 min; semi-structured telephone interviews ( <i>n</i> = 3), duration 17–27 min, mean 21 min	Thematic analysis constant comparison method
Lim, Wright et al. (2021)	Australia	<i>n</i> = 28 women previously diagnosed with PCOS (ascertainment not reported); ethnicity, age, time since diagnosis not reported	Perspectives of a publicly funded PCOS service	Recruitment for facilitated citizen panel ( <i>n</i> = 13) via electronic direct mail to participants of previous studies; data collected via teleconference, duration 3 h each Recruitment for semi-structured interview ( <i>n</i> = 15) from patients waiting for an appointment in a PCOS clinic; duration 30–72 min; format not reported	Thematic analysis

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**TABLE 1 (Continued)**

Authors	Country	Population	Domain of inquiry for experiences	Data collection method and setting	Analysis method
<i>Lin et al. (2018)<sup>c</sup></i>	USA	Women (n = 198) self-reporting a history of predictable cycles (21–35 days, comparison group) or existing diagnosis of PCOS by a medical professional (n = 134, PCOS group) PCOS group 83.6% white; mean age 28.2 years	Trust and perceived support from physicians	Recruitment via flyers and online advertisements; cross-sectional survey nested in a larger observational study about health-related behaviours (28 items)	SPSS, t-tests, X <sup>2</sup> , multiple linear regression, mixed effects regression
<i>Pirotta et al. (2021)<sup>b</sup></i>	Australia	Women with self-reported diagnosis of PCOS (survey, n = 286; interviews, n = 20) Survey sample: 33% less than 29 years of age; 83% Caucasian; time since diagnosis, 39% 5 years or less Interview sample: 45% less than 29 years; 95% Caucasian; time since diagnosis, 50% 5 years or less	Preferred characteristics and practical considerations for a PCOS lifestyle programme	Recruited from social media platforms and Australian PCOS support group; online survey and semi-structured telephone interviews; duration of interview 45–60 min	SPSS and thematic analysis with triangulation
<i>Sharma and Mishra (2018)</i>	India	n = 35 women with PCOS attending a gynaecology clinic; age, ethnicity and time since diagnosis not reported	Impact of the social construction of PCOS and of stigma	Recruited from gynaecology clinic; in-person semi-structured interviews in clinic; duration of interviews 40–45 min	Interpretative phenomenological analysis
<i>Soucie et al. (2021)</i>	Canada	n = 62 women diagnosed with PCOS by a Canadian practitioner (ascertainment not reported); 82% white, 6.5% Middle Eastern, 1.5% South Asian, 10% mixed race; aged 18–47 years (mean 28.1 years); time since diagnosis not reported	Barriers to and facilitators of PCOS care	Recruited via flyers posted in a university participant panel and local newspaper; in-person or online interviews that comprised a brainstorming activity to create a diagnosis timeline, a diagnosis narrative freely told to the interviewer based on the timeline, and a demographic and health survey; interview duration not reported	Reflexive thematic analysis
<i>Snyder (2006)</i>	USA	n = 12 premenopausal women with a confirmed medical diagnosis of PCOS based on laboratory, ultrasound or clinical findings; 10 white and 2 Black participants; aged 21–48 years; average time since diagnosis 11.4 years	Lived experience	Nurse practitioner recruited eligible patients from a large women's health practice/clinic; in-person interviews in home, 30–75 min duration	Phenomenological analysis
<i>Tay et al. (2021)</i>	Australia	n = 15 women diagnosed with PCOS attending a clinic; 10 Caucasian, 4 South Asian, 1 East/Southeast Asian; aged 20–39 years (mean 28.1 years); time since diagnosis 2–20 years (mean 7.2 years)	Evaluation of a state-wide integrated PCOS service	Recruited from women attending an integrated PCOS service/clinic; telephone semi-structured interviews and satisfaction survey, duration 30–72 min	Thematic analysis with coding mapped onto a prespecified evaluation framework
<i>Tomlinson et al. (2017)</i>	UK	n = 32 premenopausal women with confirmed PCOS diagnosis (Rotterdam criteria); aged 18–45 years	Perceptions of health and ill health in PCOS	Recruited from poster advertisements and referrals from primary and secondary care clinics (gynaecology, endocrinology, weight management); 11 focus groups were conducted on university premises; duration 60–90 min	Data coding, themes and analysis summarized in a matrix
<i>Weiss and Bulmer (2011)</i>	USA	n = 12 women clinically diagnosed with PCOS by their attending physician or healthcare provider; 9 white, 2 Black, 1 Asian; aged 18–23 years; time since diagnosis less than 1 to 4 years	Psychosocial aspects of PCOS	Recruited from three educational settings; in-depth, in-person, semi-structured interviews conducted on campus, duration 20–60 min	Naturalistic inquiry, constant comparative method
<i>Williams et al. (2015)</i>	UK	n = 9 women self-reporting suffering from symptoms of PCOS and comorbidities; aged 20–41 years, 3 did not disclose age; ethnicity and time since start of symptoms not reported	Living with PCOS and comorbidities	Recruited via posts to PCOS support groups on social media platforms; online voice-only interviews, duration 40–90 min	Thematic analysis

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TABLE 1 (Continued)

Authors	Country	Population	Domain of inquiry for experiences	Data collection method and setting	Analysis method
Williams <i>et al.</i> (2016)	UK	n = 9 women self-reporting suffering from symptoms of PCOS; aged 20–45 years, 5 did not disclose age, ethnicity and time since start of symptoms not reported	Self-generated snapshot of day-to-day life	Recruited via posts to PCOS support groups on social media platforms; data collected using Photovoice where participants took a photograph of anything that impacted their quality of life and wrote a diary entry to accompany the photograph; photographed during a 24 h period	Thematic analysis of diary entries
Wright <i>et al.</i> (2020)	USA	n = 95 randomly selected website stories posted on a support group forum and written by women with self-reported PCOS; age, ethnicity, time since diagnosis not reported	Biopsychosocial and medical experiences posted on support website	Stories posted on social support website	Low inference content analysis, line by line and axial coding

All designs exclusive qualitative except: for <sup>a</sup>Gibson-Helm *et al.* (systematic review).

<sup>b</sup>Hillman *et al.*, Kaur *et al.* and Protta *et al.* (mixed methods); and <sup>c</sup>Lin *et al.* (quantitative).  
BMI, body mass index; NIH, National Institute of Health; PCOS, polycystic ovary disease.

research aims, appropriate method and design for research aims, consideration of ethical standards, and clear statement of findings. However, the criteria for reporting of recruitment strategy, data collection methods, relationship to participant and data analysis were more variably met in these studies.

### Thematic meta-synthesis

#### Line by line, descriptive and analytic coding outcomes

A total of 68 codes were generated from the line by line coding. In the line by line coding, all text and quotes that could be coded were coded regardless of similarity to other codes to create the coding framework. This basic coding captured the content and diversity in representations of a similar challenge (e.g. separate codes were given to no follow-up on treatment, no follow-up with GP, not seen anyone since diagnosis, lack of follow-through, and no follow-up after diagnosis). The codes were then grouped into 18 descriptive themes reflecting or describing patterns of similarity among the codes in the coding framework.

The descriptive codes referred to challenges at all levels of care (primary, secondary and tertiary care), in diverse activities (screening and diagnosis, referral, treatment) and in domains of interactions (e.g. relational, communication, decision making). In the third step of the data analysis, the descriptive codes were interpreted to derive four latent or meta-level explanatory concepts, referred to as analytic themes. These were proposed to illustrate and capture the driving force behind the reported challenges of interacting with HCP in relation to PCOS.

#### Analytic themes

Four analytic themes combining the inductive and deductive coding were developed, namely, 'Interactions were challenging when medical information was not shared in the best way', 'Interactions were challenging when information provision and deliberation opportunities were insufficient to achieve outcomes that mattered to patients', 'Interactions were challenging when they prompted but did not support patient activation' and 'Interactions were challenging when health system-level barriers were present or made worse by HCP behaviour'. The thematic map in FIGURE 2 illustrates these analytic themes and the proposed relationships among them.



**TABLE 2 QUALITY APPRAISAL OF THE INCLUDED STUDIES**

**(A) Qualitative and mixed-methods studies**

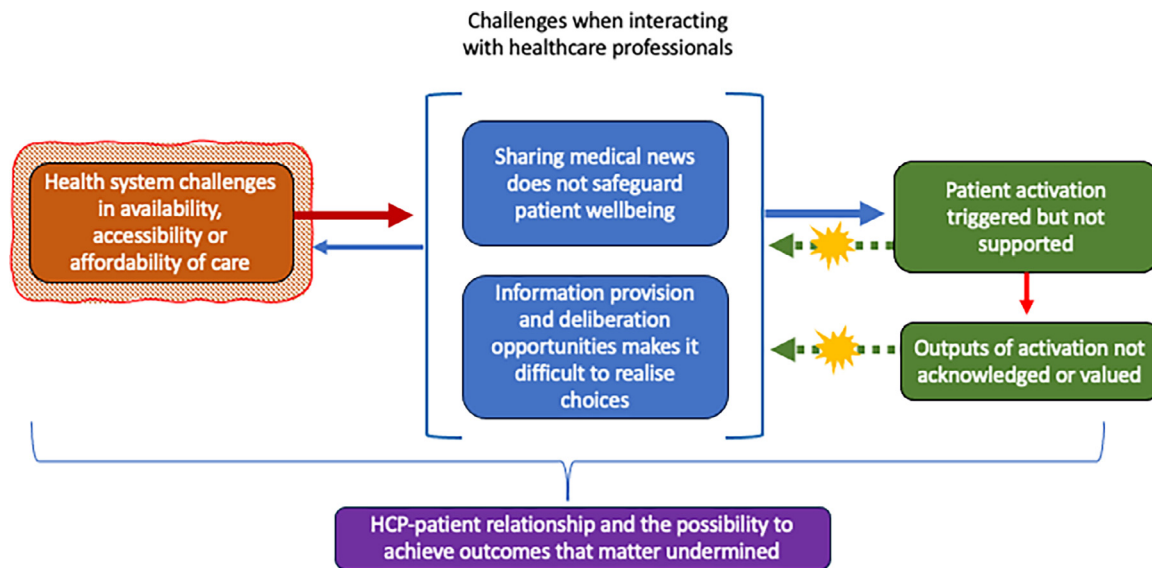
Study and design		A: Are the results valid?						B: What are the results?			C: Will the results help locally?	
Study	Design	Clear research aims	Method appropriate for goals	Design appropriate for aims	Appropriate recruitment strategy	Appropriate data collection	Relationship considered between researcher and participant	Consideration of ethical issues	Rigorous data analysis	Clear statement of findings	Research value	Overall RoB
<a href="#">Atkinson et al. (2021)</a>	Qualitative	Yes	Yes	Yes	Cannot tell	Cannot tell	No	Yes	No	Cannot tell	Yes	High
<a href="#">Authier et al. (2020)</a>	Qualitative	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Low
<a href="#">Avery and Braunack-Mayer, 2007</a>	Qualitative	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Low
<a href="#">Bazarganipour et al. (2017)</a>	Qualitative	Yes	Yes	Yes	Cannot tell	Yes	Cannot tell	Yes	Yes	Yes	Yes	Low
<a href="#">Copp et al. (2022)</a>	Qualitative	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Low
<a href="#">Crete, 2011</a>	Qualitative	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes	Yes	Yes	Low
<a href="#">Hadjiconstantinou et al. (2017)</a>	Qualitative	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Low
<a href="#">Hajivandi et al. (2022)</a>	Qualitative	Yes	Yes	Yes	Yes	Yes	No	Yes	Unclear	Yes	Yes	Low
<a href="#">Hillman et al. (2020)</a>	Mixed method	Yes	Yes	Yes	Yes	Cannot tell	No	Yes	Yes	Yes	Yes	Low
<a href="#">Halbrey (2013)</a>	Qualitative	Yes	Yes	Yes	Yes	Yes	No	Yes	Unclear	Yes	Yes	Low
<a href="#">Ismayilova and Yaya (2022a)</a>	Qualitative	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Low
<a href="#">Ismayilova and Yaya (2022b)</a>	Qualitative	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Low
<a href="#">Kaur et al. (2021)</a>	Mixed method	Yes	Yes	Yes	Yes	Cannot tell	No	Yes	Cannot tell	Cannot tell	Yes	Moderate
<a href="#">Kitzinger and Willmott (2002)</a>	Qualitative	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Low
<a href="#">Lim, Smith et al. (2021)</a>	Qualitative	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes	Yes	Yes	Low
<a href="#">Lim, Wright et al. (2021)</a>	Qualitative	Yes	Yes	Yes	Cannot tell	Cannot tell	No	Yes	Cannot tell	Yes	Yes	Moderate
<a href="#">Pirota et al. (2021)</a>	Mixed methods	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes	Low
<a href="#">Sharma and Mishra (2018)</a>	Qualitative	Yes	Yes	Yes	Cannot tell	Cannot tell	No	Yes	Cannot tell	Yes	Yes	Moderate
<a href="#">Soucie et al. (2021)</a>	Qualitative	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes	Low
<a href="#">Synder (2006)</a>	Qualitative	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Low
<a href="#">Tay et al. (2021)</a>	Qualitative	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Low
<a href="#">Tomlinson (2017)</a>	Qualitative	Yes	Yes	Yes	Yes	Yes	No	Yes	Cannot tell	Yes	Yes	Low
<a href="#">Weiss and Bulmer (2011)</a>	Qualitative	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes	Low
<a href="#">Williams et al. (2015)</a>	Qualitative	Yes	Cannot tell	Cannot tell	Cannot tell	Cannot tell	No	Yes	Cannot tell	Yes	Cannot tell	High
<a href="#">Williams et al. (2016)</a>	Qualitative	Yes	Yes	Yes	Yes	Yes	No	Yes	Cannot tell	Yes	Yes	Low
<a href="#">Wright et al. (2020)</a>	Qualitative	Yes	Yes	Yes	Cannot tell	Yes	No	Yes	Yes	Cannot tell	Yes	Moderate

**(B) Other designs**

Study and design		Selection bias			Performance bias		Detection bias			Attrition bias		Report Bias	Confounding	Other bias			
Study	Design	Comparable cases and controls	Established case definition	Established control definition	Groups treated the same	Standard measurements for exposure	Assessors blinded to case-control status	Standard measurements for outcomes	Outcomes assessed objectively and independently	% lost to follow-up	% included in analysis	Free of selective outcome reporting	Groups similar at baseline	Funding/COI reported	Sufficient power	Adequate statistical risk analysis	Overall risk
<a href="#">Lin (2018)</a>	Quantitative	Yes	Partial	Yes	Yes	Yes	No	Yes	Yes	Not applicable	All	Yes	Yes	Yes	Not reported	Yes	Low
<a href="#">Gibson-Helm et al. (2018)</a>	Systematic review																

All studies except the systematic review (i.e. [Gibson-Helm et al., 2018](#)) were evaluated with the Critical Appraisal Skills Programme (CASP).

COI, conflict of interest; RoB, risk of bias.



**FIGURE 2** Thematic map representing associations between analytic challenge domains. The blue boxes are key challenges when interacting with healthcare professionals (HCP). According to the primary studies reviewed, interactions with HCP were challenging when medical news was not shared optimally and when disease, treatment and management information provision and deliberation opportunities were insufficient. Challenges with HCP were seen to prompt patient activation to fill gaps in their knowledge and progress care and management decisions (e.g. via online searching, peer forums, medical friends, family). Patient activation and the outputs of that activation were perceived to be not well received by healthcare teams (kapow symbol). The healthcare professional was seen to be the intermediary between the health system and the patient. Although some challenges in interactions with HCP could be attributed to health system challenges (policies, guidelines, care restrictions; solid orange box) these could be exacerbated or compounded by HCP's understanding or their approach to PCOS (the hatched orange area). These challenges could undermine the HCP–patient relationship and the possibility to achieve outcomes that mattered to patients (purple box).

According to **FIGURE 2**, the two key challenges of interacting with a HCP were the suboptimal sharing of medical news and the insufficient provision of information and deliberation opportunities. These were seen to prompt patient activation to fill gaps in knowledge and progress toward outcomes that mattered (e.g. diagnosis, specific treatment and management aligned to preferences). However, the activation and the outputs of this activation were not perceived to be valued by HCP, which was challenging for patients. Health system challenges were seen to restrict care (i.e. availability, accessibility, affordability) and these system restrictions could be made worse by the behaviour of HCP. These challenges were seen to undermine the HCP–patient relationship and the possibility of achieving outcomes that mattered to patients.

The GRADE-CERQual assessment is summarized in **TABLE 3**, with ratings indicating that high confidence could be placed in two of the four key findings. The remaining two key findings were assessed as having minor concerns about adequacy of data. The minor concerns were due to uncertainty about the richness of the data in some primary studies rather than about

the quantity of the data. The analytic themes are explored in depth in the following sections.

### **Theme 1: Interactions were challenging when medical information was not shared in the best way**

Interactions were challenging when medical news related to suspected or confirmed PCOS was shared in a way that did not safeguard patient well-being. A common definition of bad news in health is 'any information that produces a negative alteration to a person's expectations about their present or future' (*Buckman, 1984*). Receiving news about a PCOS diagnosis, its management or the long-term risks is likely to meet this definition, even if patients feel relief or validation in receiving a diagnosis (*Avery and Braunack-Mayer, 2007; Snyder, 2006; Tomlinson et al., 2017*). Receiving information that produces a negative alteration in a person's expectations is typically understood as needing to be a process (versus single event) with the lead-up, the news and the aftermath of disclosure all being important in how it is shared (*Matthews et al., 2019*).

PCOS news was reported as being shared in a suboptimal way due to an inappropriate setting such as inappropriate space (*Lim, Wright et al., 2021; Tay et al.,*

*2021*), lack of privacy (*Bazarganipour, 2017; Lim, Wright et al., 2021*), an insufficient consultation time (*Crete, 2011; Hajivandi et al., 2022; Hillman et al., 2020; Snyder, 2006; Soucie et al., 2021; Williams et al., 2016*) or an atmosphere that did not permit patients to voice their thoughts without fear (*Crete, 2011; Hadjiconstantinou et al., 2017*):

I noticed the larger women were having trouble getting comfortable or sitting still in the chairs. I don't think the chairs are big enough for them. (004, Caucasian, age 25 years) (*Tay et al., 2021*).

When I had a vaginal ultrasound, several women were sitting inside the room, and it was very inconvenient. [P aged 26]. (*Bazarganipour, 2017*)

Sharing medical news could also be suboptimal because of the HCP's communication style, for example being cold or curt ('cold, callous, rude'; *Soucie et al., 2021*) or showing a lack of empathy (*Atkinson et al., 2021; Gibson-Helm et al., 2018; Ismayilova and Yaya, 2022b; Lim, Wright et al., 2021; Pirotta et al., 2021; Soucie et al., 2021; Wright et al., 2020*) or support (*Authier et al., 2020; Holbrey, 2013; Ismayilova and Yaya, 2022b; Lim, Smith et al., 2021*). This was especially seen

**TABLE 3 GRADE-QERQUAL RESEARCH RATINGS FOR EACH OF THE MAIN FINDINGS**

Summary of review finding	GRADE-CERQual assessment of confidence in the evidence	Explanation of GRADE-CERQual	Studies contributing to the review finding
Finding 1: Interactions are challenging when medical news is not shared optimally	High confidence	No/very minor concerns regarding methodological limitations No/very minor concerns regarding coherence No/very minor concerns adequacy No concerns regarding relevance	Studies: <i>Atkinson et al., 2021; Authier et al., 2020; Avery and Braunack-Mayer, 2007; Bazarganipour, 2017; Copp et al., 2022; Crete, 2011; Gibson-Helm et al., 2018; Hadjiconstantinou et al., 2017; Hajivandi et al., 2022; Hillman et al., 2020; Holbrey, 2013; Ismayilova and Yaya, 2022a, 2022b; Kaur et al., 2021; Kitzinger, 2002; Lim, Smith et al., 2021; Lim, Wright et al., 2021; Pirotta et al., 2021; Sharma and Mishra, 2018; Soucie et al., 2021; Tay et al., 2021; Tomlinson et al., 2017; Weiss and Bulmer, 2011; Williams et al., 2016; Wright et al., 2020</i>
Finding 2: Interactions are challenging when information provision and deliberation opportunities are insufficient to achieve outcomes that matter to patients	High confidence	No/very minor concerns regarding methodological limitations No/very minor concerns regarding coherence No/very minor concerns adequacy No concerns regarding relevance	Studies: <i>Atkinson et al., 2021; Authier et al., 2020; Avery and Braunack-Mayer, 2007; Bazarganipour, 2017; Copp et al., 2022; Crete, 2011; Hadjiconstantinou et al., 2017; Hajivandi et al., 2022; Holbrey, 2013; Ismayilova and Yaya, 2022a, 2022b; Kaur et al., 2021; Kitzinger, 2002; Lim, Smith et al., 2021; Lim, Wright et al., 2021; Lin et al., 2018; Pirotta et al., 2021; Sharma and Mishra, 2018; Snyder, 2006; Soucie et al., 2021; Tay et al., 2021; Tomlinson et al., 2017; Weiss and Bulmer, 2011; Williams et al., 2015; Wright et al., 2020</i>
Finding 3: Interactions are challenging when these trigger but do not support patient activation	Moderate confidence	No/very minor concerns regarding methodological limitations No/very minor concerns regarding coherence Very minor concerns adequacy No concerns regarding relevance	Studies: <i>Atkinson et al., 2021; Avery and Braunack-Mayer, 2007; Copp et al., 2022; Crete, 2011; Gibson-Helm et al., 2018; Hadjiconstantinou et al., 2017; Hajivandi et al., 2022; Hillman et al., 2020; Holbrey, 2013; Ismayilova and Yaya, 2022a, 2022b; Kaur et al., 2021; Kitzinger, 2002; Lim, Wright et al., 2021; Snyder, 2006; Soucie et al., 2021; Tay et al., 2021; Tomlinson et al., 2017; Weiss and Bulmer, 2011; Williams et al., 2015, 2016; Wright et al., 2020</i>
Finding 4: Interactions are challenging when health system-level barriers are present	Moderate confidence	No/very minor concerns regarding methodological limitations No/very minor concerns regarding coherence Very minor concerns regarding adequacy No concerns regarding relevance	Studies: <i>Atkinson et al., 2021; Bazarganipour, 2017; Hajivandi et al., 2022; Hillman et al., 2020; Holbrey, 2013; Ismayilova and Yaya, 2022a, 2022b; Kaur et al., 2021; Lim, Wright et al., 2021; Sharma and Mishra, 2018; Snyder, 2006; Soucie et al., 2021; Tay et al., 2021; Tomlinson et al., 2017; Weiss and Bulmer, 2011; Williams et al., 2015, 2016; Wright et al., 2020</i>

Methodological limitations of included studies: the extent to which there were concerns about the design or conduct of the primary studies that contributed evidence to an individual review finding.

Coherence of the review finding: an assessment of how clear and cogent (i.e. well supported or compelling) the fit was between the data from the primary studies and a review finding that synthesized those data.

Adequacy of the data contributing to a review finding: an overall determination of the degree of richness and quantity of the data supporting a review finding.

Relevance of the included studies to the review question: the extent to which the body of evidence from the primary studies supporting a review finding was applicable to the context (perspective or population, phenomenon of interest, setting) specified in the review question.

GRADE-QERQual, Confidence in the Evidence from Reviews of Qualitative Research.

in relation to discussions of weight (*Authier et al., 2020; Avery and Braunack-Mayer, 2007; Copp et al., 2022; Hajivandi et al., 2022; Ismayilova and Yaya, 2022b; Lim, Wright et al., 2021; Pirotta et al., 2021; Tomlinson et al., 2017; Wright et al., 2020*):

one of the 5 gynaecologists I met told me that if I did not lose at least 30 kg (66

pounds) I would not be able to have a child. And then they came up with this sentence that makes me so angry: Lose weight! (*Authier et al., 2020*).

In discussing symptoms or the diagnosis, patients often reported feeling dismissed (*Crete, 2011; Hadjiconstantinou et al., 2017; Hillman et al., 2020; Ismayilova and*

*Yaya, 2022b; Lim, Wright et al., 2021; Soucie et al., 2021*), blamed or shamed (*Authier et al., 2020; Soucie et al., 2021*), or that news was shared in an insensitive way or in a manner insensitive to their situation, for example due to a young age, infertility or diet history (*Authier et al., 2020; Copp et al., 2022; Hadjiconstantinou et al., 2017; Hillman et*

al., 2020; Kitzinger, 2002; Lim, Smith et al., 2021; Pirota et al., 2021; Sharma and Mishra, 2018; Snyder, 2006; Soucie et al., 2021; Tay et al., 2021; Tomlinson et al., 2017; Weiss and Bulmer, 2011; Wright et al., 2020):

Another participant's doctor shamed her for her weight, saying if/when she has children, '... you're gonna be a whale ... You have to start losing weight.' (Soucie et al., 2021)

... she was studying in 10th standard at that time and doctor straightway told her mother that she would not be able to conceive after marriage. She said that she was terrified at the mention of pregnancy at such tender age. (Sharma and Mishra, 2018)

I told her that I have an eating disorder history, and then she went on in the conversation to suggest that I might be interested in getting a gastric sleeve which was like extremely distressing for me. (Tay et al., 2021)

As reported in the systematic review of information needs, many women felt that primary care doctors lacked knowledge about PCOS (Gibson-Helm et al., 2018), making it difficult to receive news of a diagnosis from their HCP (Crete, 2011; Hadjiconstantinou et al., 2017; Hillman et al., 2020; Holbrey, 2013; Ismayilova and Yaya, 2022a, 2022b; Snyder, 2006). Patients could experience a sense of relief at having their symptoms recognized and validated, especially after an extended period trying to confirm the cause of symptoms (Avery and Braunack-Mayer, 2007; Snyder, 2006; Tomlinson et al., 2017). Despite the relief, the poor sharing of a PCOS diagnosis resulted in individuals feeling uninformed or poorly informed (Authier et al., 2020; Crete, 2011; Hajivandi et al., 2022; Ismayilova and Yaya, 2022b; Kaur et al., 2021; Weiss and Bulmer, 2011), uncertain or confused about their diagnosis (Copp et al., 2022; Crete, 2011; Kaur et al., 2021) or upset, alarmed and worried about their future, especially when they were young when they received the news (Authier et al., 2020; Crete, 2011; Soucie et al., 2021). In some cases, a suboptimal sharing of diagnostic news meant that patients did not take their syndrome seriously (Avery and Braunack-Mayer, 2007; Ismayilova and Yaya, 2022b):

No one really sat there and told me anything. ... so they didn't tell me much

... The doctors don't know much about it. (Crete, 2011)

I told [my doctor] what was going on and she suspected PCOS but didn't explain it very well. She basically made me think that I had cancer and was going to die. (Soucie et al., 2021)

the information they gathered during the consultation of the announcement (diagnosis) in particular, the fear of not being able to have children. This sort of phrasing was very badly experienced by the women, who felt very stressed and even more discouraged after the medical consultations. (Authier et al., 2020)

Margaret (age 33 y) detailed how her unconcerned GP, who initially diagnosed her in her early 20s, affected her attitude towards her health: It's kind of really funny because even I discounted it because everybody was so casual about it ... my GP now ... she actually took it seriously ... Then I kind of clued in to like 'Hey somebody should have been doing something about this like 10 years ago'. (Ismayilova and Yaya, 2022b)

Also challenging were the mixed or opposing communications when sharing PCOS news of any kind (Authier et al., 2020; Avery and Braunack-Mayer, 2007; Kaur et al., 2021; Soucie et al., 2021; Tomlinson et al., 2017; Wright et al., 2020) and the lack of clear statements or follow-up plans when sharing a new diagnosis (Copp et al., 2022; Hadjiconstantinou et al., 2017; Hillman et al., 2020; Ismayilova and Yaya, 2022b; Tomlinson et al., 2017; Weiss and Bulmer, 2011). Specifically, HCP did not always provide patients with a well formulated explanation of the future management of the PCOS (Copp et al., 2022; Crete, 2011; Ismayilova and Yaya, 2022b; Kaur et al., 2021; Soucie et al., 2021) or a detailed follow-up plan (Authier et al., 2020; Copp et al., 2022; Hillman et al., 2020; Ismayilova and Yaya, 2022b; Lim, Smith et al., 2021; Lim, Wright et al., 2021; Pirota et al., 2021; Tay et al., 2021; Tomlinson et al., 2017; Williams et al., 2016) that could have helped absorb or understand whatever news was being shared (e.g. diagnosis, future risks):

I went through a series of doctors that undiagnosed me, re-diagnosed me, diagnosed me as a possible 'maybe you have it, but you shouldn't really be that concerned if you do or don't'. (Wright et al., 2020)

You don't just tell someone they have this and walk away. How unfair to lay a diagnosis on somebody and say, 'Oh well, that's it.' Right. (P9). (Snyder, 2006)

I feel like the access that you get to support and advice is not really around. I feel like there should be follow-up once you have been diagnosed ... Maybe put a plan in place of how often you need to be reviewed depending on how severe your symptoms are, that would be good. (Participant 12, age 29). (Hadjiconstantinou et al., 2017)

... lack of management options. Some sort of a management plan, you know, how do we go forward from here, whether that be diet, exercise, regular check-ups or whatever, but none of that has happened. (32 years, age diagnosed: 30) (Copp et al., 2022).

HCP who acknowledged their lack of PCOS expertise and who took the time to research the condition, explain PCOS to patients and support them when sharing news were perceived positively (Snyder, 2006; Weiss and Bulmer, 2011; Wright et al., 2020):

We were there I think for like two hours ... the first hour, she was explaining everything to me ... about like eating healthier and exercising because I guess it puts you at greater risk for heart disease and diabetes. She drew pictures and showed me how my uterus was and everything. And the other hour she examined me. She explained everything, I think, really well, so I understand a lot of it. (Weiss and Bulmer, 2011)

Also, a health care provider who explained everything made women feel more in control. "Once I found the right doctor, I felt, so much stress went away. I wanted to know. I told him, 'Explain to me what we are doing and then what the next step is. And if that doesn't work, what's the next step after that?' Then I got a sense of control." (P1). (Snyder, 2006)

## **Theme 2: Interactions were challenging when information provision and opportunities for deliberation were insufficient to achieve outcomes that mattered to patients**

Interactions were reported to be challenging when patients were not provided with content that could help them make decisions about unexplained symptoms before a diagnosis or, after a

diagnosis, content about the treatment or management of confirmed PCOS. The complexity of PCOS as a syndrome (e.g. genetic, hormonal), its features and correlates (e.g. hirsutism, acne, higher weight, infertility) and its future risks (e.g. diabetes, cardiovascular disease) make it highly likely that individuals with PCOS will need to make decisions considered suitable for SDM, namely, decisions where more than one course of action is reasonable, where the consequences of actions are significant, and where HCP and patients make decisions together using the best possible evidence (G. *Elwyn, 2021*).

The qualitative synthesis review suggests that SDM was not achieved because of deficits in information provision (options, pathways), deliberation opportunities (e.g. discussion of options according to preferences) or support for the choices made (e.g. facilitating preferred options). Once diagnosed, HCP were often perceived to lack knowledge about PCOS (*Authier et al., 2020; Avery and Braunack-Mayer, 2007; Crete, 2011; Hadjiconstantinou et al., 2017; Holbrey, 2013; Ismayilova and Yaya, 2022a, 2022b; Lim, Wright et al., 2021; J. A. Lin and Cook, 2020; Tomlinson et al., 2017; Weiss and Bulmer, 2011; Williams et al., 2016; Wright et al., 2020*) and, consequently, information provision about treatment and management options was not seen to be meeting patients' needs (*Crete, 2011; Hajivandi et al., 2022; Lim, Wright et al., 2021; Weiss and Bulmer, 2011*).

Information was reported to be suboptimal, being far too much (*Crete, 2011; Lim, Wright et al., 2021*) or too little (*Authier et al., 2020; Avery and Braunack-Mayer, 2007; Bazarganipour, 2017; Crete, 2011; Hillman et al., 2020; Ismayilova and Yaya, 2022a; Williams et al., 2015*), too complex (*Authier et al., 2020; Kaur et al., 2021; Soucie et al., 2021*) or in the wrong format (*Avery and Braunack-Mayer, 2007; Crete, 2011; Lim, Wright et al., 2021*). Due to gaps in information provision, a preference for specialist doctors was expressed (e.g. endocrinologist, gynaecologist; *Lin et al., 2018; Pirota et al., 2021; Snyder, 2006; Wright et al., 2020*):

... no one in the health system is willing to answer their questions and concerns about their illness properly, which aggravates their worries and stress. (*Hajivandi et al., 2022*)

One participant expressed distress at not knowing the full implications of PCOS on her overall health ... "They never told me ... this is something that is part of your overall health just so you know this is something you have to keep watch of. It's going to cause different issues in your life. Never, never told me that." (*Crete, 2011*)

Yeah, I think it might be helpful to see an endocrinologist, someone, especially someone who does research with PCOS and could talk about the latest treatments and the latest research. I think that would just be helpful to hear. (*Pirota et al., 2021*)

Patients reported that only a subset of PCOS treatment and management options were given to them, often restricted to the contraceptive pill (*Atkinson et al., 2021; Bazarganipour, 2017; Kaur et al., 2021; Kitzinger, 2002; Soucie et al., 2021; Weiss and Bulmer, 2011*), making it difficult to make fully informed decisions about all the available options:

No point going to doctor, again and again, every time I go, I am given a hormonal tablet. (*Kaur et al., 2021*)

Similarly, lean women also described frustration at their doctors' advice to "keep doing what you're doing" and lack of alternative options to improve their condition due to their already healthy weight. (*Copp et al., 2022*)

Doctor only really offers to address 1 symptom at a time – Pick one. (*Lucy, AU. Williams et al., 2016*)

Only 33.8% (n = 23/68) of women with a BMI classified as overweight and 49.3% (n = 67/136) of women with a BMI classified as obese recalled that weight loss was explored by their GP as a treatment option for PCOS. (*Hillman et al., 2020*)

Some respondents thought that the reduced options were due to system-imposed restrictions (*Williams et al., 2016*) but patients often perceived that doctors unjustifiably omitted options due to the patient's characteristics (e.g. weight, fertility, age), which also reduced their ability to consider all the options (*Avery and Braunack-Mayer, 2007; Copp et al., 2022; Hadjiconstantinou et al., 2017; Ismayilova and Yaya, 2022b; Kaur et al., 2021; Tomlinson et al., 2017*):

They told me it was a genetic condition, there was nothing I could do about it and

because I'm not overweight, there's really no need to see a dietician or a diabetes educator. (*Copp et al., 2022*)

I was more or less told that you're chubby, you're overweight, there's nothing we can do, we're not giving you any fertility treatment because you're overweight, that would be a danger to a baby, um and 'bye-bye' and I was quite traumatized by that. (*Jess. Tomlinson et al., 2017*)

I consulted a doctor. But he said, 'You should wait; I cannot start hormones at this age.' (*Kaur et al., 2021*)

When options were given, preferences were not solicited or patient factors not integrated in presenting the options, reducing the possibility of patients choosing according to them. For example, consideration was not given to the acceptability of options given the patient's social or life context (*Copp et al., 2022; Hadjiconstantinou et al., 2017; Ismayilova and Yaya, 2022b; Kaur et al., 2021; Lim, Smith et al., 2021; Sharma and Mishra, 2018; Williams et al., 2015*), past failed attempts with an option (*Copp et al., 2022*) or experience of side effects (*Copp et al., 2022; Crete, 2011*):

I'm from an Asian family, where obviously he [doctor] did say it was a contraceptive pill and that's a very taboo thing for an unmarried girl to be taking, a contraceptive pill. (Participant 5, age 29). (*Hadjiconstantinou et al., 2017*)

... every doctor tells me that I need to start thinking about having children sooner rather than later, that's quite a change ... 'cause I'm an army wife ... I was hoping to establish a career, a settled base and then have children. (*Williams et al., 2015*)

I suffered from really bad headaches and so I didn't want to go back on the pill, but that always seemed to be the quick fix ... we'll just put you on the pill and then you'll be regular. (*Crete, 2011*)

... many expressed frustrations at being told to lose weight when they felt they had already tried everything over several years. (*Copp et al., 2022*)

Alternatively, doctors could overly prioritize some symptoms based on their own perceptions of what mattered, usually fertility, even when fertility was not the primary concern for the patient (*Avery and Braunack-Mayer, 2007; Hillman et al.,*

2020; Lim, Wright et al., 2021; Sharma and Mishra, 2018; Soucie et al., 2021; Williams et al., 2015). This doctor-centredness meant that other important symptoms were ignored (Crete, 2011; Hillman et al., 2020; Ismayilova and Yaya, 2022b; Lim, Wright et al., 2021; Pirootta et al., 2021; Tay et al., 2021; Weiss and Bulmer, 2011), or no options were offered until people were ready to have children (Atkinson et al., 2021; Avery and Braunack-Mayer, 2007; Copp et al., 2022; Crete, 2011; Ismayilova and Yaya, 2022b; Kaur et al., 2021; Sharma and Mishra, 2018; Soucie et al., 2021; Tay et al., 2021; Williams et al., 2015). A focus on fertility sometimes caused worry about future fertility as well (Avery and Braunack-Mayer, 2007; Sharma and Mishra, 2018):

... a lot of doctors do see PCOS as more a fertility issue. They ignore the weight issues they ignore the insulin issues. (Lim, Wright et al., 2021)

Some women were left feeling as though they were powerless to do anything about their condition until they wanted children ... "When I went back to see him, he said, 'Bit of a hormonal imbalance, come back and see me if you ever have trouble having children'." (Avery and Braunack-Mayer, 2007)

Patients often felt that the choices they made regarding diagnosis and treatment were not enabled or supported. Most often this was due to being unable to progress with testing (Authier et al., 2020; Kaur et al., 2021), diagnosis (Avery and Braunack-Mayer, 2007; Gibson-Helm et al., 2018; Hillman et al., 2020; Ismayilova and Yaya, 2022a; Kitzinger, 2002; Lim, Smith et al., 2021; Tomlinson et al., 2017; Weiss and Bulmer, 2011; Wright et al., 2020) or access to preferred treatments (Atkinson et al., 2021; Snyder, 2006; Soucie et al., 2021; Tay et al., 2021; Tomlinson et al., 2017). Doctors were reported to be reluctant to help get the required care needed for women to realize their choices (Ismayilova and Yaya, 2022b; Lim, Wright et al., 2021; Tay et al., 2021):

When I went to the GP and, finally, they relented and said, 'we'll send you to the specialist' ... it wasn't until I came to see Dr X that I got offered medication for it – the doctors didn't really want to give me medication. I didn't know there was any medication. (Louise). (Tomlinson et al., 2017)

Participants often did not have great confidence in practitioners to fully understand their circumstances, nor do they find practitioners helpful in helping them navigate the health system to receive appropriate treatment, including in lifestyle management. (Lim, Wright et al., 2021)

Several of the women interviewed felt ... they had missed out on opportunities to start treatment that might have altered the course of their symptomatology. I feel like I lost a lot of time and could've already been pregnant if I had had the right doctor when I had found out that I had PCOS. So, I really feel like I was kind of cheated, because I didn't have the information that I needed. (P9). (Snyder, 2006)

As a consequence of insufficient information provision and deliberation opportunities, patients reported feeling excluded from the decision-making process about treatment (Avery and Braunack-Mayer, 2007; Bazarganipour, 2017; Soucie et al., 2021; Weiss and Bulmer, 2011; Williams et al., 2015) or management (Avery and Braunack-Mayer, 2007; Crete, 2011; Ismayilova and Yaya, 2022b). This often led to poor adherence with recommendations (Bazarganipour, 2017; Hajivandi et al., 2022; Tomlinson et al., 2017) or an erosion of trust and confidence in the advice given (Authier et al., 2020; Crete, 2011; Ismayilova and Yaya, 2022a):

[Methods by which treatment was prescribed] ... cut Lana out of the decision-making process. (Weiss and Bulmer, 2011)

Many participants felt unsupported by healthcare providers and ... made health decisions (short- and long-term) on their own. (Ismayilova and Yaya, 2022b)

The participating girls ... stated that if they knew the side effects of the disease and its connection with nutritional behaviors, they would further follow the doctors' recommendations to lose weight. (Hajivandi et al., 2022)

Participants expressed [that] ... most lost trust due to the lack of information and/or involvement from their physicians. (Ismayilova and Yaya, 2022a)

None of the participants attributed their past successes in lifestyle and weight management to a strong partnership with a healthcare professional, including being

involved in shared decision-making and participating in the co-development of health management plans. (Lim, Wright et al., 2021)

In contrast, interactions that engaged SDM processes, although time-consuming for HCP, were viewed positively (Ismayilova and Yaya, 2022b; Lim, Wright et al., 2021; Snyder, 2006; Soucie et al., 2021), as were HCP who referenced their limited knowledge:

But I know even just going into her [doctor's office] and saying 'You know this is what I've heard and this is what I'm thinking for this, what lines are you coming in on?' She's open to discussing, she doesn't always like my ideas ... But she's pretty involved and 'Ok, well let's think about it' ... she's pretty good. (Ismayilova and Yaya, 2022b)

An open dialogue with practitioners that women feel comfortable with was considered important, this includes connecting with the individual and understanding what their personal goals are. (Lim, Wright et al., 2021)

She (HCP) felt that she wasn't adequately educated enough about [PCOS] to ... make a diagnosis or talk to me about it. She felt it was out of her scope of practice, and so she's like "I want you to get the best information that you can, so I'm gonna refer you on." (Soucie et al., 2021)

### **Theme 3: Interactions were challenging when they prompted but did not support patient activation**

Interactions could be challenging when HCP prompted, but did not support, patient activation or efforts to gain the knowledge needed for diagnosis, treatment or management. PCOS requires patients to actively participate in their own care (self-management). Patient activation is about patients' confidence in achieving this goal (Hibbard et al., 2004) and depends on modifiable knowledge, skills, ability and willingness to manage one's own health and care (James, 2013). The capacity or level of patient activation could be affected by disease characteristics (e.g. cognitive impairment, fatigue, anxiety) (Newland et al., 2021). When self-initiated, patient activation is viewed as positive and critical to overall health and health-related quality of life (Hibbard and Greene, 2013). However, in the context of PCOS, patient activation was often prompted by gaps in care, which was frustrating for patients,

especially when the outputs of that activation were not acknowledged or valued by HCP.

The driving force for patient activation was often to fill gaps in information provision, due to the lack of deliberation opportunities provided to patients or because of the lack of doctor involvement in their care (*Copp et al., 2022; Crete, 2011; Holbrey, 2013; Ismayilova and Yaya, 2022b; Kaur et al., 2021; Soucie et al., 2021; Tay et al., 2021; Tomlinson et al., 2017; Williams et al., 2015, 2016*).

Descriptions of patient activation often implied patients' frustration or resentment at having to be what they perceived as 'my own doctor' (*Ismayilova and Yaya, 2022a*):

One woman said, 'I was trying to look up my symptoms online and go into the doctor's office with some sense of direction because they really didn't spend a lot of time with you ... They wouldn't listen.' (*Soucie et al., 2021*)

It's very frustrating because I usually have to basically tell her [doctor] 'You need to refer me to this' ... I'm usually the one googling how to deal with this. I'm usually being my own doctor. (*Ismayilova and Yaya, 2022a*)

A high level of patient activation was often reported to be required to find appropriate help (*Avery and Braunack-Mayer, 2007; Crete, 2011; Gibson-Helm et al., 2018; Hajivandi et al., 2022; Kaur et al., 2021; Lim, Wright et al., 2021; Snyder, 2006; Soucie et al., 2021; Tomlinson et al., 2017; Williams et al., 2015; Wright et al., 2020*):

My mother, finally after going from GP to GP, the GP just saying: "Teenagers have irregular periods", found another GP who referred me to a gynaecologist. (*Avery and Braunack-Mayer, 2007*)

After seeing two providers, one for management of hirsutism and one for pelvic pain, she was informed by a third provider that she had PCOS ... Participants' ability to gain control often meant visits to several doctors, but rarely total management. (*Crete, 2011*)

The need for patient activation (e.g. persistence, taking charge, personal research) led many patients to feeling that they had diagnosed themselves (*Avery and Braunack-Mayer, 2007; Crete, 2011; Hadjiconstantinou et al., 2017; Snyder,*

*2006; Tomlinson et al., 2017*) or that they were more knowledgeable than their doctors (*Avery and Braunack-Mayer, 2007; Crete, 2011; Holbrey, 2013; Kitzinger, 2002; Tomlinson et al., 2017*):

"Nobody was diagnosing me. I actually diagnosed myself." (P1) "I diagnosed myself through a lot of reading and research and finding it out." (P2). (*Snyder, 2006*)

... participants had done a great deal of research on their condition ... with women complaining that they were more knowledgeable about the condition than, for instance, their GP. (*Kitzinger, 2002*)

I am usually significantly better informed on PCOS than the registrars I see when the consultant farms me out. (*Holbrey, 2013*)

Despite involving much effort and being a consequence of gaps in care, patient activation was perceived to not be responded to positively by HCP. Patients did not feel valued as expert witnesses of their own health. Symptoms brought to a doctor's attention were discounted using unhelpful strategies (e.g. normalization, minimizing) (*Hillman et al., 2020; Kaur et al., 2021; Soucie et al., 2021; Tomlinson et al., 2017; Weiss and Bulmer, 2011*). Patients' understanding of their symptoms were also dismissed or not taken seriously (*Atkinson et al., 2021; Hadjiconstantinou et al., 2017; Ismayilova and Yaya, 2022a; Kitzinger, 2002; Soucie et al., 2021; Tomlinson et al., 2017; Williams et al., 2015; Wright et al., 2020*). This challenge could be greater for young people:

I've just been told it's not bad enough. And I was like well who are you to say it's not bad enough? It's bad enough for me. (*Atkinson et al., 2021*)

Doctors said nothing about it. She is young; her hormones are changing. With time, everything will be normal. (*Kaur et al., 2021*)

I remember him just kind of looking at me and was like "Well, you're very young still, you're 15, so I don't think anything's wrong with you. You're OK." ... I just assumed, this is a doctor, he is a medical professional ... what do I know about it? I'm a 15-year-old girl. (*Soucie et al., 2021*)

The outputs of patient activation (e.g. knowledge, treatment suggestions, self-

reported comorbidities) were not acknowledged or valued, and in some cases were seen to upset the doctor-patient relationship (*Avery and Braunack-Mayer, 2007; Ismayilova and Yaya, 2022b; Kitzinger, 2002; Soucie et al., 2021; Wright et al., 2020*):

I know PCOS is potentially linked to mental health issues too. I've read it. And I remember bringing these types of things up and he would just kind of shy away from it like he didn't want to deal with it. (*Ismayilova and Yaya, 2022b*)

One participant said that "[my doctor] was angry when I brought my own information with me to the consultation, but I was frustrated not having any answers." (*Soucie et al., 2021*)

most of the participants had done a great deal of research on their condition, and this also led to problems in the doctor-patient relationship, with women complaining that they were considered to be acting inappropriately in being assertive in asking for specific treatments. (*Kitzinger, 2002*)

A main consequence of not supporting patient activation or outputs of that activation was that patients worried about what they found, especially future risks (*Copp et al., 2022, Tay et al., 2021*), made decisions on their own or by trusting popular opinion, for example trying untested or ineffective treatments without expert support (*Ismayilova and Yaya, 2022b*), and at times disengaged with healthcare:

By not receiving information in the face of this unknown (to her) disorder ... many had to instead figure out how to reconcile these fears: "I wonder what's going to change as I get older, what other symptoms do I not know about that are going to rear their head?" (*Soucie et al., 2021*)

... my GP knows nothing about it so I have to go and figure it out myself. So, then I trust the information in all of these books and looking at kind of what the popular opinion is on certain things. Like testing out all these different supplements and then trial and error myself. (*Ismayilova and Yaya, 2022b*)

I'm not going to wait for months and months and months to get an appointment with a dietician, so I went to Google and I

looked up low GI diets and I found my way to a couple of health sites. (Tomlinson et al., 2017)

HCP were viewed positively when they supported patient agency by validating concerns (Avery and Braunack-Mayer, 2007; Hadjiconstantinou et al., 2017; Snyder, 2006; Soucie et al., 2021) or providing reassurance about these (Authier et al., 2020; Hadjiconstantinou et al., 2017; Hajivandi et al., 2022; Hillman et al., 2020; Tay et al., 2021) and by being knowledgeable and supportive of patients' preferences and research (Ismayilova and Yaya, 2022a, 2022b; Lim, Wright et al., 2021). Also viewed positively were doctors who supported patient agency in consultations (Hadjiconstantinou et al., 2017; Hajivandi et al., 2022; Lim, Wright et al., 2021; Snyder, 2006; Soucie et al., 2021) and facilitated outcomes that mattered to patients (Avery and Braunack-Mayer, 2007; Hillman et al., 2020; Ismayilova and Yaya, 2022a, 2022b; Lim, Wright et al., 2021; Soucie et al., 2021):

The thing I enjoyed about talking to that doctor was that he seemed to know what I was talking about. The symptoms and things like that. (Avery and Braunack-Mayer, 2007)

He sort of made me feel like this isn't some sort of like awful life sentence where you never ... have a baby ... I think I'd catastrophized a lot through my own research so he put that at ease, I felt. (013, age 33). (Tay et al., 2021)

Most women from the Monash Health PCOS clinic had a positive review of the lifestyle service, with most positive comments relating to goal setting, the discussion of strategies to engage in healthy lifestyle behaviors. (Lim, Wright et al., 2021)

Practitioners who were most helpful were those who were ... provided space for an open dialogue. Dialogues were not only validating but also informed and led by the women. (Soucie et al., 2021)

At that point I didn't really understand terribly much. And she (HCP) also didn't, looking back. But she cared enough that she sent me on these tests and she would listen to me when I'd come in and say 'Okay I think I should be on this drug'. She would research it obviously or look it up in the drug book. But she listened to me. (Ismayilova and Yaya, 2022b)

Patient activation could be positive and driven by patients' desire to improve discussions of their symptoms or options with HCP (Avery and Braunack-Mayer, 2007; Crete, 2011) or to counter-argue doctors' treatment decisions (Holbrey, 2013):

Often the women would share the information with their doctors, in order to become involved with managing their health. (Avery and Braunack-Mayer, 2007)

I would summarize my first experience as naïve, unaware ... I had a very limited view of what it was, and here I'm much more educated and I think my doctors are aware and they are able to talk to me a little bit more. (Crete, 2011)

I've felt that I had [after going to patient forum] the information to challenge unfair treatment, particularly from my GPs surgery who don't appear to understand PCOS. (P64). (Holbrey, 2013)

#### **Theme 4: Interactions were challenging when health system-level barriers were present or made worse by HCP behaviour**

A fourth challenge in interactions with HCP emerged when people were confronted with system-level restrictions or when these were made worse by the behaviour of HCP. Many health system factors (i.e. policies and guidelines, incentives, HCP education and licensing) and organizational characteristics (i.e. culture, leadership, priorities, teamwork, resources, workflows) could undermine healthcare delivery, even for the best HCP (Scholl et al., 2018). Diverse examples of system-level challenges were reported.

First, many patients said that the required or preferred treatment was not available. This could be due to the lack of a care pathway (Hajivandi et al., 2022), the service not being offered in a national health plan (Holbrey, 2013), long delays (Authier et al., 2020; Kaur et al., 2021; Snyder, 2006; Soucie et al., 2021; Tay et al., 2021; Tomlinson et al., 2017) or patients having access to one or another service, but not both (Tomlinson et al., 2017):

... although girls' health is in fact a guarantee of family health, the health system's reproductive health programs are mainly related to prenatal, delivery, and postpartum care. They stressed that there

are no centers to monitor the health of adolescent girls. (Hajivandi et al., 2022)

... the help we want (for example laser treatment on the NHS) is not available. (P30). (Holbrey, 2013)

Second, when services were available, participants reported that a lack of staff created long waiting times (Bazarganipour, 2017; Ismayilova and Yaya, 2022b; Kaur et al., 2021), especially in some geographical regions (Sharma, Soucie, Wright) or during the pandemic (Atkinson et al., 2021):

To visit a gynecologist, I had to sit from morning to noon in the waiting room of the clinics. It is extremely frustrating. (Bazarganipour, 2017)

... you really do have to advocate and that I think is the most frustrating part is that there just aren't enough doctors to give you that quality and that level of care. So, you have to fill in the gaps yourself. (Ismayilova and Yaya, 2022b)

Participants described experiencing reduced access to HCPs and services during the COVID-19-related lockdown. This included access to their usual clinicians, as well as delays to services they were waiting to receive pre-pandemic. (Atkinson et al., 2021)

Third, communication inefficiency between levels of care or the lack of a coordinated care plan was frustrating, disappointing or expensive (Bazarganipour, 2017; Kaur et al., 2021; Lim, Wright et al., 2021; Soucie et al., 2021). Some patients preferred for their GPs to be involved but that was not always possible:

A fragmented system where women have to organize and attend multiple visits spread across medical and allied health services and keep track of information from multiple practitioners was not only difficult and exhausting but also financially expensive. (Lim, Wright et al., 2021)

Every time I consult a new doctor, the tests are repeated; even when I show them previous reports. (Kaur et al., 2021)

Although HCP probably lacked the power to change system-level challenges, they were often reported to make these worse due to their approach to PCOS. HCP were in some cases reported to be inexplicably obstructive, especially in securing a referral to specialists or to specialist services within



the health system (Hillman et al., 2020; Ismayilova and Yaya, 2022a, 2022b; Soucie et al., 2021; Tomlinson et al., 2017; Weiss and Bulmer, 2011; Williams et al., 2015, 2016; Wright et al., 2020):

The GP was described as a gatekeeper who could be obstructive, particularly in gaining access to specialist PCOS or fertility services . . . letters to GPs saying “look, I’ve got this, this, and this; it’s pretty clear to me what it is, is it possible to have this referral? . . .” There seems to be a bit of a barrier, for whatever reason. (Hillman et al., 2020)

Many participants had long journeys to their diagnosis and described instances of PCPs brushing off concerns, not providing referrals, and not ordering tests to investigate their concerns. (Ismayilova and Yaya, 2022a)

. . . participants self-advocated for specialist referrals but were mostly unsuccessful. Participants expressed that their physicians “were hesitant to refer [them],” “expressed resistance to refer, despite not knowing what PCOS was”. (Soucie et al., 2021)

Finally, personal barriers could also interact with system-level factors, for instance the geographical scarcity of healthcare providers in some regions (Sharma and Mishra, 2018; Soucie et al., 2021; Wright et al., 2020) along with patients’ inability to cover the cost of travel or treatment closer to home (Bazarganipour, 2017; Ismayilova and Yaya, 2022a; Kaur et al., 2021; Lim, Wright et al., 2021; Wright et al., 2020):

I have no prescription medical coverage and I’m about to lose medical insurance all together.” “We could not afford to keep trying [to get pregnant]. As many of you know insurance did not cover the treatments.” (Wright et al., 2020)

One woman recalls experiencing “a long wait list to see [the specialist], and he was an hour drive away, and he was in and out and the appointment was 10 minutes long.” (Soucie et al., 2021)

Doctors who helped patients overcome system level barriers were perceived positively:

She said that even though we had only been trying for 8 months, because I had had no period at all she would push for an

early referral to the fertility clinic. (Hillman et al., 2020)

Participants believed that a knowledgeable and well-versed PCP could speed up diagnoses for patients by avoiding the need for referrals to specialists. (Ismayilova and Yaya, 2022a)

When I saw my endocrinologist, she was amazing, and she would CC all my relevant allied health professionals into her letters and I’ll get CC’d to them as well. (Lim, Wright et al., 2021)

## DISCUSSION

The aim of this QES was to identify and interpret the challenges people with PCOS encounter when interacting with HCP. Coding of the 28 included studies (1657 women with PCOS) made it possible to identify four interrelated domains of challenges that could cumulatively undermine the achievement of diagnosis, management, and treatment outcomes from interactions with healthcare professionals that matter to people with PCOS. These centred on suboptimal sharing of medical news, insufficient information provision and deliberation opportunities, lack of support for patient activation and its outputs, and system challenges that could be worsened by HCP behaviour. Confidence in the identified themes was high, with only minor concerns related to adequacy for the findings that interactions are challenging when these trigger but do not support patient activation and when health system-level barriers are present (see TABLE 3).

Future research needs to implement and evaluate well-established and effective frameworks to address challenges, most notably those for sharing medical news, SDM and support for patient activation for the clinical diagnosis, management and treatment of PCOS that matters to patients. HCP should receive more training in these domains, and health systems should create opportunities to address these challenges. Biases within healthcare interactions that could worsen system-level challenges in the availability, accessibility and affordability of care should also be explored. To address the areas of challenging interactions identified, frameworks need to be determined but approaches known to be effective in other domains overlapping with PCOS (e.g.

infertility, diabetes, cardiovascular disease) could be considered first.

In terms of sharing medical news, interactions with HCP were found to be challenging when medical news related to suspected or confirmed PCOS was not shared in a way that safeguarded patients’ well-being. Much empirical research evaluates optimal ways of sharing medical news that could transfer to the PCOS context. The SPIKES framework proposes six steps: Setting up the interview, assessing the patient’s Perception of the situation, obtaining the patient’s Invitation to deliver the news, giving Knowledge and information to the patient, addressing the patient’s Emotions empathically, and providing a Summary discussing prognosis and treatment options (Baile et al., 2000). SPIKES is aligned with patient preferences (Mirza et al., 2019), including on fertility care, which many people with PCOS will use (Leone et al., 2017). There is significant ethnic, religious and individual variability in preferences for how medical news should be shared (e.g. amount of detail, who should be present) (Matthews et al., 2019) but systematic reviews and meta-analyses (17 studies) show that the SPIKES framework for training doctors to break bad or difficult news, out-performs other approaches (e.g. observer-rated news delivery skills, doctor confidence) in many countries (e.g. Belgium, Germany, Israel, Japan, Hong Kong, UK, USA) (Johnson and Panagioti, 2018).

In relation to SDM, interactions were also reported to be challenging when patients were not provided with content that could help them make decisions about unexplained symptoms, or the management or treatment of undiagnosed and/or diagnosed PCOS. The SDM framework (Elwyn et al., 2010; Elwyn et al., 2017; NICE, 2021) could be used to address challenges in information provision and deliberation opportunities in PCOS. SDM is a collaborative process between healthcare providers and patients, where both parties contribute to healthcare decisions based on the best available evidence and the patient’s values and preferences (Elwyn et al., 2010). Research on the use of SDM in areas of relevance to PCOS results is positive, showing decision aids to reduce decisional conflict and improve patient knowledge (Poprzeczny et al., 2020; 35 studies). SDM is often supported using patient decision aids (supporting patients) and decision support tools (supporting HCP), including

resources for PCOS ([Poprzeczny et al., 2020](#))

The review also identified that interactions were challenging when patients' efforts to seek further information and education to fill in gaps in their knowledge, often due to HCP's lack of information provision, were not supported by HCP. To address challenges in supporting patient activation, understanding the patient activation framework ([Hibbard et al., 2004](#)) and an associated assessment tool ([Hibbard et al., 2005](#)) would facilitate supporting patients through different levels of activation (low, disengaged, overwhelmed) to high (maintaining; [Hibbard et al., 2004](#)). A narrative review indicates that greater levels of patient activation are associated with the uptake of preventive behaviours (e.g. check-ups, screening), healthy behaviours (healthy diet, regular exercise), health literacy (e.g. disease knowledge) and asking questions during consultations ([Hibbard and Greene, 2013](#); [Kinney et al., 2015](#)). A meta-analysis in chronic diseases showed benefits across a wide range of outcomes (physiological, psychosocial, behavioural, health-related quality of life; [Lin et al., 2020](#)), many of which could be relevant to PCOS due to the hyperinsulinaemia, hyperandrogenism and neuroendocrine disturbances caused by this disorder ([Regeer et al., 2022](#)).

An additional challenge for patients with PCOS when interacting with HCP was identified to be system-level restrictions and HCP's restrictive behaviour. Challenges included lack of access and delays in service provision, and HCP (according to patient perspective) obstructing referrals to specialists or specialist services within the healthcare system. In the present review, health system challenges restricting HCP's behaviour were not directly mentioned but could be inferred from perceived helpful actions, for example 'push for an early referral to an infertility clinic' ([Hillman et al., 2020](#)). Several studies recommended more holistic or integrated care where education, screening, diagnosis and treatment are provided, together covering emotional well-being, cardiometabolic diseases and the dermatological and reproductive elements of PCOS ([Atkinson et al., 2021](#); [Hadjiconstantinou et al., 2017](#); [Lim, Wright et al., 2021](#); [Tay et al., 2021](#)). A review suggests that these models are viewed positively ([Melson et al., 2023](#)). Education and training of HCP regarding the use of new PCOS models of care and

frameworks would be needed but requires health systems to provide the opportunities as barriers are often at system level (e.g. consultation time; [Legare et al., 2008](#))).

Recommendations can be provided from the integration of primary evidence (narratives) and meta-level analysis (inductive and deductive coding). The analytic themes were used to propose meta-concepts that go beyond the primary reported data to explain the challenges reported. Although interpretive, these meta-level concepts were very much present in the included studies, although not necessarily explicitly stated. For example, SDM was referred to as the need to elicit preferences in all aspects of care and involve women in decisions. The current authors see this congruence as supporting the proposed meta-level concepts. However, they also note that experts with different disciplinary backgrounds could have interpreted the data to accommodate other frameworks, for example health communication or social theories ([Malikhao, 2020](#)). They do not consider such a possibility as invalidating the meta-concepts proposed, but rather have the view that more meta-level conceptualization – whether from social, psychological or behavioural theories – is more likely to prompt the kind of broad strategic developments needed to develop optimal PCOS care.

Based on a consideration of the data and the analysis in this review, the GDG 2 proposed and integrated two evidence-based recommendations in the 2023 update of the International Evidence-based PCOS Guideline ([Teede et al. 2023a](#)), namely that 'Healthcare professionals should employ shared decision-making and support patient agency or ability to take independent actions to manage their health and care' and 'The importance of being knowledgeable about PCOS, of applying evidence-based practices when sharing news on diagnosis, treatment, and health implications, and of ascertaining and focusing on patient priorities, should be recognized.' A further consensus recommendation was made – that 'Healthcare system leaders should enable system wide changes to support healthcare professional training, knowledge and practice in sharing news optimally, shared decision making and patient agency, including ensuring adequate consultation time and accessible resources' – with additional practice

points for the use of available frameworks and resources to address these challenges (see Table 4 in [Teede et al., 2023a](#)).

The strengths and limitations of the included studies and the review process warrant consideration. One strength of the review was that it addressed a novel important topic prioritized by guideline stakeholders ([Teede et al., 2023a](#); [Teede et al., under review](#)). It also identified important positives and negatives about interactions with healthcare professionals, and frameworks for addressing these, that could be considered in future implementation. In addition, the CERQual ratings showed that many of the 28 studies contributed to each identified domain of challenge and were of sufficient robustness for the analytic themes to be perceived as reliable.

There were limitations in both the included studies and the review process. In the included studies there was a lack of diversity, as these mainly came from developed nations. The diagnosis was often self-reported and there was a possibility of recall bias in some experiences (e.g. time since diagnosis <1 year to 17 years across studies; see [TABLE 1](#)). Moreover, patient-related factors (e.g. family history of premature ovarian failure, low BMI) could have influenced the time to diagnosis and subsequent interactions with healthcare professionals but these factors were not explored by the included literature. Limitations in the review process were that the initial screening for the included studies where quality appraisal was performed by only one author, although any uncertainty was discussed with the GDG.

This study used search terms 'female' and 'women' and may have missed healthcare challenges experienced by non-binary or transgender populations ([Wugalter et al. 2023](#)). The authors perceive that their coding of the lived experience would achieve congruence among participant, researcher and synthesizer but that was not confirmed ([Noyes and Lewin, 2011](#)). Lastly, the synthesis by design focused on patients' perceptions of challenges in their interactions with HCP and therefore primarily reported on the negative aspects of care despite many examples of good practice in patient narratives.

Research on PCOS is lacking. There are many unanswered questions about the cause of PCOS and treatment options are

often largely inadequate, contributing to the frustrations experienced by HCP and women. The current results could be considered alongside another review that instead focused on challenging interactions that HCP perceived having with patients with gynaecological conditions, including PCOS (Briscoe *et al.*, 2022). The challenges reported in that HCP review indicate that doctors know about these challenges but might interpret these differently. For example, their lack of knowledge was attributed to infrequent exposure to gynaecological conditions caused by patient preferences for female doctors. Integrating review findings could suggest that solutions and frameworks to address the challenges identified will need to be co-produced with HCP and patients, as recommended in the few studies in the present review that examined both (Copp *et al.*, 2022; Hajivandi *et al.*, 2022).

## CONCLUSIONS

This QES has integrated and provided an explanatory frame for the multifaceted challenges faced by people with PCOS when interacting with HCP. The explanatory concepts indicate that challenges can be addressed using well-established and evidenced frameworks, namely for sharing medical news, SDM and patient activation. Together with facilitative system-level changes allowing education, training and the implementation of these frameworks, PCOS consultations could be improved. Future research needs to examine what would work best for PCOS care and identify how these could be implemented for all patients and without bias due to patient or clinical characteristics. The body of work synthesized in this review has led to the inclusion of evidence-based recommendations, consensus recommendations and good practice points for refining the International Guidelines.

## DATA AVAILABILITY

Data will be made available on request.

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## AUTHOR CONTRIBUTIONS

J.B., C.T.T., M.A.B., A.M. and H.T. contributed significantly to the conception and design of the work, including the review question. C.T.T. carried out the searches, selected the studies and performed the critical appraisal of the studies. J.B. and C.H. performed all the data extraction and coding, CERQual evaluation, data synthesis and interpretation. J.B. and C.H. drafted the manuscript, and all authors reviewed this work critically. All authors replied to reviewer comments and provided final approval of the version to be published. All authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

## SUPPLEMENTARY MATERIALS

Supplementary material associated with this article can be found in the online version at [doi:10.1016/j.rbmo.2024.104293](https://doi.org/10.1016/j.rbmo.2024.104293).

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