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1 **Title:** What are key challenges for those with polycystic ovary syndrome when interacting with
2 healthcare professionals? A qualitative evidence synthesis

3

4 **Running title:** Patient-doctor interactions in PCOS

5

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27

28 **Abstract**

29 Studies report interaction difficulties between patients with polycystic ovary syndrome (PCOS) and
30 healthcare professionals. This systematic review and qualitative evidence synthesis aimed to collate
31 and synthesise the existing peer reviewed literature investigating challenges for people with PCOS
32 when interacting with healthcare professionals (HCPs). Medline, PsycInfo, EMBASE, All EBM, and
33 CINAHL were searched from inception to September 2022. Study risk of bias (RoB) was performed
34 and all textual data relevant to challenging interactions between patients with PCOS and HCPs were
35 extracted and analysed using thematic synthesis. Of the 6353 studies identified, 28 were included. Six
36 were appraised high, four as moderate and 22 as low RoB. Four analytic themes were derived
37 illustrating interactions were challenging when: (1) medical information (PCOS, its management) was
38 not shared in the best way; (2) information provision and deliberation opportunities were insufficient
39 to achieve outcomes that mattered to patients; (3) they prompt but do not support patient activation;
40 and (4) health system level barriers (e.g., policies, guidelines) were present or made worse by HCP
41 behaviour. Future research should examine methods for the implementation and evaluation of
42 established frameworks for sharing medical information and supporting patient agency in the context
43 of PCOS care.

44

45 **Key words:** PCOS, polycystic ovary syndrome, qualitative, doctor-patient communication, decision-
46 support

47

48 **Introduction**

49 PCOS affects about 12% of women globally (Bozdag et.al, 2016; Skiba et al., 2018) and is a
50 polygenic endocrine disorder characterised by hyperinsulinemia and hyperandrogenism. According to
51 the International Guideline criteria, the diagnosis in adults requires two of three features including: i)
52 oligoanovulation, ii) hyperandrogenism (HA), and iii) polycystic ovarian morphology (PCOM) on
53 ultrasound or an elevated level of anti-mullerian hormone (AMH) (Teede et al., 2023b). Adolescent
54 diagnosis requires both ovulatory disturbance and HA, but PCOM and AMH are not indicated as they
55 lack specificity for PCOS at this life stage (Kiconco et al., 2023). PCOS results in diverse and
56 significant health burdens that imply a high need for self-management, namely associated metabolic
57 (type 2 diabetes, obesity, metabolic syndrome, cardiovascular disease), reproductive (irregular
58 periods, infertility, pregnancy complications), psychological (depression, anxiety, disordered eating),
59 and dermatological (hirsutism, acne, androgenic alopecia) features, across the lifespan. The impact of
60 the diagnosis and experience of PCOS on quality of life has been shown to be marked, similar to, or
61 greater than other chronic conditions such as diabetes (Rempert et al., 2023).

62 Interactions between patients, their doctors, and the wider healthcare team about polycystic ovary
63 syndrome (PCOS) (hereafter referred to as “interactions”) are important for patients to learn about
64 their health, make informed decisions that are in line with their preferences and values, and be
65 supported to achieve their desired outcomes (e.g., quality of life, metabolic, dermatologic etc).

66 International research additionally suggests recurrent challenges in interactions of patients with PCOS
67 with their HCPs. Patients often report that HCPs dismiss or do not take their concerns seriously
68 (Ismayilova & Yaya, 2022; Atkinson, 2021), or they do not address them in a sensitive or empathetic
69 way (Soucie et al., 2021). Also reported is that the PCOS care pathway is often not explained with
70 sufficient clarity (e.g., information about options, referral, treatment, next steps) (Kaur et al., 2021).

71 Patients with PCOS and HCPs perceive that challenging interactions undermine the positive diagnosis
72 and treatment outcomes intended to be achieved from healthcare interactions (Copp et al., 2022).

73 Namely, patients report feeling unable to make satisfying or quality decisions about their health or

74 treatment (Weiss & Bulmer, 2011), accept or adjust to their diagnosis (Holbrey, 2013) or feel
75 competent in the management of their condition after diagnosis (Ismayilova & Yaya, 2022).
76 Major gaps in research, education and dedicated care pathways have been linked to delayed diagnosis
77 and high dissatisfaction in patients with PCOS (Teede et al., 2023b). Healthcare in PCOS is
78 fragmented with few documented models of care (Melson et al. 2023). Challenges of PCOS
79 management include variation in clinical presentation due to e.g., ethnicity (Sendur & Yildiz, 2021)
80 and age (Witchel et al., 2019), varied effectiveness of treatment directed at different symptoms
81 (Hoyos et al., 2020), and differing patient priorities about the most bothersome symptoms (Martin et
82 al., 2017). There are also health system and organisational factors (e.g., limited education about
83 PCOS, limited access to secondary care) hindering effective PCOS care (Briscoe et al., 2022). Such
84 variability contributes to missed and delayed diagnosis and poor patient healthcare experiences
85 (Teede et al., 2014).

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

90

91 **METHODS**

92 The review question, “What are the key challenges for individuals with PCOS when interacting with
93 healthcare professionals about PCOS?”, was prioritised by multiple key stakeholders in the 2023
94 International Guideline, including individuals with PCOS lived experience and clinical and academic
95 experts (Teede et al., 2023b). The protocol of the review was developed a priori by experts of the
96 PCOS Guideline Development Group (HT, JB, MB) and is publicly available online in the 2023
97 PCOS Guideline technical report (Mousa et al., 2023).

98 We report the review in accordance with the PRISMA (Preferred Reporting Items for Systematic
99 Reviews and Meta-Analyses, (Tricco et al., 2016) and ENTREQ (Enhancing Transparency in
100 Reporting the Synthesis of Qualitative Research (Tong et al., 2012)) guidelines.

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Information sources and search strategy

We searched five main bibliographic databases: MEDLINE (Ovid), PsycINFO (Ovid), EMBASE (Ovid), All EBM (Ovid), and CINAHL (EBSCOhost) from 1990 to 13th September 2022. The search criteria included pre-defined 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 framework (i.e., Participants, Intervention/exposure, Comparison, Outcomes, Study Type) (see Supplementary Table 2). The population of interest was females 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. We excluded studies reporting on women without PCOS, interactions with non-HCPs, articles reporting the perspectives of HCPs as participants, and those focusing solely on patients' experiences or feelings related to receiving a PCOS diagnosis rather than their interactions with healthcare professionals during the diagnostic process. Unpublished studies, dissertations, theses, editorials or commentaries, conference abstracts, letters to editors, protocols, and non-English studies were excluded.

Study selection

Search results were imported into Covidence (www.covidence.org) and duplicates were removed. A single reviewer (CTT) screened each title/abstract and full text article according to the predefined inclusion/exclusion criteria. Any uncertainty with the study selection was discussed with the

127 Guideline Development Group (GDG) 2 (members AM, CTT, MB, JB (deputy chair GDG2), HT
128 (chair GDG)).

129

130 **Quality appraisal**

131 We determined the value of the primary studies to the review question in two ways. A single reviewer
132 (CTT) performed study quality appraisal using the Critical Appraisal Skills Programme (CASP)
133 checklist for qualitative or mixed methods studies and the Monash Centre for Health Research and
134 Implementation (MCHRI) Evidence Synthesis Program Critical Appraisal Tool (MCHRI, 2013) for
135 cross-sectional studies. Study quality was ranked as low, moderate, or high risk of bias based on
136 overall judgement by a single reviewer (CTT). Study quality did not determine study inclusion or
137 weighting of study results. Additionally, the Confidence in the Evidence from Reviews of Qualitative
138 research (GRADE - CERQual) assessment was used to assess confidence in the findings of the
139 qualitative evidence synthesis by CH, JB (Lewin et al., 2015). The assessment is based on limitations
140 of the research, the relevance of studies to the review question, the coherence of the review findings
141 and the adequacy of the data supporting the review findings.

142

143 **Data extraction and meta-synthesis**

144 Data extraction included study characteristics (e.g., author, year, country, PICO characteristic, data
145 collection and analysis method) and relevant research findings and implications related to challenging
146 interactions with HCPs. To avoid omitting findings of potential value to the synthesis (Noyes &
147 Lewin, 2011), we were inclusive in extraction of findings and included quotes from participant speech
148 or text, and authors' interpretations (i.e., results, themes, sub-themes as relevant) even when not
149 corroborated with participant quotes (Noyes & Lewin, 2011). Data extraction was performed by JB
150 and CH in parallel for all studies. Any disagreements were resolved by discussion. For data synthesis,
151 the PDFs of included studies were uploaded to NVivo 20 (NVivo, 2023), where all data relevant to
152 the review were highlighted and directly coded.

153 We used qualitative evidence synthesis (QES) to establish a deeper understanding of existing peer-
154 reviewed studies (Flemming & Noyes, 2021). The most common method of synthesis, and the one
155 used in the present QES is thematic synthesis (Thomas & Harden, 2008). Thematic analysis is an
156 adaption for the purpose of secondary data synthesis of thematic analysis. This realist-pluralist
157 approach assumes that it is possible to uncover people’s reality from their reported experiences and
158 understandings (Braun & Clarke, 2006), that it is possible to reconcile differences among studies
159 (concepts, methods, theories) and possible to produce reproducible, meaningful, and novel
160 explanation (Johnson, 2017). Our knowledge of the field also suggested this approach because we
161 expected significant diversity in the available research (e.g., international, cross-disciplinary, varied
162 healthcare systems, sampling, lifespan, aims).

163 We adopted the three-stage thematic synthesis procedure (Thomas and Harden, 2008) to synthesise
164 the data: 1) line-by-line coding; 2) development of descriptive themes; and 3) generation of analytic
165 themes. First, CH and JB performed inductive coding of all relevant data pertaining to interactions
166 between HCPs and patients. A coding frame was developed comprising codes derived from the data.
167 Coding was performed by CH and then the coding framework was checked by JB. Any disparities or
168 discrepancies in coding were resolved by discussion and the coding frame was adjusted accordingly
169 and applied to all the included literature. In the second stage, JB and CH inductively grouped codes
170 into descriptive themes reflecting or describing patterns of similarity among codes within and across
171 studies. JB and CH compared descriptive themes and discussed these until consensus were agreed.
172 Although described linearly, in practice, line by line coding and development of descriptive themes
173 occurred in parallel, iterative fashion and new concepts identified when deemed necessary. In the final
174 stage, JB and CH generated analytic themes to propose meta-concepts that go beyond the primary
175 reported data and explained the challenges in interactions with health professionals for patients with
176 PCOS. Analytic themes were deductive insofar as the interpretation of the aggregated descriptive
177 themes was influenced by the literature included in the review, knowledge of broader psychological
178 and health theories. This type of hybrid thematic analysis is used in mixed methods research to
179 provide a method by which participant voices can be heard (e.g., was not consulted about options, “I

180 didn't like that they would just prescribe birth control pills without talking to me about the options",
181 Weiss & Bulmer, 2011) yet complemented by related theoretical concepts (e.g., shared decision-
182 making). The analytic themes were used to underpin the set of recommendations for research, policy,
183 and training. A thematic map illustrating the proposed relationships among analytic themes was
184 generated. Analytic themes are presented with accompanying quotes from the included studies with
185 sufficient information provided to ensure clarity about whether the quote is from a person with PCOS
186 or from a researcher.

187

188 **Results**

189 **Study selection results**

190 Figure 1 shows the PRISMA review flowchart. In total, 7901 records were retrieved, of which 1548
191 duplicates were removed. The remaining 6353 studies were screened by title and abstract, after which
192 173 full-text articles were retrieved and 145 were excluded (Supplemental Table 3 shows study
193 exclusions with reasons). In total, 27 studies and 1 systematic review of 1657 women with PCOS met
194 inclusion criteria for this specific review (See Supplemental Table 4 for a list of the included studies).

195

196 **Characteristics and topics of the included studies**

197 Table 1 presents characteristics of the included studies. Most studies were published in the last five
198 years (n=19) and were primarily from high income, anglophone, western countries (UK n=8,
199 Australia n=7, USA n=3, Canada n=3, France n=1). Four studies were from Iran (n=2) and India
200 (n=2). The majority of studies (n=16) sampled women self-reporting a diagnosis of PCOS. Of 11
201 studies recruiting from health settings and with confirmed diagnoses, one study used National
202 Institute of Health (NIH) criteria (Avery & Braunack-Mayer, 2007); five used Rotterdam criteria
203 (Bazarganipour, 2017; Hadjiconstantinou et al., 2017; Kaur et al., 2021; Lim, Smith, et al., 2021;
204 Tomlinson et al., 2017) and five did not specify criteria used (Crete, 2011; Hajivandi et al., 2022;
205 Sharma & Mishra, 2018; Synder, 2006; Tay et al., 2021). Most studies recruited participants from
206 social media or community posts to PCOS support groups. Nine studies recruited women in

207 gynaecology or PCOS clinics (Bazarganipour, 2017; Crete, 2011; Hadjiconstantinou et al., 2017;
208 Hajivandi et al., 2022; Lim, Wright, et al., 2021; Sharma & Mishra, 2018; Snyder, 2006; Tay et al.,
209 2021; Tomlinson et al., 2017). All but two studies sampled across the lifespan (from 18 to 66 years,
210 depending on study). The other two studies specifically sampled adolescent or emerging adults aged
211 15 to 21 years (Hajivandi et al., 2022) and 18 to 23 years (Weiss & Bulmer, 2011). Three studies were
212 mixed methods (Hillman et al., 2020; Kaur et al., 2021; Pirotta et al., 2021), one a systematic review
213 (Gibson-Helm et al., 2018) and one cross-sectional study (Lin et al., 2018), with the remaining studies
214 being qualitative. Among the latter, the predominant data collection method was interview alone or in
215 combination with other methods (e.g., focus groups). Duration of interviews ranged from 17 (Lim,
216 Smith, et al., 2021) to 90 minutes (Avery & Braunack-Mayer, 2007; Kitzinger, 2002; Tomlinson et
217 al., 2017; Williams et al., 2015). One study using a citizen panel reported a three-hour duration (Lim,
218 et al., 2021). All studies investigated and referred to experiences of having PCOS, but not all studies
219 had the same domain of inquiry with most studies investigating domains directly related to care (see
220 Table 1).

221

222 **Study selection quality**

223 The results of study quality assessments are presented in Table 2. Two studies were assigned a high-
224 risk of bias (RoB) rating (Atkinson et al., 2021; Williams et al., 2015), four studies a moderate RoB
225 (Kaur et al., 2021; Lim, Wright, et al., 2021; Sharma & Mishra, 2018; Wright et al., 2020), with the
226 remaining 22 studies (78.6%) assigned a low-RoB. The low-RoB studies generally met CASP criteria
227 for research aims, appropriate method and design for research aims, consideration of ethical
228 standards, and clear statement of findings. However, criteria for reporting of recruitment strategy, data
229 collection methods, relationship to participant and data analysis were more variably met in these
230 studies.

231

232 **Thematic meta-synthesis**

233 **Line by line. descriptive and analytic coding outcomes**

234 A total of 68 codes were generated from the line-by-line coding. In the line-by-line coding, all text
235 and quotes that could be coded were coded regardless of similarity to other codes to create the coding
236 framework. This basic coding captured the content and diversity in representations of a similar
237 challenge (e.g., no follow up on treatment, no follow-up with GP, not seen anyone since diagnosis,
238 lack of follow through, no follow up after diagnosis were all given separate codes). The codes were
239 then grouped into 18 descriptive themes reflecting or describing patterns of similarity among codes in
240 the coding framework. The descriptive codes referred to challenges at all levels of care (primary,
241 secondary and tertiary care), in diverse activities (screening and diagnosis, referral, treatment) and
242 domains of interactions (e.g., relational, communication, decision-making). In the third step of data
243 analysis, we interpreted the descriptive codes to derive four latent or meta-level explanatory concepts
244 referred to as analytic themes. These were proposed to illustrate and capture the driving force behind
245 the reported challenges of interacting with HCPs about PCOS.

246

247 **Analytic themes**

248 Four analytic themes combining the inductive and deductive coding were developed, namely,
249 'Interactions were challenging when medical information was not shared in the best way', 'Interactions
250 were challenging when information provision and deliberation opportunities were insufficient to
251 achieve outcomes that matter to patients', 'Interactions were challenging when they prompt but do not
252 support patient activation' and 'Interactions were challenging when health system level barriers were
253 present or made worse by HCP behaviour'. The thematic map in Figure 2 illustrates these analytic
254 themes and the proposed relationships among them. According to Figure 2, the two key challenges of
255 interacting with a HCP were the suboptimal sharing of medical news and the insufficient provision of
256 information and deliberation opportunities. These were seen to prompt patient activation to fill gaps in
257 knowledge, and progress toward outcomes that mattered (e.g., diagnosis, specific treatment and
258 management aligned to preferences). However, the activation and the outputs of this activation were
259 not perceived to be valued by HCPs, which was challenging for patients. Health system challenges
260 were seen to restrict the care (i.e., availability, accessibility, affordability) and these system

261 restrictions could be made worse by the behaviour of HCPs. These challenges were seen to undermine
262 the HCP-patient relationship and the possibility of achieving outcomes that mattered to patients.
263 The GRADE-CERQual assessment is summarised in Table 3 with ratings indicating high confidence
264 could be placed in two of four key findings. The remaining two key findings were assessed as having
265 minor concerns about adequacy of data. The minor concerns were due to uncertainty about the
266 richness of data in some primary studies rather than about the quantity of data. The analytic themes
267 are explored in depth in next sections.

268

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

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

279

280 PCOS news were reported as being shared in a suboptimal way due to an inappropriate setting such as
281 inappropriate space (Lim, Wright, et al., 2021; Tay et al., 2021), lack of privacy (Bazarganipour,
282 2017; Lim, Wright, et al., 2021), insufficient consultation time (Crete, 2011; Hajivandi et al., 2022;
283 Hillman et al., 2020; Snyder, 2006; Soucie et al., 2021; Williams et al., 2016) or having an
284 atmosphere that did not permit patients to voice their thoughts without fear (Crete, 2011;
285 Hadjiconstantinou et al., 2017):

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

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

291 Sharing medical news could also be suboptimal because of the HCP’s communication style, for
292 example being cold or curt [“cold, callous, rude” Soucie] or showing a lack of empathy (Atkinson et
293 al., 2021; Gibson-Helm et al., 2018; Ismayilova & Yaya, 2023; Lim, Wright, et al., 2021; Pirota et
294 al., 2021; Soucie et al., 2021; Wright et al., 2020), and support (Authier et al., 2020; Holbrey, 2013;
295 Ismayilova & Yaya, 2023; Lim, Smith, et al., 2021). This was especially in relation to discussion of
296 weight (Authier et al., 2020; Avery & Braunack-Mayer, 2007; Copp et al., 2022; Hajivandi et al.,
297 2022; Ismayilova & Yaya, 2023; Lim, Wright, et al., 2021; Pirota et al., 2021; Tomlinson et al.,
298 2017; Wright et al., 2020):

299 “...one of the 5 gynaecologists I met told me that if I did not lose at least 30 kg (66 pounds) I
300 would not be able to have a child. And then they came up with this sentence that makes me so
301 angry: Lose weight!” (Authier et al., 2020).

302 In discussing symptoms or the diagnosis, patients often reported feeling dismissed (Crete, 2011;
303 Hadjiconstantinou et al., 2017; Hillman et al., 2020; Ismayilova & Yaya, 2023; Lim, Wright, et al.,
304 2021; Soucie et al., 2021) blamed or shamed (Authier et al., 2020; Soucie et al., 2021), or that news
305 was shared in an insensitive way or insensitive to their situation, for example due to young age,
306 infertility or diet history (Authier et al., 2020; Copp et al., 2022; Hadjiconstantinou et al., 2017;
307 Hillman et al., 2020; Kitzinger, 2002; Lim, Smith, et al., 2021; Pirota et al., 2021; Sharma & Mishra,
308 2018; Snyder, 2006; Soucie et al., 2021; Tay et al., 2021; Tomlinson et al., 2017; Weiss & Bulmer,
309 2011; Wright et al., 2020):

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

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

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

318 As reported in the systematic review of information needs, many women felt that primary care doctors
319 lacked knowledge about PCOS (Gibson-Helm et al., 2018) making it difficult to receive news of a
320 diagnosis from their HCP (Crete, 2011; Hadjiconstantinou et al., 2017; Hillman et al., 2020; Holbrey,
321 2013; Ismayilova & Yaya, 2022, 2023; Snyder, 2006). Patients could experience a sense of relief at
322 having symptoms recognised and validated especially after an extended period trying to confirm the
323 cause of symptoms (Avery & Braunack-Mayer, 2007; Snyder, 2006; Tomlinson et al., 2017). Despite
324 relief, poor sharing of a PCOS diagnosis resulted in patients feeling uninformed or poorly informed
325 (Authier et al., 2020; Crete, 2011; Hajivandi et al., 2022; Ismayilova & Yaya, 2023; Kaur et al., 2021;
326 Weiss & Bulmer, 2011), uncertain or confused about their diagnosis (Copp et al., 2022; Crete, 2011;
327 Kaur et al., 2021), upset, alarmed, and worried about their future, especially when told young (Authier
328 et al., 2020; Crete, 2011; Soucie et al., 2021). In some cases, suboptimal sharing of diagnostic news
329 meant patients did not take their syndrome seriously (Avery & Braunack-Mayer, 2007; Ismayilova &
330 Yaya, 2023):

331 “No one really sat there and told me anything. ... so they didn’t tell me much...The doctors
332 don’t know much about it.” (Crete, 2011)

333 “I told [my doctor] what was going on and she suspected PCOS but didn’t explain it very
334 well. She basically made me think that I had cancer and was going to die.” (Soucie et al.,
335 2021)

336 “...the information they gathered during the consultation of the announcement (diagnosis) in
337 particular, the fear of not being able to have children. This sort of phrasing was very badly

338 experienced by the women, who felt very stressed and even more discouraged after the
339 medical consultations.” (Authier et al., 2020)
340 “Margaret (age 33 y) detailed how her unconcerned GP, who initially diagnosed her in her
341 early 20s, affected her attitude towards her health: It’s kind of really funny because even I
342 discounted it because everybody was so casual about it... my GP now ... she actually took it
343 seriously ... Then I kind of clued in to like ‘Hey somebody should have been doing
344 something about this like 10 years ago’ (Ismayilova & Yaya, 2023)

345 Also challenging were the mixed or opposing communications when sharing PCOS news of any kind
346 (Authier et al., 2020; Avery & Braunack-Mayer, 2007; Kaur et al., 2021; Soucie et al., 2021;
347 Tomlinson et al., 2017; Wright et al., 2020) and the lack of clear statements or follow-up plans when
348 sharing a new diagnosis (Copp et al., 2022; Hadjiconstantinou et al., 2017; Hillman et al., 2020;
349 Ismayilova & Yaya, 2023; Tomlinson et al., 2017; Weiss & Bulmer, 2011). Specifically, HCPs did
350 not always provide patients with a well formulated explanation of PCOS future management (Copp et
351 al., 2022; Crete, 2011; Ismayilova & Yaya, 2023; Kaur et al., 2021; Soucie et al., 2021) or a detailed
352 follow-up plan (Authier et al., 2020; Copp et al., 2022; Hillman et al., 2020; Ismayilova & Yaya,
353 2023; Lim, Smith, et al., 2021; Lim, Wright, et al., 2021; Pirota et al., 2021; Tay et al., 2021;
354 Tomlinson et al., 2017; Williams et al., 2016), that could have helped absorb or understand whatever
355 news was being shared (e.g., diagnosis, future risks):

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

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

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

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

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

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

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

380

381

382 ***Theme 2: ‘Interactions were challenging when information provision and opportunities for***
383 ***deliberation are insufficient to achieve outcomes that matter to patients’***

384 Interactions were reported to be challenging when patients were not provided with content that could
385 help them make decisions about unexplained symptoms before a diagnosis or, when post-diagnosis,
386 provided content about treatment or management of confirmed PCOS. The complexity of PCOS as a
387 syndrome (e.g., genetic, hormonal), its features and correlates (e.g., hirsutism, acne, higher weight,
388 infertility), and future risks (e.g., diabetes, cardiovascular disease) make it highly likely that those
389 with PCOS will need to make decisions considered suitable for shared decision-making. Namely,
390 decisions where more than one course of action is reasonable, where the consequences of actions are

391 significant, and where HCPs and patients make decisions together using the best possible evidence
392 (G. Elwyn, 2021).

393

394 The qualitative synthesis review suggests shared decision-making was not achieved because of
395 deficits in information provision (options, pathways), deliberation opportunities (e.g., discussion of
396 options according to preferences) or support for the choices made (e.g., facilitating preferred options).
397 Once diagnosed, HCPs were often perceived to lack knowledge about PCOS (Authier et al., 2020;
398 Avery & Braunack-Mayer, 2007; Crete, 2011; Hadjiconstantinou et al., 2017; Holbrey, 2013;
399 Ismayilova & Yaya, 2022, 2023; Lim, Wright, et al., 2021; J. A. Lin & Cook, 2020; Tomlinson et al.,
400 2017; Weiss & Bulmer, 2011; Williams et al., 2016; Wright et al., 2020) and, consequently,
401 information provision about treatment and management options was not seen to be meeting patients’
402 needs (Crete, 2011; Hajivandi et al., 2022; Lim, Wright, et al., 2021; Weiss & Bulmer, 2011).
403 Information was reported to be suboptimal, being far too much (Crete, 2011; Lim, Wright, et al.,
404 2021) or too little (Authier et al., 2020; Avery & Braunack-Mayer, 2007; Bazarganipour, 2017; Crete,
405 2011; Hillman et al., 2020; Ismayilova & Yaya, 2022; Williams et al., 2015), too complex (Authier et
406 al., 2020; Kaur et al., 2021; Soucie et al., 2021) or in the wrong format (Avery & Braunack-Mayer,
407 2007; Crete, 2011; Lim, Wright, et al., 2021). Due to gaps in information provision, a preference for
408 specialist doctors was expressed (e.g., endocrinologist, gynaecologist, (Lin et al., 2018; Pirota et al.,
409 2021; Snyder, 2006; Wright et al., 2020):

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

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

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

419 Patients reported that only a subset of PCOS treatment and management options were given to them,
420 often restricted to the contraceptive pill (Atkinson et al., 2021; Bazarganipour, 2017; Kaur et al.,
421 2021; Kitzinger, 2002; Soucie et al., 2021; Weiss & Bulmer, 2011) making it difficult to make fully
422 informed decisions about all the available options:

423 "No point going to doctor, again and again, every time I go, I am given a hormonal tablet"

424 Kau et al. 2021

425 “Similarly, lean women also described frustration at their doctors’ advice to “keep doing what
426 you’re doing” and lack of alternative options to improve their condition due to their already
427 healthy weight.” (Copp et al., 2022)

428 “Doctor only really offers to address 1 symptom at a time - Pick one. (Lucy, AU)” (Williams
429 et al., 2016)

430 “Only 33.8% (n = 23/68) of women with a BMI classified as overweight and 49.3% (n =
431 67/136) of women with a BMI classified as obese recalled that weight loss was explored by
432 their GP as a treatment option for PCOS.” (Hillman et al., 2020)

433 Some thought reduced options was due to system-imposed restrictions (Williams et al., 2016) but
434 often patients perceived doctors to unjustifiably omit options due to patient’s characteristics (e.g.,
435 weight, fertility, age) which also reduced their ability to consider all options (Avery & Braunack-
436 Mayer, 2007; Copp et al., 2022; Hadjiconstantinou et al., 2017; Ismayilova & Yaya, 2023; Kaur et al.,
437 2021; Tomlinson et al., 2017):

438 “They told me it was a genetic condition, there was nothing I could do about it and because
439 I’m not overweight, there’s really no need to see a dietician or a diabetes educator.” (Copp et
440 al., 2022)

441 “...I was more or less told that you’re chubby, you’re overweight, there’s nothing we can do,
442 we’re not giving you any fertility treatment because you’re overweight, that would be a

443 danger to a baby, um and ‘bye-bye’ and I was quite traumatized by that. (Jess)” (Tomlinson et
444 al., 2017)

445 “I consulted a doctor. But he said, ‘You should wait; I cannot start hormones at this age.’”
446 (Kaur et al., 2021)

447 When options were given, preferences were not solicited or patient factors not integrated in option
448 presentation, reducing the possibility of patients choosing according to them. For example,
449 consideration was not given to option acceptability given the patient’s social or life context (Copp et
450 al., 2022; Hadjiconstantinou et al., 2017; Ismayilova & Yaya, 2023; Kaur et al., 2021; Lim, Smith, et
451 al., 2021; Sharma & Mishra, 2018; Williams et al., 2015), past failed attempts with an option (Copp et
452 al., 2022) or experience of side effects (Copp et al., 2022; Crete, 2011):

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

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

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

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

464 Alternatively, doctors could overly prioritise some symptoms based on their own perceptions of what
465 mattered, usually fertility, even when fertility was not the primary concern for the patient (Avery &
466 Braunack-Mayer, 2007; Hillman et al., 2020; Lim, Wright, et al., 2021; Sharma & Mishra, 2018;
467 Soucie et al., 2021; Williams et al., 2015). This doctor-centredness meant that other important
468 symptoms were ignored (Crete, 2011; Hillman et al., 2020; Ismayilova & Yaya, 2023; Lim, Wright, et
469 al., 2021; Pirota et al., 2021; Tay et al., 2021; Weiss & Bulmer, 2011), or no options were offered

470 until people were ready to have children (Atkinson et al., 2021; Avery & Braunack-Mayer, 2007;
471 Copp et al., 2022; Crete, 2011; Ismayilova & Yaya, 2023; Kaur et al., 2021; Sharma & Mishra, 2018;
472 Soucie et al., 2021; Tay et al., 2021; Williams et al., 2015). A focus on fertility sometimes could cause
473 worry about future fertility too (Avery & Braunack-Mayer, 2007; Sharma & Mishra, 2018):

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

476 “Some women were left feeling as though they were powerless to do anything about their
477 condition until they wanted children ... ‘When I went back to see him, he said, ‘Bit of a
478 hormonal imbalance, come back and see me if you ever have trouble having children’”.

479 (Avery & Braunack-Mayer, 2007)

480 Patients often felt that the choices they made regarding diagnosis and treatment were not enabled or
481 supported. Most often this was due to being unable to progress with testing (Authier et al., 2020; Kaur
482 et al., 2021), diagnosis (Avery & Braunack-Mayer, 2007; Gibson-Helm et al., 2018; Hillman et al.,
483 2020; Ismayilova & Yaya, 2022; Kitzinger, 2002; Lim, Smith, et al., 2021; Tomlinson et al., 2017;
484 Weiss & Bulmer, 2011; Wright et al., 2020) or access to preferred treatments (Atkinson et al., 2021;
485 Snyder, 2006; Soucie et al., 2021; Tay et al., 2021; Tomlinson et al., 2017). Doctors were reported to
486 be reluctant to help get the required care needed for women to realise their choices (Ismayilova &
487 Yaya, 2023; Lim, Wright, et al., 2021; Tay et al., 2021):

488 “When I went to the GP and, finally, they relented and said, ‘we’ll send you to the specialist’
489 ...it wasn’t until I came to see Dr X that I got offered medication for it – the doctors didn’t
490 really want to give me medication. I didn’t know there was any medication. (Louise)”

491 (Tomlinson et al., 2017)

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

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

501 As a consequence of insufficient information provision and deliberation opportunities, patients
502 reported feeling excluded from the decision-making process about treatment (Avery & Braunack-
503 Mayer, 2007; Bazarganipour, 2017; Soucie et al., 2021; Weiss & Bulmer, 2011; Williams et al., 2015)
504 or management (Avery & Braunack-Mayer, 2007; Crete, 2011; Ismayilova & Yaya, 2023), and this
505 often led to poor adherence with recommendations (Bazarganipour, 2017; Hajivandi et al., 2022;
506 Tomlinson et al., 2017) or erosion of trust and confidence in advice (Authier et al., 2020; Crete, 2011;
507 Ismayilova & Yaya, 2022):

508 “...cut Lana out of the decision-making process...” (Weiss & Bulmer, 2011)

509 “Many participants felt unsupported by healthcare providers and ... made health decisions
510 (short- and long-term) on their own” (Ismayilova & Yaya, 2023)

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

514 “Participants expressed ...most lost trust due to the lack of information and/or involvement
515 from their physicians.” (Ismayilova & Yaya, 2022)

516 “None of the participants attributed their past successes in lifestyle and weight management to
517 a strong partnership with a healthcare professional, including being involved in shared
518 decision-making and participating in the co-development of health management plans.” (Lim,
519 Wright, et al., 2021)

520 In contrast, interactions that engaged shared decision-making processes, although time consuming for
521 HCPs, were positively viewed (Ismayilova & Yaya, 2023; Lim, Wright, et al., 2021; Snyder, 2006;
522 Soucie et al., 2021), as were HCPs that referenced their limited knowledge:

523 “But I know even just going into her [doctor’s office] and saying ‘You know this is what I’ve
524 heard and this is what I’m thinking for this, what lines are you coming in on?’ She’s open to
525 discussing, she doesn’t always like my ideas...But she’s pretty involved and ‘Ok, well let’s
526 think about it’ ... she’s pretty good.” (Ismayilova & Yaya, 2023)

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

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

534

535

536 ***Theme 3: ‘Interactions were challenging when they prompt but do not support patient***
537 ***activation’***

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

548

549 Often the driving force for patient activation was to fill gaps in information-provision, due to the lack
550 of deliberation opportunities provided to patients or because of the lack of doctor involvement in their
551 care (Copp et al., 2022; Crete, 2011; Holbrey, 2013; Ismayilova & Yaya, 2023; Kaur et al., 2021;
552 Soucie et al., 2021; Tay et al., 2021; Tomlinson et al., 2017; Williams et al., 2015, 2016). Descriptions
553 of patient activation often implied patient frustration or resentment at having to be what they
554 perceived as “my own doctor” (Ismayilova & Yaya, 2022):

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

558 “It’s very frustrating because I usually have to basically tell her [doctor] ‘You need to refer
559 me to this’ ... I’m usually the one googling how to deal with this. I’m usually being my own
560 doctor” (Ismayilova & Yaya, 2022)

561 A high level of patient activation was often reported to be required to find appropriate help (Avery &
562 Braunack-Mayer, 2007; Crete, 2011; Gibson-Helm et al., 2018; Hajivandi et al., 2022; Kaur et al.,
563 2021; Lim, Wright, et al., 2021; Snyder, 2006; Soucie et al., 2021; Tomlinson et al., 2017; Williams et
564 al., 2015; Wright et al., 2020),

565 “My mother, finally after going from GP to GP, the GP just saying: “Teenagers have irregular
566 periods”, found another GP who referred me to a gynaecologist,” (Avery & Braunack-Mayer,
567 2007)

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

571 The need for patient activation (e.g., persistence, taking charge and personal research) led many
572 patients to the feeling that they had diagnosed themselves (Avery & Braunack-Mayer, 2007; Crete,
573 2011; Hadjiconstantinou et al., 2017; Snyder, 2006; Tomlinson et al., 2017) or that they were more
574 knowledgeable than their doctors (Avery & Braunack-Mayer, 2007; Crete, 2011; Holbrey, 2013;
575 Kitlinger, 2002; Tomlinson et al., 2017):

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

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

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

583 Despite being effortful and a consequence of gaps in care, patient activation was perceived to not be
584 responded to positively by HCPs. Patients did not feel valued as expert witnesses of their own health.
585 Symptoms brought to a doctor’s attention were discounted using unhelpful strategies (e.g.,
586 normalisation, minimising) (Hillman et al., 2020; Kaur et al., 2021; Soucie et al., 2021; Tomlinson et
587 al., 2017; Weiss & Bulmer, 2011). Patients’ understanding of their symptoms were also dismissed or
588 not taken seriously (Atkinson et al., 2021; Hadjiconstantinou et al., 2017; Ismayilova & Yaya, 2022;
589 Kitzinger, 2002; Soucie et al., 2021; Tomlinson et al., 2017; Williams et al., 2015; Wright et al.,
590 2020). This challenge could be greater for young people:

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

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

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

599 The outputs of patient activation (e.g., knowledge, treatment suggestions, self-reported comorbidities)
600 were not acknowledged or valued, and in some cases were seen to upset the doctor-patient
601 relationship (Avery & Braunack-Mayer, 2007; Ismayilova & Yaya, 2023; Kitzinger, 2002; Soucie et
602 al., 2021; Wright et al., 2020):

603 “I know PCOS is potentially linked to mental health issues too. I’ve read it. And I remember
604 bringing these types of things up and he would just kind of shy away from it like he didn’t
605 want to deal with it.” (Ismayilova & Yaya, 2023)

606 “One participant said that “[my doctor] was angry when I brought my own information with
607 me to the consultation, but I was frustrated not having any answers.” (Soucie et al., 2021)
608 “...most of the participants had done a great deal of research on their condition, and this also
609 led to problems in the doctor–patient relationship, with women complaining that they were
610 considered to be acting inappropriately in being assertive in asking for specific treatments.”
611 (Kitzinger, 2002)

612 A main consequence of not supporting patient activation or outputs of that activation was that patients
613 worried about what they found, especially future risks (Copp et al., 2022, Tay et al., 2021), made
614 decisions on their own or trusting popular opinion for example, tried untested or ineffective
615 treatments, without expert support (Ismayilova & Yaya, 2023), and at times disengaged with
616 healthcare:

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

621 “...my GP knows nothing about it so I have to go and figure it out myself. So, then I trust the
622 information in all of these books and looking at kind of what the popular opinion is on certain
623 things. Like testing out all these different supplements and then trial and error myself
624 (Ismayilova & Yaya, 2023)

625 “I’m not going to wait for months and months and months to get an appointment with a
626 dietician, so I went to Google and I looked up low GI diets and I found my way to a couple of
627 health sites ...” (Tomlinson et al., 2017)

628 HCPs were viewed positively when they supported patient agency by validating concerns (Avery &
629 Braunack-Mayer, 2007; Hadjiconstantinou et al., 2017; Snyder, 2006; Soucie et al., 2021) or

630 reassurance about these (Authier et al., 2020; Hadjiconstantinou et al., 2017; Hajivandi et al., 2022;
631 Hillman et al., 2020; Tay et al., 2021) and being knowledgeable and supportive of patient preferences
632 and research (Ismayilova & Yaya, 2022, 2023; Lim, Wright, et al., 2021). Also viewed positively
633 were doctors that supported patient agency in consultations (Hadjiconstantinou et al., 2017; Hajivandi
634 et al., 2022; Lim, Wright, et al., 2021; Snyder, 2006; Soucie et al., 2021) and facilitated outcomes that
635 mattered to patients (Avery & Braunack-Mayer, 2007; Hillman et al., 2020; Ismayilova & Yaya,
636 2022, 2023; Lim, Wright, et al., 2021; Soucie et al., 2021):

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

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

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

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

648 “At that point I didn’t really understand terribly much. And she (HCP) also didn’t, looking
649 back. But she cared enough that she sent me on these tests and she would listen to me when
650 I’d come in and say ‘Okay I think I should be on this drug’. She would research it obviously
651 or look it up in the drug book. But she listened to me” (Ismayilova & Yaya, 2023)

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

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

657 “I would summarize my first experience as naïve, unaware...I had a very limited view of
658 what it was, and here I’m much more educated and I think my doctors are aware and they are
659 able to talk to me a little bit more” (Crete, 2011)
660 “I’ve felt that I had [after going to patient forum] the information to challenge unfair
661 treatment, particularly from my GPs surgery who don’t appear to understand PCOS.” (P64)
662 (Holbrey, 2013)

663

664

665 ***Theme 4: ‘Interactions are challenging when health system level barriers are present or made***
666 ***worse by HCP behaviour’***

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

673

674 First, many patients expressed that the required or preferred treatment was not available. This could
675 be due to the lack of a care pathway (Hajivandi et al., 2022), the service not being offered in a
676 national health plan (Holbrey, 2013), long delays (Authier et al., 2020; Kaur et al., 2021; Snyder,
677 2006; Soucie et al., 2021; Tay et al., 2021; Tomlinson et al., 2017) or patients having access to one or
678 another service, but not both (Tomlinson et al., 2017):

679 “...although girls’ health is in fact a guarantee of family health, the health system’s
680 reproductive health programs are mainly related to prenatal, delivery, and postpartum care.
681 They stressed that there are no centers to monitor the health of adolescent girls” (Hajivandi et
682 al., 2022)

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

685 Second, when services were available, participants reported that a lack of staff created long waiting
686 times (Bazarganipour, 2017; Ismayilova & Yaya, 2023; Kaur et al., 2021), especially in some
687 geographic regions (Sharma, Soucie, Wright) or during the pandemic (Atkinson et al., 2021):

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

690 “... you really do have to advocate and that I think is the most frustrating part is that there just
691 aren’t enough doctors to give you that quality and that level of care. So, you have to fill in the
692 gaps yourself” (Ismayilova & Yaya, 2023)

693 “Participants described experiencing reduced access to HCPs and services during the COVID-
694 19-related lockdown. This included access to their usual clinicians, as well as delays to
695 services they were waiting to receive pre-pandemic.” (Atkinson et al., 2021)

696 Third, communication inefficiency between levels of care or lack of a coordinated care plan was
697 frustrating, disappointing, or expensive (Bazarganipour, 2017; Kaur et al., 2021; Lim, Wright, et al.,
698 2021; Soucie et al., 2021). Some patients preferred for their GPs to be involved but that was not
699 always possible:

700 “A fragmented system where women have to organize and attend multiple visits spread across
701 medical and allied health services and keep track of information from multiple practitioners
702 was not only difficult and exhausting but also financially expensive.” (Lim, Wright, et al.,
703 2021)

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

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

709 the health system (Hillman et al., 2020; Ismayilova & Yaya, 2022, 2023; Soucie et al., 2021;
710 Tomlinson et al., 2017; Weiss & Bulmer, 2011; Williams et al., 2015, 2016; Wright et al., 2020):
711 “The GP was described as a gatekeeper who could be obstructive, particularly in gaining
712 access to specialist PCOS or fertility services ... letters to GPs saying “look, I’ve got this, this,
713 and this; it’s pretty clear to me what it is, is it possible to have this referral? ... There seems to
714 be a bit of a barrier, for whatever reason.” (Hillman et al., 2020)
715 “Many participants had long journeys to their diagnosis and described instances of PCPs
716 brushing off concerns, not providing referrals, and not ordering tests to investigate their
717 concerns.” (Ismayilova & Yaya, 2022)
718 “...participants self-advocated for specialist referrals but were mostly unsuccessful.
719 Participants expressed that their physicians “were hesitant to refer [them],” “expressed
720 resistance to refer, despite not knowing what PCOS was,” ... (Soucie et al., 2021)
721 Finally, personal barriers could also interact with system level factors. For instance, the geographical
722 scarcity of healthcare providers in some regions (Sharma & Mishra, 2018; Soucie et al., 2021; Wright
723 et al., 2020) with patients’ inability to cover the cost of travel or treatment closer to home
724 (Bazarganipour, 2017; Ismayilova & Yaya, 2022; Kaur et al., 2021; Lim, Wright, et al., 2021; Wright
725 et al., 2020):
726 “I have no prescription medical coverage and I’m about to lose medical insurance all
727 together.” “We could not afford to keep trying [to get pregnant]. As many of you know
728 insurance did not cover the treatments.” (Wright et al., 2020)
729 “One woman recalls experiencing “a long wait list to see [the specialist], and he was an hour
730 drive away, and he was in and out and the appointment was 10 minutes long.” (Soucie et al.,
731 2021)
732 Doctors that helped patients overcome system level barriers were perceived positively:
733 “She said that even though we had only been trying for 8 months, because I had had no period
734 at all she would push for an early referral to the fertility clinic.” (Hillman et al., 2020)

735 “Participants believed that a knowledgeable and well-versed PCP could speed up diagnoses
736 for patients by avoiding the need for referrals to specialists” (Ismayilova & Yaya, 2022)
737 “When I saw my endocrinologist, she was amazing, and she would CC all my relevant allied
738 health professionals into her letters and I’ll get CC’d to them as well” (Lim, Wright, et al.,
739 2021)

740 **Discussion**

741 The aim of this qualitative evidence synthesis was to identify and interpret the challenges people with
742 PCOS encounter when interacting with HCPs. Coding of the 28 included studies (1657 women with
743 PCOS) made it possible to identify four interrelated domains of challenges that cumulatively could
744 undermine achievement of diagnosis, management, and treatment outcomes from interactions with
745 healthcare professionals that matter to people with PCOS. These centred on suboptimal sharing of
746 medical news; insufficient information provision and deliberation opportunities; lack of support for
747 patient activation and its outputs; and system challenges that could be worsened by HCP behaviour.
748 Confidence in the identified themes was high with only minor concerns in the adequacy for the
749 findings interactions are challenging when these trigger but do not support patient activation and when
750 health system level barriers are present (see QERQual Table 2). Future research needs to implement
751 and evaluate well-established and effective frameworks to address challenges, most notably those for
752 sharing medical news, shared decision-making, and support for patient activation for clinical
753 diagnosis, management, and treatment for PCOS that matters to patients. HCPs should receive more
754 training in these domains, and health systems should create opportunities to address these challenges.
755 Biases within healthcare interactions that could worsen system level challenges in the availability,
756 accessibility, and affordability of care should also be explored.
757 To address the areas of challenging interactions identified, frameworks need to be determined but
758 approaches known to be effective in other domains overlapping with PCOS (e.g., infertility, diabetes,
759 cardiovascular disease) could be considered first.

760

761 **Sharing medical news**

762 Interactions with HCPs were found to be challenging when medical news related to suspected or
763 confirmed PCOS were not shared in a way that safeguard patients' wellbeing. Much empirical
764 research evaluates optimal ways of sharing medical news that could transfer to PCOS context. The
765 SPIKES framework proposes six steps: Setting up the interview, assessing the patient's Perception of
766 the situation, obtaining the patient's Invitation to deliver the news, giving Knowledge and information
767 to the patient, addressing the patient's Emotions empathically, and providing a Summary discussing
768 prognosis and treatment options (Baile et al., 2000). SPIKES is aligned with patient preferences
769 (Mirza et al., 2019), including fertility care which many people with PCOS will use (Leone et al.,
770 2017). There is significant ethnic, religious and individual variability in preferences for how medical
771 news should be shared (e.g., amount of detail, who should be present) (Matthews et al., 2019) but
772 systematic reviews and meta-analyses (17 studies) show the SPIKES framework for training doctors
773 to break bad or difficult news, out-performs other approaches (e.g., observer-rated news delivery
774 skills, doctor confidence) in many countries (e.g., Belgium, Germany, Israel, Japan, Hong Kong, UK,
775 USA) (Johnson & Panagioti, 2018).

776

777 **Shared decision-making**

778 Interactions were also reported to be challenging when patients were not provided with content that
779 could help them make decisions about unexplained symptoms, management, or treatment of
780 undiagnosed and/or diagnosed PCOS. The shared decision-making (SDM) framework (Elwyn et al.,
781 2017; Elwyn et al., 2010; NICE, 2021) could be used to address challenges in information provision
782 and deliberation opportunities in PCOS. Shared decision-making is a collaborative process between
783 healthcare providers and patients, where both parties contribute to healthcare decisions based on the
784 best available evidence and the patient's values and preferences (Elwyn et al., 2010). The research on
785 use of SDM in areas of relevance to PCOS results is positive, showing decision aids to reduce
786 decisional conflict, and improve patient knowledge (Poprzeczny et al., 2020), 35 studies). Shared
787 decision-making is often supported using patient decision aids (supporting patients) and decision
788 support tools (supporting HCPs) including resources for PCOS (Poprzeczny et al., 2020)

789

790 **Patient activation**

791 The review also identified interactions to be challenging when patients' efforts to seek further
792 information and education to fill in gaps in their knowledge often due to HCPs lack of information
793 provision, were not supported by HCPs. To address challenges in supporting patient activation,
794 understanding the patient activation framework (Hibbard et al., 2004) and associated assessment tool
795 (Hibbard et al. 2005) would facilitate supporting patients through different levels of activation (low,
796 disengaged and overwhelmed) to high (maintaining (Hibbard et al., 2004)). A narrative review
797 indicates that greater levels of patient activation is associated with uptake of preventive behaviours
798 (e.g., check-ups, screening), healthy behaviours (healthy diet, regular exercise), health literacy (e.g.,
799 disease knowledge) and asking questions in consultation (Hibbard & Greene, 2013; Kinney et al.,
800 2015). A meta-analysis in chronic diseases showed benefits across a wide range of outcomes
801 (physiological, psychosocial, behavioural and health related quality of life (Lin et al., 2020), many of
802 which could be relevant to PCOS due to the hyperinsulinemia, hyperandrogenism and neuroendocrine
803 disturbances caused by this disorder (Regeer et al., 2022).

804

805 **Improving access to care through system level changes**

806 An additional challenge for patients with PCOS when interacting with HCPs was identified to be
807 system level restrictions and HCPs restrictive behaviour. Challenges included lack of access and
808 delays in service provision, and HCPs (according to patient perspective) obstructing referrals to
809 specialists or specialist services within the healthcare system. In the present review health system
810 challenges restricting HCPs behaviour were not directly mentioned but could be inferred from
811 perceived helpful actions, e.g., "...push for an early referral to an infertility clinic" (Hillman et al.,
812 2020). Several studies recommended that more holistic or integrated care where education, screening,
813 diagnosis, and treatment are provided together covering emotional well-being, cardiometabolic
814 diseases, and dermatological and reproductive elements of PCOS (Atkinson et al., 2021;
815 Hadjiconstantinou et al., 2017; Lim, Wright, et al., 2021; Tay et al., 2021). A review suggests these

816 models are viewed positively (Melson et al., 2023). Education and training of HCPs regarding the use
817 of new PCOS models of care and frameworks would be needed but requires health systems to provide
818 the opportunities as barriers are often at system level (e.g., consultation time (Legare et al., 2008)).

819

820 **Recommendations from integration of primary evidence (narratives) and meta level analysis**
821 **(inductive and deductive coding)**

822 The analytic themes were used to propose meta-concepts that go beyond the primary reported data to
823 explain the challenges reported. Although interpretive, these meta-level concepts were very much
824 present in included studies, though not necessarily explicitly stated. For example, shared decision-
825 making referred to as need to elicit preferences in all aspects of care and involve women in decisions.
826 We see this congruence as supporting the proposed meta-level concepts. However, we also note that
827 experts with different disciplinary backgrounds could have interpreted the data to accommodate other
828 frameworks, for example health communication or social theories (Malikhao, 2020). We do not
829 consider such a possibility as invalidating the meta-concepts proposed, but rather have the view that
830 more meta-level conceptualisation – whether from social, psychological or behavioural theories – is
831 more likely to prompt the kind of broad strategic developments needed to develop optimal PCOS
832 care.

833 Based on consideration of the data and analysis in this review, the Guideline Development Group 2,
834 proposed and integrated two evidenced based recommendations in the 2023 update of the
835 International Evidence-based PCOS Guideline (Teede et al. 2023a), namely that ‘Healthcare
836 professionals should employ shared decision-making and support patient agency or ability to take
837 independent actions to manage their health and care’ and ‘The importance of being knowledgeable
838 about PCOS, of applying evidence-based practices when sharing news on diagnosis, treatment, and
839 health implications, and of ascertaining and focusing on patient priorities, should be recognized’. A
840 further consensus recommendation was made ‘Healthcare system leaders should enable system wide
841 changes to support healthcare professional training, knowledge and practice in sharing news
842 optimally, shared decision making and patient agency, including ensuring adequate consultation time

843 and accessible resources' with additional practice points for the use of available frameworks and
844 resources to address these challenges (see Teede et al., 2023a, Table 4, 'Patient Care').

845

846 **Strengths and limitations**

847 The strengths and limitations of the included studies and the review process warrant consideration.

848 The strengths of the review were that it addressed a novel important topic prioritised by guideline

849 stakeholders (Teede et al, under review; Teede et al. 2023a). It also identified important positives and

850 negatives about interactions with healthcare professionals, and frameworks for addressing these, that

851 could be considered in future implementation. In addition, the CERQual ratings showed that many of

852 the 28 studies contributed to each identified domain of challenge and were of sufficient robustness for

853 analytic themes to be perceived as reliable. There were limitations in both the included studies and the

854 review process. In the included studies there was a lack of diversity, as these mainly came from

855 western countries. Diagnosis was often self-reported and there was possibility of recall bias in some

856 experiences (e.g., time since diagnosis < 1 year to 17 years across studies, see Table 1). Moreover,

857 patient related factors (e.g., family history of premature ovarian failure, low BMI) could have

858 influenced time to diagnosis and subsequent interactions with health care professionals but these

859 factors were not explored by the included literature. Limitations in the review process were that the

860 initial screening for included studies and quality appraisal was performed by only one author,

861 although any uncertainty was discussed with the GDG.

862 We used search terms female and women and may have missed healthcare challenges experienced by

863 non-binary or transgender populations (Wugalter et al. 2023). We perceive that our coding of the lived

864 experience would achieve congruence among participant, researcher, and synthesiser but that was not

865 confirmed (Noyes & Lewin, 2011). Lastly, the synthesis by design focused on patient perceptions of

866 challenges in interactions with HCPs and therefore primarily reported on the negative aspects of care

867 despite many examples of good practice in patient narratives. Research on PCOS is lacking. There are

868 many unanswered questions about the cause of PCOS and treatment options are often largely

869 inadequate, contributing to frustrations experienced by HCPs and women. Our results could be

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

878

879 **Conclusion**

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

890

891 **Data availability**

892 The data underlying this article will be shared on reasonable request to the corresponding author.

893

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897

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899 JB, CTT, MAB, AM, and HT contributed significantly to the conception and design of the work,
900 including the review question. CTT carried out the searches, selected the studies and performed the
901 critical appraisal of the studies. JB and CH performed all data extraction and coding, CERQual
902 evaluation, data synthesis and interpretation. JB and CH drafted the manuscript, and all authors
903 reviewed this work critically. All authors replied to reviewer comments and provided final approval of
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907

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917

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924

925 **Figure legends**

926 *Figure 1.* The PRISMA flowchart detailing the process of identification, screening, eligibility for the
927 systematic review.

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

941

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