

RESEARCH

Women's use of online health and social media resources to make sense of their polycystic ovary syndrome (PCOS) diagnosis: a qualitative study

Julia Gomula¹, Mark Warner^{1*} and Ann Blandford¹

*Correspondence:

mark.warner@ucl.ac.uk
Computer Science Department,
UCL, Gower Street, London, UK
Full list of author information is
available at the end of the article

Abstract

Background: With the growing availability of online health resources and the widespread use of social media to better understand health conditions, people are increasingly making sense of and managing their health conditions using resources beyond their health professionals and personal networks. However, where the condition is complex and poorly understood, this can involve extensive “patient work” to locate, interpret and test the information available. The overall purpose of this study was to investigate how women with polycystic ovary syndrome (PCOS) across two healthcare systems engage with online health resources and social media to better understand this complex and poorly understood lifelong endocrine disorder.

Methods: A semi-structured interview study was conducted with women from the US ($N = 8$) and UK ($N = 7$) who had been diagnosed with PCOS within the previous five years. Transcribed data was analysed using a reflexive thematic analysis method.

Results: We highlight the information needs and information-seeking strategies women use to make sense of how PCOS affects them, to gain emotional support, and to help them find an effective treatment. We also show how women with PCOS use online health and social media resources to compare themselves to women they view as “normal” and other women with PCOS, to find their sense of “normal for me” along a spectrum of this disorder.

Conclusion: We draw on previous models of sense-making and finding normal for other complex and sensitive health conditions to capture the nuances of making sense of PCOS. We also discuss implications for the design and use of social media to support people managing PCOS.

Keywords: PCOS; polycystic ovaries syndrome; information interaction; finding normal; online health communities; sense-making; peer support

1

2

3 Introduction

4 Polycystic ovary syndrome (PCOS) is a lifelong endocrine disorder experienced by
5 between 6% and 13% of women [1] and is the most common endocrine disorder
6 found in women. PCOS is a heterogeneous disorder with a spectrum of pheno-
7 types [2, 3, 4, 5]. The criteria for diagnosis differ [1], but are commonly menstrual
8 irregularities, hyperandrogenism, and/or polycystic ovary morphology detected via
9 ultrasound [3, 6]. Other symptoms that present in women vary greatly, making
10 clinical care and research challenging [3, 6]; these include hirsutism, alopecia, acne,
11 obesity, anxiety, depression, and stress [3, 6], as well as psycho-social impacts such

12 as feeling “different”, struggling with notions of femininity, and wanting to be “nor-
13 mal” [7, 8, 9]. As well as the health complications outlined above [10], women with
14 PCOS also have an increased risk of developing eating disorders [11], suicide [12],
15 and sexual dysfunction [13, 3, 11]

16 The clinical recommendations for managing PCOS focus on targeting specific
17 symptoms through medication and implementing lifestyle changes such as adjust-
18 ments to diet and exercise [14, 15, 16, 17, 6]. Finding the most effective medication
19 options and lifestyle changes for PCOS can be challenging for women due to the
20 different ways in which PCOS presents itself. As a result, there is a growing focus
21 on women’s lived experiences with PCOS and on their information needs [18, 19].
22 Although information on PCOS is widely available online, it is often contradic-
23 tory and of variable quality [20], lacks comprehensive, specific, and accurate de-
24 tails on lifestyle changes for managing PCOS symptoms [21], is not culturally spe-
25 cific [18, 22], and is not developed at appropriate education levels [22]. Moreover,
26 it can be difficult to obtain reliable information from doctors and general online
27 health resources [23, 24, 25, 26, 19, 27]. These shortcomings mean women can have
28 incomplete information, limiting their ability to make effective lifestyle changes,
29 such as to diet and exercise [21]. Little is known about how women with PCOS
30 find or make sense of information to help them fully understand their condition and
31 adjust their lifestyles to manage it.

32 Prior research has considered women’s experiences of PCOS (e.g., [9, 18, 19]),
33 their information-needs [28, 19, 29, 30], the accuracy of PCOS information online
34 (e.g., [31]) and women’s information-seeking behaviour relating to PCOS [28, 30].
35 Most prior research on information-seeking and information needs focuses on
36 women’s practical and clinical needs – e.g., for diagnosis and treatment plans.
37 Holbrey and Coulson [32] investigated women’s experiences of online peer support
38 within a defined online community, and identified factors that made participants feel
39 more or less empowered by participating in the community; they did not, however,
40 investigate how women sought out or made sense of information.

41 Within the broader literature on information-seeking and sense-making related
42 to health conditions, it has been recognised that interpersonal information-seeking
43 allows people to engage in an information exchange [33], to share their views and
44 lived experiences and help them make sense of health information (i.e., interpret
45 and integrate information into their own understanding) [34, 35]. This process
46 of information-seeking and sharing can help people to develop an understanding
47 of what is normal for them, personally, experiencing their condition [36]. More
48 broadly, people with long-term conditions are often concerned with feeling “nor-
49 mal” [37, 38, 39] and tend to compare themselves to their peers to normalise their
50 experiences [40]. The behaviour of seeking information online to compare the per-
51 sonal experience of an illness to the lived experiences of peers is a recurrent theme
52 in the literature on living with long-term conditions [41, 42, 43, 44]. However, none
53 of the prior literature on seeking information online to “find a new normal” has ex-
54 plicitly considered PCOS: either to understand women’s experiences of engaging in
55 this kind of information-seeking online (going beyond seeking clinical and practical
56 information) or to compare “finding normal” for PCOS with “finding normal” for
57 other long-term health conditions.

58 This study aimed to investigate online information-seeking, sense-making, and
59 “finding normal” behaviours to better understand the types of support women look
60 for online and how support is used to help them manage their condition. It offers
61 a new understanding of how women with PCOS manage an abundance of both
62 clinical evidence-based information and experiential information derived from other
63 people’s lived experiences to “find a new normal” for themselves.

64 **Method**

65 **Recruitment and ethics**

66 In developing our recruitment protocol, we were mindful of the potential impact
67 that our research could have on participants, as well as the quality of the infor-
68 mation we obtained through our interviews. We implemented several stages into
69 our recruitment process to ensure freely informed consent was obtained. To allow
70 prospective participants to learn about the study without having to reveal them-
71 selves to the research team, we published a study website that detailed information
72 about the research, and what participants would be asked to do. The website also
73 disclosed that the first author had been diagnosed with PCOS; this was intended
74 to enable potential participants to anticipate her background (e.g., not a health
75 professional) before deciding whether or not to participate in the study. As shown
76 in the topic guide, the interviewer did not explicitly draw on her own experiences
77 during the interviews, but this shared background may have increased rapport be-
78 tween interviewer and interviewee. Links to the website were posted on online PCOS
79 support groups hosted on Facebook and Reddit. No individuals were directly ap-
80 proached by the research team, with participants themselves instigating contact.
81 Once contact had been made, participants were provided with an information sheet
82 and consent form, with guidance on how to withdraw from the study, without being
83 disadvantaged.

84 To be eligible to participate in the study, participants were required to be over
85 18, be living in either the US or UK, and have received a formal PCOS diagnosis
86 within the previous five years. A maximum of 5 years was chosen to increase the
87 likelihood of participants remembering their experiences of receiving a diagnosis;
88 and to cover a period (2014-2019) where we could assume that women would have
89 had access to a reasonable volume of information about PCOS online; and reflect-
90 ing the rise of social media use. No minimum time since diagnosis was set as this
91 allowed us to capture insights from those who were going through this process of
92 understanding their condition. While experiencing a diagnosis of PCOS can be dis-
93 tressing, our interviews focused on participants’ information practices, as opposed
94 to their emotional journeys. Moreover, the indirect nature of our recruitment pro-
95 tocol meant participants were free to make their own assessment over whether they
96 wished to participate, with the option to withdraw at any time. We included par-
97 ticipants across two different geographical areas (the US and the UK) to obtain
98 a broader understanding of information-seeking behaviours across different health-
99 care systems. The US and UK were chosen as the lead author (and interviewer) had
100 resided in both countries and was familiar with both healthcare systems.

101 Participants all gave informed consent before the interview. No participants were
102 known to any of the authors prior to the start of the study. The project was approved

103 under UCL departmental ethics (UCLIC/1819/006/BlandfordProgrammeEthics).
 104 Participants were compensated for their time with a 15GBP (approx. 19USD)
 105 voucher.

Table 1 Location, time since diagnosis and age for participants included in the analysis. Note: all data are approximate.

ID	Location	Time since diagnosis	Age
P1	US	3 years	28
P2	US	2.5 years	27
P3	US	4 years	20
P4	UK	1 month	23
P5	US	5 years	34
P6	US	1 year	31
P7	US	4 years	29
P8	UK	2.5 years	31
P9	UK	1 year	20
P10	US	4 years	28
P11	US	1.5 years	21
P12	UK	1 year	27
P13	UK	5 months	20s
P14	UK	4 years	27
P15	UK	1 year	24

106 Participants

107 The study website attracted 507 unique visitors. Of these, 156 completed the contact
 108 form. Some were eliminated from the potential participant pool as they resided
 109 outside the US and UK. Others self-reported to have been diagnosed more than
 110 five years ago. For those that met the inclusion criteria, selection was based on
 111 whomever could schedule a mutually convenient interview time. 17 interviews were
 112 conducted between June and July 2019. However, one participant was found not to
 113 meet the inclusion criteria (she had been diagnosed more than five years ago) and
 114 for another, the recording failed. The remaining 15 women were aged between 20
 115 and 34 (mean of 26 years), with 8 living in the US and 7 living in the UK at the
 116 time of the study. All self-reported to be living with PCOS with time since diagnosis
 117 ranging from 1 month to 5 years (mean of 28 months). Demographic information
 118 collected on the pre-interview contact form is shown in Table 1. Some participants
 119 self-reported other demographic information (e.g., profession) during interviews,
 120 which we reference in our findings where relevant.

121 Procedure

122 Semi-structured interviews (face-to-face and online) were conducted to explore the
 123 information needs, behaviours, and technology use of women who had been diag-
 124 nosed with PCOS. The interview questions were inspired by Dervin [45]'s sense-
 125 making methodology and incorporated elements of the Micro-Moment Time-Line
 126 Interview, in which interviewees are asked to consider a situation they had en-
 127 countered, describe what happened, describe what questions they had, how they
 128 answered those questions, what helped or hindered them in the process, how they
 129 used those answers, and how that affected them (see: Additional Files).

130 In the first part of the interview, participants were asked to recall how much
 131 information they had received from their doctors during their diagnosis, whether

132 they were satisfied with that information, whether they looked for any information
133 on their own, and what digital resources they used to do so (e.g., apps, websites,
134 forums). Participants were then asked to reflect on their information journey before
135 and post-diagnosis and to recall a specific example of information-seeking. The
136 subsequent questions examined why participants chose the information resources
137 they did and how effective they found them. In the second part of the interview,
138 they were asked how well they felt they currently understood PCOS and their
139 symptoms, how their information-seeking practices had changed over time, and what
140 information sources and technologies they were currently using to help them manage
141 their condition. Interviews lasted between 45-90 minutes, averaging approximately
142 1 hour.

143 *Data Analysis*

144 We used the reflexive thematic analysis (RTA) approach [46, 47] to inductively
145 analyse our data as this approach is method and theory-agnostic, meaning we were
146 able to use RTA with a constructivist approach [48]. Joffe [49] suggests that this
147 paradigm is well aligned with RTA as data analysis can help surface how social
148 constructs develop. Using this approach we drew from prior research (theoretical
149 frameworks) to help interpret our data and themes as they were developing, as
150 opposed to deductively mapping the data to pre-existing frameworks. This approach
151 encouraged the investigation and consideration of prior literature without forcing
152 prior knowledge into the analysis process. Moreover, RTA allowed us to analyse our
153 data for both semantic and latent codes and was a more accessible form of analysis
154 for the early career researcher leading the analysis [50, 47].

155 Audio recordings of interviews were transcribed verbatim, omitting filler words
156 and opening and closing formalities. In keeping with RTA [46, 47], the first author
157 became familiar with the data while transcribing through initial memo taking to
158 record any insights and observations. Then, the first author read the data and
159 performed inductive open coding to develop an initial set of semantic and latent
160 codes which were then grouped into candidate themes. To facilitate immersion, data
161 were hand-coded. The first author reflected on the data, the codes, and themes by
162 examining relevant theories within existing literature which allowed them to inform
163 the themes further. Themes were reviewed and refined through discussions with the
164 second and third authors (i.e., conceptualisation ‘checks’) who both have experience
165 in digital health research, and particular expertise in health-related information-
166 seeking and sense-making; however, neither have personal or professional expertise
167 in PCOS. Finally, new themes were named, grouped further, and refined. To ensure
168 quality practice in our analysis, we again drew from the RTA [47], and in particular
169 from [50]; this included the thorough transcribing of audio records and checking
170 of themes against each other and the original data and codes to ensure coherent,
171 consistent, and distinctive themes. In keeping with RTA [51], we did not perform
172 data saturation as the constructivist approach does not lend itself to this method.
173 Assumptions embedded within a constructivist paradigm are that new meaning
174 is always theoretically possible, and so defining an objective point where no new
175 meaning can be derived is not appropriate.

176 Findings

177 Two main themes and several sub-themes were developed from our analysis. The
178 first main theme was information needs and participants' strategies for finding in-
179 formation they required to fill a current information gap between what they knew
180 and what they felt they needed to know. Under this theme, we explore the role of
181 clinicians in supporting sense-making, the challenges of establishing relevance and
182 reliability of information, and the need for experiential information in addition to
183 evidence-based information to fill gaps and provide emotional support. The sec-
184 ond theme was how participants redefined "normal" for themselves as they went
185 through their PCOS information journey, how they compared themselves to "nor-
186 mal" women, to other women with PCOS, and how they found their "normal for
187 me" through a process of trial and error. In presenting the themes, we incorporate
188 several participant quotes, which we expand on in Table 1A (See: Additional Files).

189 Information Needs and Strategy

190 *Pre-diagnosis: triggers for seeking information and a diagnosis*

191 Although participants were not asked directly about their experiences prior to diag-
192 nosis, thirteen of the fifteen participants described what led them to seek a diagnosis.
193 Two were diagnosed during a routine clinical appointment without specifically ask-
194 ing about it. For example, P1^{US} explained: "I was diagnosed when I was seeing a
195 nurse practitioner just for a general checkup. She said she noticed three criteria I
196 met". Some participants had done a substantial amount of research, so were antic-
197 ipating a PCOS diagnosis, for example, P14^{UK} said: "I was pretty sure, without a
198 doubt about it and I had learned a lot about it up until that point. So, just being
199 told, 'Yeah, you have it,' I was like, 'OK, I kind of know everything, really, at this
200 point,' because it had been so long without any support or diagnosis up till that
201 point".

202 *Lack of information from health practitioners drives independent* 203 *information-seeking*

204 Most participants were dissatisfied with the information they received from health
205 practitioners at the time of diagnosis. Some reported receiving no information from
206 their doctors and were instead told to search the Internet. P15^{UK} said: "I asked [my
207 doctor] about it, she just said, 'Look it up on the internet, there's a lot of infor-
208 mation on there'". Some felt that their doctors offered them medications and oral
209 contraceptives instead of presenting them with a broader range of treatment options,
210 with P2^{US} saying: "they didn't seem to inform, just to throw these medications at
211 you and then, that's it". Most participants reported leaving appointments without
212 having understood what PCOS was, and what it was going to mean for them. They
213 felt that their health practitioner offered limited emotional support. To help ad-
214 dress this lack of information from their health practitioner, some women turned to
215 online social platforms for support from others with PCOS; this often helped them
216 navigate their doctor-patient relationships. P2^{US} experienced this, saying: "A lot
217 of women on there [Reddit] were saying how they weren't satisfied with whatever
218 their gynaecologist told them, and a lot of them were saying, 'Go to a reproductive
219 endocrinologist'. That's what tipped me off".

220 When women experienced emotionally supportive and informative conversations
221 with medical practitioners, they reported a more positive journey following diag-
222 nosis. P11^{US} sought advice from a specialist in endocrine disease who was both
223 supportive and informative, which empowered her to seek further information on-
224 line: “She gave me all of the basic information I needed [...] to start my research”.
225 Yet for others, information received from medical practitioners had a less posi-
226 tive effect, with P1^{US} becoming “overwhelmed”, thinking that having PCOS was
227 “world-ending”. For P2^{US}, online research enabled her to see PCOS as a manageable
228 condition.

229 *Online medical information is seen as too general and impersonal*

230 Participants reported initial internet searches for PCOS leading them to popular
231 and established health information and PCOS-specific websites. While these were
232 seen as broadly informative, they were often not specific enough to address some
233 of the unique needs our participants had. For example, P1^{US} said: “A lot of them
234 didn’t go into depth as to what caused certain side effects or reactions, which is what
235 I was looking for”. Using research platforms such as Google Scholar to search for
236 peer-reviewed articles about PCOS was a common strategy for finding information
237 that was considered reliable and specific. Moreover, specific search strategies were
238 discussed when using these platforms, such as applying additional filters. P8^{UK} said:
239 “I will use Google Scholar [...] and I’ll filter it by my phenotype and other potential
240 treatment options”.

241 One woman (P14^{UK}) described experiencing a rare symptom (Acanthosis ^[1]) that
242 was not listed on the UK National Health Service (NHS) website, but was mentioned
243 on the online social platform Reddit where “there were other people talking about
244 it”, which helped her to understand her symptoms. For many, the use of social
245 platforms provided a more personal experience and were considered more “real”.
246 P3^{US} said: “I want it to be personal, not cold. Maybe medical facts and then related
247 questions and then advice or others’ experiences”.

248 *Experiential information fills gaps and offers emotional support*

249 All participants supplemented evidence-based medical information with experiential
250 information sources, such as social media and personal blogs. P10^{US} said: “I wanted
251 more information, so I read all these blogs and people’s own experiences”. Online
252 medical advice lacked the emotional and personal aspects that many women sought.
253 P3^{US} said she wanted the “advice of people that have already been through this or
254 know what it means”.

255 Women valued the more emotional nature of social media sources as it made
256 them feel less alone and more “normal”. P1^{US} highlighted this, saying: “reading
257 through posts [...] showed me that I wasn’t the only one going through similar
258 thought processes”. Social platforms offered women a broader understanding of
259 their condition. P13^{UK} said: “I’d only heard one person’s account of it [...] I just
260 wanted to know what other people were going through and their symptoms and
261 their stories”. These sources also had a motivating effect which P10^{US} highlighted

^[1]Acanthosis is an indicator of a rare PCOS subphenotype characterised by hyper-
androgenism and insulin resistance [52]

262 when she said: “I feel more empowered seeing it more, especially with social media,
263 people who kind of ‘beat it’ almost. If I see their lifestyle, I’m like, ‘Oh look, that’s
264 where I want to get to’, and that kind of gives a little guiding light”.

265 Most participants were encouraged by personal stories and intimate information
266 that online social platforms offered. However, one woman reported negative feelings
267 towards experiential information she read. P7^{US} compared her own symptoms with
268 others and identified those who had similar symptoms but no solutions. She said:
269 “[these women] were all in the same boat or worse off. I can’t say that made me
270 feel great. It seemed like what I was dealing with was mild compared to them. And
271 none of them had even found a solution, really, so it kind of made me feel worse”.

272 *Navigating an abundance of information and its relevance and reliability*

273 The volume of information available online was often considered overwhelming, and
274 concerns were raised as to its reliability. P3^{US} said: “there is so much information
275 and some of it’s contradicting itself a little bit. You’ll go on one website and it’ll
276 tell you everything that they claim like, ‘Oh, this is the holy grail, everything you’ll
277 need to know about birth control’. You go on some other site and it’s got two other
278 points and you’re like, ‘Well, that didn’t match up with that’”.

279 Information from peer-reviewed sources as well as trusted brands such as the UK
280 NHS were considered the most trustworthy. Yet, how information was evaluated
281 often depended on the individual reviewing it, and their background. For instance,
282 P8^{UK} was a scientific researcher, and whilst peer-reviewed articles were typically
283 seen as being reliable by most, she was able to identify flaws within many of the
284 study designs.

285 Although social media platforms provide women with emotional support, they
286 tend to be seen as subjective sources of information. For example, P13^{UK} said:
287 “Facebook, obviously, you kind of take with a pinch of salt, I guess. What one
288 person is saying is kind of true for one person”. The emergence of women presenting
289 themselves as “PCOS specialists” on applications like Instagram was a concern to
290 some participants. Moreover, many participants noted that they were distrustful
291 of websites and posts that tried to commercialise PCOS advice. P8^{UK} said about
292 Instagram: “Occasionally, you’ll see people posting on there and they’re clearly just
293 trying to sell you something. One pill isn’t going to magically make the whole thing
294 disappear. You have people using language like, ‘I cured my PCOS’”.

295 Many participants had concluded that, whilst there was an abundance of informa-
296 tion available online, there was limited evidence-based information available about
297 PCOS that was considered trusted, and this may contribute to misleading infor-
298 mation being shared. Although many participants were aware that some of the
299 information was inaccurate, they still felt informed enough to make decisions about
300 their treatment. P10^{US} said: “I definitely feel more empowered with my diagnosis.
301 Even though some of my knowledge may not be entirely accurate, I definitely know
302 what works for me, even though it’s a slow and steady process.”

303 *Cross-referencing experiential and medical information*

304 Participants rarely made decisions about medications and lifestyle changes without
305 drawing from both medical and experiential information. P2^{US} explained how she

306 was “cross-referencing what people have to say with actual journals”. Typically,
 307 participants would first seek medical information, and then find more individually
 308 relevant information through social media. Finally, they would confirm the validity
 309 of others’ experiences against peer-reviewed articles or medical websites through
 310 focused internet searches. P1^{US} would “start off with whatever I found in Reddit
 311 and I would have a question, ‘Well, why does this work? How does this really affect
 312 different symptoms?’” and then used “Google Scholar and try to narrow it down”.
 313 Social media often helped women seek information about topics that they may have
 314 otherwise not thought of, for example, P4^{UK} said “things like the supplements, I
 315 hadn’t thought of that on my own. I’d only thought, ‘diet’ because I’ve always been
 316 a bit sceptical about vitamins and taking things”. Whilst most of our participants
 317 cross-referenced information, not everyone compared sources: some women preferred
 318 to rely on a single source, primarily for ease and simplicity. P3^{US} stated that: “once
 319 I found Reddit, there was no need for me to narrow it down in Google because I
 320 could narrow it down and get information that I actually needed just from that one
 321 source.”

322 Re-defining normal

323 *Comparing self to “normal” women*

324 All participants made references to feeling “abnormal”, “different”, and “other”.
 325 Many reported how their menstrual irregularities, hyperandrogenism, hirsutism,
 326 and/or obesity made them feel less feminine. Not feeling like a “normal” or “real”
 327 woman greatly affected their self-esteem and identities. This lack of perceived femi-
 328 ninity caused some to question their worthiness of love with P7^{US} saying: “It made
 329 me start to question my level of femininity and I guess my worthiness of love, es-
 330 pecially with such an aesthetic problem that I was having. It brought about some
 331 type of identity crisis”.

332 The realisation of their new normal caused some participants to be concerned that
 333 they would never go back to their previous normal selves and that their future paths
 334 had permanently shifted. For example, P9^{UK} reported thinking: “‘Is this forever?’
 335 Kind of, ‘There’s something wrong with me and I won’t be able to have a normal
 336 life’”. Cultural and family expectations created additional fertility concerns for some
 337 participants, for example, P12^{UK} said that she was “from a Mexican family, so they
 338 all have four kids. [...] It would be so annoying if I can’t”.

339 *Comparing self to other women with PCOS*

340 Participants also compared themselves to other women with PCOS. Most compar-
 341 isons were made against other women’s experiences reported online. Whilst prior
 342 work shows how women utilise online support for information, and emotional sup-
 343 port [28] that they often lack from healthcare providers [27], we also found women
 344 using these resources to help them understand what was “normal” for those experi-
 345 encing PCOS. As an example, P9^{UK} was asking others online: “‘Is it normal for this
 346 to happen?’ then you get a response saying, ‘Yeah, it’s normal. It’s completely fine.’
 347 Just things you’re worried about, you can post it on there and other women will be
 348 like, ‘Yeah, it’s normal. I’ve had this’. It’s great”. This type of online information
 349 exchange can for some result in feelings of reassurance.

350 Some women described online communities as a “double-edged sword” in that
351 they were simultaneously helpful and detrimental. Online communities were capable
352 both of inspiring action and damaging self-esteem, of offering support and causing
353 feelings of isolation, and of spreading both positivity and negativity. As an example,
354 P4^{UK} described feeling reassured when others discussed similar issues related to
355 their weight, yet “other people were managing it really well and I was feeling kind
356 of ashamed that I wasn’t”. This finding supports prior work on self-tracking that
357 has highlighted how engagement with data can result in both positive and negative
358 experiences [53].

359 Our findings also highlight social divisions between groups experiencing different
360 PCOS phenotypes, especially between those experiencing weight gain and those not.
361 ‘Lean PCOS’ is a label commonly attached to a specific PCOS phenotype that is not
362 associated with weight gain or obesity, whilst ‘obese PCOS’ is a label commonly
363 associated with weight gain or obesity [54, 55, 56]. The differences in symptoms
364 and severity of symptoms across different PCOS phenotypes often made it difficult
365 for women to understand and sympathise with others. P3^{US} said “I don’t have
366 the weight gain or some of the other symptoms. Then you see sometimes, on there,
367 they’ll be like, ‘Oh, you don’t understand my struggle. No, you don’t understand my
368 struggle’”. For those with “lean PCOS” there was pushback from some who would
369 question the validity of their diagnosis. P11^{US} described how online members would
370 sometimes state “Oh, lean PCOS isn’t real PCOS”, limiting the voice of this group
371 in online forums through attempts to delegitimise them.

372 Knowing that people were experiencing PCOS with more severe symptoms was a
373 source of guilt for some. Yet, it also offered positive feelings of being fortunate that
374 their symptoms were not “the worst case” (P6^{US}). In contrast, women whose symp-
375 toms seemed less manageable described feeling “jealous” and “unlucky”. P13^{UK} said
376 “You find yourself comparing yourself to everybody and you didn’t come on there
377 to do that [...] I feel really jealous of people that can manage it and that are getting
378 on really well with it”.

379 Participants recognised the heterogeneous nature of their disorder and its spec-
380 trum of phenotypes. This recognition allowed women interacting online to better
381 place themselves in relation to other people’s experiences making PCOS feel more
382 manageable. For example: P6^{US} said: “It just helped me make up a spectrum of the
383 PCOS and kind of metaphorically place myself on the spectrum, which made me
384 feel better [...] like ‘I can do this, I can possibly get pregnant if I wanted to.’ I don’t
385 have to scare myself into this hole of, ‘I’m just this worthless human being.’”. Al-
386 though some women stated that they found comparing themselves to other women
387 unhelpful, for others it helped them realise that women with PCOS experience it
388 differently which led to them recognising the need to find an individualised approach
389 to managing their symptoms. P9^{UK} said: “You have to really find what works for
390 you and essentially, that takes a lot of time to research, to try things.”

391 *Finding “normal for me” through trial and error*

392 Participants experienced a journey towards finding their “normal for me”; this in-
393 volved trial and error with various medications, apps, and lifestyle changes. Many
394 of the women interviewed had tested medications and lifestyle changes to find an

395 individualised approach for minimising their symptoms. Whilst this trial and error
396 journey made them feel more in control of their futures and more comfortable in
397 their bodies, it required significant effort, especially where women reported little
398 support from health practitioners. For example, P14^{UK} said: “I’ve tried all of the
399 diets and the exercises and things like that, and medications over the years. I know
400 what works for me”.

401 On this journey, all of our participants reported using health-tracking apps to
402 manage their PCOS, which included apps for tracking menstruation, diet, exercise,
403 fertility, mental health and medication. Participants talked about tracking changes
404 in their symptoms and menstrual cycles to help them pinpoint the cause of changes.
405 For example, P10^{US} said: “I think I correlate [my menstrual cycle] with maintaining
406 my PCOS because the more normal I get, the less symptoms I face from PCOS, so
407 I can clearly track that. [...] I tried different diets and stuff, so I could see when
408 things were working and when things weren’t”.

409 Women attributed their successful management of PCOS to their knowledge of
410 PCOS. Through the process of being diagnosed, finding information, comparing
411 themselves to others, and experimenting with what works for them, women were
412 able to learn about themselves and, ultimately, were able to find their new “normal”.

413 Discussion

414 This study extends prior work on women’s information-seeking relating to PCOS [28,
415 30], their need to establish what is normal for them [57], and the broader literature
416 on health information-seeking, sense-making and finding a “new normal” based on
417 information-seeking [43, 58, 41, 44, 40, 37, 38, 39, 36, 59]. Working at the intersec-
418 tion of these three themes, this study has identified health information-seeking and
419 sense-making behaviours being applied across a spectrum for PCOS. We uncover
420 a sense-making behaviour that involves women comparing their own health expe-
421 riences to that of others through online information-seeking. This allows them to
422 develop a mental picture of the spectrum, and place themselves somewhere on it so
423 they can contextualise their own experiences of PCOS and find their “normal for
424 me”.

425 Women engaged with online PCOS communities to find similar others to help
426 them understand whether they were “normal” within that context. Prior work has
427 highlighted the difficulties women face when looking for relevant information around
428 health topics, where vast amounts of information exist [60]. Our work provides
429 insights into how women use the spectrum of PCOS to identify information that is
430 relevant to them, amongst the vast amount of PCOS information that is broadly
431 available. In practice, these information-seeking and sense-making practices involved
432 women engaging in online PCOS communities to seek the experiences of those who
433 were close to them on the PCOS spectrum, allowing them to understand what was
434 “normal” for them. However, the differences in symptoms and their severity often
435 made it difficult for women to connect, understand and sympathise with others. Our
436 work highlights how women engage in an often rigorous process of sense-making
437 to understand where they lie on the PCOS spectrum, and what treatments and
438 lifestyle changes work for them. We also highlight the tension that women experience
439 between being overloaded with information about their condition and identifying

440 information that is relevant to them and reliable. Within this discussion, we first
441 compare our broader findings to those from prior work. We then describe in more
442 detail the spectrum-based information-seeking and sense-making behaviour that
443 we uncover in this work and in doing so we start to unpack the tension between
444 excessive amounts of information related to PCOS and individual relevance and
445 reliability.

446 Women's experiences of PCOS

447 Our findings support existing literature on experiences of PCOS [32, 7, 16, 9, 61],
448 in that many women questioned their femininity and whether they were “normal”
449 because of their symptoms, turning to others with PCOS to provide context for
450 their own experiences. As prior work has found, online peer support helped women
451 feel less isolated, gain access to advice and information, learn to navigate their re-
452 lationships with doctors and make decisions about lifestyle management and treat-
453 ment [28, 62, 57], but also increased some women's anxiety about their own health
454 situation [32]. Nearly half of our participants experienced a delayed diagnosis, which
455 had a negative effect on psychological and physical well-being; this finding is sup-
456 ported by previous studies [63, 64, 30, 16, 9, 65].

457 We found participants being overloaded with PCOS related information, yet we
458 found that most women were not receiving adequate information from their doctors
459 at the time of diagnosis which resulted in them turning to online sources such as
460 evidence-informed websites (e.g., NHS), social media (e.g., Reddit), and blogs; this
461 supports prior work [63, 64, 30, 16, 9, 29, 65]. However, as found by Chiu *et al.* [66]
462 and others, women reported that information from PCOS-specific medical websites
463 was too general.

464 Chopra *et al.* [57] studied the use of information technology to support people
465 self-managing PCOS, so there is value in explicitly comparing our findings with
466 theirs. The findings from their analysis of interviews with women with PCOS are
467 consistent with ours in that both highlight the variability across individual expe-
468 riences of PCOS and the limited understanding of the condition, in terms of both
469 symptoms and management strategies. Hence it is a difficult condition to manage.
470 Chopra *et al.* [57] focus on the requirements of technologies for self-tracking and
471 co-management. While many of our participants also reported on the value of self-
472 tracking (and the need for better apps, particularly for tracking menstrual cycles),
473 co-management was not identified as a theme in our data. Whereas Chopra *et al.*
474 emphasise the stigma attached to PCOS, none of our participants mentioned this
475 as an issue. However, our participants did highlight sometimes distressing divisions
476 within the population of women managing PCOS – particularly related to the sever-
477 ity of symptoms and whether or not weight management was an issue (obese vs.
478 lean PCOS).

479 Information-seeking and sense-making on a spectrum

480 All participants in this study recognised their need for information both prior to
481 and following diagnosis. They accessed information systems (the internet) and other
482 people (peers with PCOS) to find information and evaluate whether it applied
483 to them. The findings provide evidence to support Wilson's [67] suggestion that

484 information-seeking is collaborative and that people participate in “information
485 exchanges”. Women in our study shared posts within online communities to support
486 others. It can be argued that even “liking” another woman’s post is a modern-day
487 version of an “information exchange” as liked posts are often promoted and gain
488 more exposure.

489 When these findings are examined using Dervin’s [45] gaps metaphor around
490 sense-making, the biggest gap that women experienced was a consequence of not
491 understanding their own bodies, as women did not understand why they were experi-
492 encing their symptoms. Searching online for potential causes and being diagnosed
493 with PCOS were the first steps in managing uncertainty [57]. As women’s knowledge
494 of PCOS increased, so too did their understanding of the condition; this may have
495 also contributed to increased confidence in managing the condition [62]. Gaining
496 knowledge of the self through experimentation with treatments is consistent with
497 research by O’Kane *et al.* [41] around complex long-term conditions, and by Chopra
498 *et al.* [57] and Ismayilova and Sanni [25] around PCOS.

499 Consistent with our findings, Burgess *et al.* [44] found that once patients accepted
500 their condition, they moved from a learning phase to a phase of living with their
501 condition. In keeping with literature on long-term conditions [40, 37, 38, 39, 36], we
502 found that women with PCOS are concerned with feeling “normal” and that they
503 compare themselves to their peers to normalise their illness experience. Similarly,
504 in line with findings from Groven and Galdas [59], people experiencing a disruption
505 to their perceived “normal” would directly compare themselves with others.

506 We found information-seeking, sense-making, and finding normal being closely
507 linked, and that uncertainty of normality acts as a catalyst for taking action and
508 seeking information. Moreover, turning to peers to understand “normal” is essen-
509 tial to supplement evidence-based information. This supports O’Kane *et al.*’s [41]
510 findings that evidence-based medical sources are insufficient in validating normalcy.
511 Their participants, like ours, were not satisfied with evidence-based medical infor-
512 mation alone, and so supplemented it with less formal information sources such
513 as forums and blog posts. The processing of both evidence-based and experiential
514 information allowed our participants to compare their experiences with their peers’,
515 and to validate the normalcy of their own experiences.

516 In summary, elements of our findings support those from previous studies that
517 considered different conditions, providing evidence that those earlier findings gener-
518 alise. Importantly, our study of PCOS identified and describes health information-
519 seeking and sense-making behaviours being applied across a spectrum, and in doing
520 so we develop a refined model (see: Figure 1) that links together these different
521 phases of information-seeking and sense-making.

522 Finding “normal for me” for PCOS

523 Building on previous studies and our findings, we propose a model of informa-
524 tion interaction and finding “normal for me” for PCOS (Figure 1). This model is
525 adapted from models of information interaction proposed by others for different
526 health conditions (e.g., [36, 43]).

527 Several authors [68, 69] describe the initial phase of sense-making as being “life
528 before the health condition” and note that the initial breakdown (of feeling nor-
529 mal) triggers information-seeking. Huttunen and Kortelainen [68] and Karp [69]

530 describe this as just having a sense that something is not quite right. Leventhal
531 et al.'s Common-Sense Model helps to explain these prior findings. Their model
532 looks to understand how people respond to and manage illness threats, modelling
533 how people use past experiences of illnesses to develop a collection of mental mod-
534 els of health conditions (e.g., the common cold), using these to help them identify
535 where symptoms deviate from their usual "normative" self [70]. Within our study
536 some participants reported similar: as they start to experience a breakdown of "nor-
537 mal", they sense that something about their health is not right, although they often
538 struggle to articulate it. We find women comparing themselves to "normal" women
539 (including their pre-diagnosis/symptomatic selves). Women's journeys to identify-
540 ing their PCOS differ. For some, PCOS is suspected as a result of online research
541 after experiencing symptoms. For others, the first they learn about PCOS is during
542 their formal clinical diagnosis.

543 Most models identify the next important stage as seeking (or interacting with)
544 and making sense of information about the relevant condition. Based on our anal-
545 ysis which found that, following diagnosis, participants generally sought out, and
546 made what sense they could of, medical information about PCOS before turning to
547 social media. Women begin to explore what is "normal" to experience with PCOS.
548 Participants engage in information-seeking to make sense of their condition, which
549 is consistent with findings from prior research in other health contexts [36, 43].
550 Our participants either began or continued their general PCOS search by accessing
551 evidence-based medical websites. Supporting prior research (e.g., [36, 42, 43, 58]),
552 we found our participants utilising both evidence-based medical information and
553 experiential information through online social support networks, to better under-
554 stand their condition. Where experiential information was thought to be unreliable,
555 medical evidence-based information was used to check its veracity.

556 Genuis and Bronstein [36] and Patel et al. [43] focus on how people find personal
557 meaning, or a "new normal" relating to their health. They differentiate between
558 a "socially constructed normal" and an individual "new normal", leaving it im-
559 plicit that people live with that new normal. In our study, we found that seeking
560 peer information involves understanding what is considered normal across the peer
561 group (of people managing PCOS). However, because PCOS presents differently
562 for each individual it is also essential to find "normal for me", so "living with"
563 includes self-management based on that understanding of what is normal for the
564 individual. Thus, this sense-making process is contextually specific, with women
565 identifying how PCOS and its symptoms vary between women, resulting in a fur-
566 ther personalised contextualisation of information. We highlight how women with
567 PCOS engage in sense-making to understand where they "fit" along the spectrum of
568 PCOS by engaging with other women in online PCOS groups and reading blog posts
569 about other women's experiences. Determined to find their own, personal, unique
570 "normal", women used information from others to target their internet searches
571 and find lifestyle changes and medications to evaluate for themselves. They tracked
572 these changes and their results either mentally or using non-PCOS-specific health-
573 tracking apps, which helped them gain a greater understanding of their bodies.
574 Prior health information-seeking research has identified challenges that individuals
575 face in efficiently identifying relevant information, despite there being vast amounts

576 of information available [60]. In placing themselves on a spectrum of PCOS, they
577 were better able to cope with the excessive amount of PCOS related information
578 available to them, as women found it easier to identify what was relevant to them
579 and their experiences with having the condition.

580 If their condition stabilises, women may rely less on information resources and
581 peers, though many continue to engage with online resources and peer groups.
582 Many also reported having adapted their lifestyles, including routinely monitoring
583 their bodies (e.g., menstruation cycles) to manage their condition effectively over
584 the longer term.

585 Implications and further work

586 As highlighted in the previous section, it will be important to extend these findings
587 to account for relevant protected characteristics such as race, culture and gender di-
588 versity. It would also be valuable to develop and test social media tools that support
589 individuals in articulating their symptoms (“something just isn’t quite right”), iden-
590 tifying possible diagnoses (and the tests that would confirm them), evaluating the
591 reliability of the information, and deciding on next steps. It would also be valuable
592 to both test existing platforms that are designed to support people in comparing
593 their experiences to those of others and to develop and test a novel platform that
594 supports people in finding “normal for me” for conditions where different individu-
595 als can have significantly different symptoms and where different interventions and
596 management strategies are most effective.

597 Limitations

598 The external validity of this study may have been affected by recruiting participants
599 through social media groups that were associated with PCOS. Participants recruited
600 using these channels are likely to also use social media personally, thus skewing
601 data towards women who already use digital tools to research or manage PCOS.
602 However, the purpose of this study was to examine how women use digital tools
603 and communities to seek information on and manage PCOS, not to investigate the
604 prevalence of technology use in women with PCOS.

605 Our recruitment method meant that participants were self-selecting within our
606 recruitment criteria, which resulted in a lack of homogeneity within our sample,
607 with participants having been diagnosed with PCOS from 1 month to 5 years,
608 and receiving clinical care across two different healthcare systems. Although the
609 care systems in the UK and the US are substantially different, participants largely
610 had access to the same information resources. Moreover, although the time since
611 diagnosis differed across our sample, this allowed us to learn about information
612 practices at different stages of people’s PCOS journey.

613 There are questions that, with the wisdom of hindsight, it would have been useful
614 to address in the interviews: for example, what triggered people to start looking for
615 information or seek a medical diagnosis? Have people explored specialised patient
616 forums such as PatientsLikeMe, and do such forums address some of the needs
617 they have articulated? However, our focus on information-seeking and sense-making
618 highlighted some important needs that merit further investigation.

619 We did not gather information on race, culture, gender, or sexuality so are unable
620 to add to the understanding of how these factors might influence information-seeking

621 or - probably more importantly - the social construction of “normal” within partic-
622 ular cultural communities. This theme has been partially addressed by Chopra et
623 al. [57], but merits further study.

624 In addition, the language used to recruit participants may have discouraged indi-
625 viduals with PCOS who identify as men or as non-binary from participating. These
626 individuals may not relate to the findings of this study, especially since some find-
627 ings are so closely tied to notions of femininity. Future research on PCOS should
628 examine how this sub-population experiences PCOS.

629 Conclusion

630 This study set out to investigate women’s information-seeking, sense-making, and
631 “finding normal” practices when managing PCOS. Our analysis resulted in the
632 development of two themes (1) Information Needs and Strategy and (2) Re-defining
633 normal. Within the first theme, we describe how women use both evidence-based
634 medical information from clinicians and online websites, as well as experiential
635 information from online sources such as social media, forums, and blogs. They use
636 this information to help them make decisions about potential treatments, with both
637 types of information being necessary for women to feel that their knowledge about
638 PCOS and their bodies is sufficiently reliable and detailed and that they are getting
639 adequate emotional support. Within the second theme, we describe how women with
640 PCOS seek a sense of “normal” by comparing themselves to other women whom
641 they consider “normal” (including their pre-diagnosis/symptomatic selves) as well
642 as to other women with PCOS. However, when they do so, they discover that PCOS
643 is a broad-spectrum disorder that affects each woman differently. This leads them
644 to perform a context-specific evaluation of information to help them discover what
645 works for them as individuals so that they can find their own “normal for me”.

646 Declarations

647 Ethics approval and consent to participate

648 This study is based on a research project approved by the ethics committee of the Computer Science Department at
649 University College London (UCL), UK with reference UCLIC/1819/006/BlandfordProgrammeEthics. Prior to data
650 collection, informed consent was obtained from participants. Participants were compensated for their time with a
651 15GBP (approx. 19USD) voucher. The study protocol conforms to ethical standards set by the institution and they
652 align with the ethical principles set out in the Helsinki declaration.

653 Availability of data and materials

654 To protect the privacy of participants involved in this research, and the difficulties in truly anonymising our
655 qualitative dataset, transcripts have not been made publicly available but are available on request by contacting
656 Professor Ann Blandford.

657 Consent for publication

658 Not applicable.

659 Competing interests

660 The authors have no conflicts of interests.

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663 Author’s contributions

664 JG led the study design, data collection, and analysis. MW and AB provided guidance and support on all aspects of
665 the study design, and supported in the data analysis. JG wrote the first draft of the paper and MW and AB revised
666 it to make the final manuscript. All authors have read and approved the final manuscript.

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670 **Author details**671 ¹ Computer Science Department, UCL, Gower Street, London, UK.672 **References**

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848 **Figures**


Model.png

Figure 1 Refined model of information interaction and finding “normal for me” for PCOS