Exploring the diagnosis experiences and support needs of individuals living with Polycystic Ovary Syndrome (PCOS)

Sharon Manship, Research Associate/Principal Investigator
Kate Day, Research Assistant

Centre for Health Services Studies
School of Social Sciences, University of Kent

March 2026

Acknowledgement

We extend our gratitude to the research participants who so generously gave their time and openly shared their experiences. We are also very thankful to our Expert Advisory Group members whose valuable input and feedback helped to shape the research – Sharon Aldridge, Veron Aldridge, Alex Allan and Lauren Foreman. Thank you also to Dr Sarah Hotham who provided mentorship and ongoing support for this work.

This research is funded by the National Institute for Health Research (NIHR) Applied Research Collaboration Kent, Surrey, Sussex. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

Contents

Introduction

Women make up 51% of the population, yet historically their health has not been seen as a priority (Cleghorn, 2021). The health and care system uses a 'male as default' approach, leading to gaps in the data and evidence base, meaning that not enough is known about conditions that only affect women (DHSC, 2022).

Polycystic Ovary Syndrome ('PCOS') is a common endocrine disorder that affects between 8% and 13% of individuals assigned female at birth, yet it is suggested that up to 70% remain undiagnosed (WHO, 2023). PCOS is a multifaceted condition with broad manifestations, including irregular menstrual cycles (which may result in fertility issues), male-pattern hair growth (hirsutism), scalp hair loss, acne, difficulties managing weight, sleep and mental health issues, and more. PCOS also increases the risk of developing a variety of reproductive, metabolic and psychological comorbidities, diabetes, heart disease and some cancers, which poses a significant public health issue.

Treatment and effective management of PCOS includes lifestyle modification, pharmacologic management, infertility treatment (if required) and symptoms-based treatment for hair, skin and other issues (Shukla et al 2025). Since individuals experience symptoms differently and to varying degrees, it is important that diagnosis and treatment are timely and personalised (Sharma & Mahajan, 2021). However, current evidence suggests dissatisfaction of the experiences of being diagnosed and lack of information regarding the ongoing management of PCOS (Presswala & De Souza, 2023; Ismayilova & Yaya, 2022; Lau et al, 2022; Peña et al, 2021; Hillman et al, 2020; Gibson-Helm et al, 2017).

Hillman et al (2020) presented the first study exploring experiences of women with PCOS specifically in UK general practice. Their findings highlight time lags from presentation to diagnosis, dissatisfaction with the amount of information regarding the condition, and little discussion with GPs regarding associated experiences of mental health issues and comorbidities.

This study seeks to address current gaps in research, particularly in relation to the lived experience of those who have been diagnosed and sought treatment for PCOS. This work aligns with the work of the Women's Health Strategy (DHSC, 2022), the government's 10-year plan to improve the health and wellbeing of women and girls in England. Such research is also warranted as women's health issues have wide economic implications. According to an NHS Confederation report, the cost of absenteeism due to severe period pain and heavy periods alongside endometriosis, fibroids and ovarian cysts is estimated to be nearly £11 billion per annum (Gorham & Langham, 2024). They recommend that the NIHR invests in and prioritises research into innovative options for women's health conditions that prioritise early diagnosis and intervention

Research question, aims and objectives

To date, research in relation to PCOS is limited in terms of exploring lived experiences, therefore this study aimed to explore experiences of diagnosis and post-diagnosis support. The research question was:

What are the diagnosis experiences of individuals living with PCOS in the UK and what support is needed in relation to post-diagnosis care pathways?

The study aims and objectives were to:

- Understand the current evidence regarding experiences of PCOS diagnosis and care pathways, both globally and in the UK
- Explore the experiences of individuals living with PCOS in Kent, Surrey and Sussex in relation to diagnosis and post-diagnosis care pathways
- Co-produce recommendations for a holistic resource in relation to diagnosis and support needs for those involved in the care of individuals with PCOS

Methodology

The overall study adopted a phenomenological approach to gain in-depth insights into subjective experiences of individuals. Initially, an evidence synthesis was undertaken via a systemised scoping review of the literature to explore relevant global research and elicit findings and gaps in the UK. To conduct the scoping review, Arksey and O'Malley's (2005) methodological framework was undertaken, which involves six stages: identifying the research question; searching for relevant studies; selecting studies; charting the data; collating, summarizing and reporting the results; and collating with stakeholders to inform or validate findings.

Following the scoping review, semi-structured one-to-one interviews were conducted with a purposive sample of 12 individuals living with PCOS and based in Kent, Surrey and Sussex to explore their experiences in relation to diagnosis. The interview schedule was partly informed by the findings of the scoping review. The sample size was deemed manageable within the confines of a small-scale study, whilst generating comprehensive data from which main themes and sub-themes could be drawn. Researcher field notes were also recorded to aid analysis.

Interviews were recorded and transcribed via MS Teams and screened by the researchers for accuracy. Qualitative data was coded using NVivo and thematically analysed to provide a descriptive narrative of the key issues. Framework analysis (Ritchie & Spencer, 2004), a type of analysis that offers a structured, systematic approach to summarising and analysing qualitative data, was undertaken. Framework analysis involves five key stages: familiarization; identifying a thematic framework; indexing; charting; mapping and interpretation. This approach was particularly useful in the case of this project since it allowed combining exploring pre-determined themes with more open and emerging categories from the data.

The study was supported and shaped by an Expert Advisory Group (EAG) which comprised four lay members who lived with or supported someone living with PCOS. The EAG provided feedback on the scoping review and interviews findings, collaborated with the research team in making decisions about research priorities and contributed to the dissemination plan to communicate findings and recommendations across primary care and wider healthcare and support systems.

The study was reviewed and granted a favourable ethical opinion by the School of Social Sciences Staff Review Committee at University of Kent (Ref: 1166).

Findings

Scoping review

Stage 1 of the study involved undertaking a scoping review in relation to diagnosis experiences and support needs of individuals living with PCOS. The purpose of the scoping review was to explore relevant findings globally, and also to summarise existing findings and research gaps in the UK.

Search strategy

The scoping review search strategy was employed to obtain relevant and recent literature. Relevant databases, including PubMed, PsycInfo and Google Scholar were searched in February 2025 and the references of relevant literature, including reviews, were also hand searched to identify key papers. Key search terms included:

- Polycystic*
- Polycystic ovary syndrome
- Polycystic ovarian syndrome
- diagnos*
- experience*
- support

Inclusion and exclusion criteria were as follows:

- Inclusion criteria - literature about experiences of diagnosis of PCOS or support needs, published in last 10 years (2014 onwards)
- Exclusion criteria - literature solely about experiences of living with PCOS, literature about the experiences of healthcare professionals (HCPs), not written in the English language

The search strategy produced 1786 results. Initial title screening was conducted by both researchers (SM and KD), which elicited 213 potentially relevant papers. Abstracts were further reviewed and discussed against the criteria, resulting in 89 remaining. Twenty-One papers were removed as duplicates. Full text screening by both reviewers resulted in 16 papers being selected for the scoping review.

Overview of included studies

- Articles ranged in date of publication from 2014 to 2024
- Papers covered a range of methodologies including qualitative (n=5), quantitative (n=5), mixed methods (n=4) and scoping/narrative reviews (n=2)
- In terms of country of publication:
    - 5 articles were from the Canada
    - 4 articles were from Australia (of which 1 contained a small UK sample)
    - 3 articles were from the UK

    - 1 article was from Saudi Arabia
    - 1 article had a mixed global sample
    - The 2 reviews cited global references, with one authored by researchers in Canada, and the other written by authors from Australia and USA
- Papers subjects of focus:
    - 14 were in relation to diagnosis
    - 1 was in relation to support needs
    - 1 was in relation to both diagnosis and support needs
- 15 papers were peer reviewed journal articles and 1 paper was a PhD thesis

The scoping review uncovered three main themes, which are discussed in the following sections.

Scoping Review Theme 1: Negative experiences of PCOS diagnosis

There were a number of negative experiences of PCOS diagnosis reported in the literature. The most notable negative experience was time delays experienced in the diagnosis journey (n=8), which was mostly attributed to having to seek help from numerous different healthcare professionals (HCPs), including General Practitioners (GPs) and specialists, in the lead up to being diagnosed (n=7). Another factor was feeling dismissed by GPs and other HCPs (n=4).

There was a wide perception that HCPs lacked knowledge and understanding of PCOS (n=9), which resulted in a lack of understanding of patients regarding the long-term impacts and risks of PCOS as well as increased uncertainty and anxiety (n=5). Diagnosis experiences were also negatively impacted by access issues, including perceptions that GPs were 'gatekeeping' referrals to specialists.

Reported perceptions of HCPs included a lack of empathy regarding having PCOS, and experiencing stigma, mostly in relation to excess weight. These experiences led to a distrust of HCPs, which was reported as a barrier to individuals seeking help or accessing support. Such attitudes and experiences of HCPs further increased the distress experienced by individuals, who felt that emotional support in particular was very limited, along with a lack of general support. During diagnosis, symptom management was felt to be either missing or inconsistent with a focus mainly on fertility and weight.

These reports of negative experiences highlight that the diagnostic journey of PCOS can be adversely impacted by the knowledge, approach and personal bias of HCPs, along with unequal power dynamics. Such issues can act as barriers to receiving timely diagnosis and subsequent support, and further exacerbate illness burden by putting the onus on individuals to self-advocate for their care.

Scoping Review Theme 2: Positive experiences of diagnosis

The scoping review did uncover some positive experiences and captured approaches that individuals living with PCOS felt had worked well (n=9). The most prominent positive experience was the impact of having a HCP express compassion and being well informed about the condition. Some studies highlighted particularly valuable skills of GPs when communicating the diagnosis, including listening to the patient from the outset as the expert of their own body, appropriately discussing fertility and using neutral language.

One UK study suggested that language was important in relation to diagnosis as it impacted on consultation satisfaction, body esteem and quality of life (Ogden & Bridge, 2022). Such communication skills facilitated satisfaction with the diagnostic experience and also potentially decreased the time it took to be diagnosed

Receiving a diagnosis was a positive event for some individuals as it legitimised their experiences and enabled them to better understand their symptoms and take control, either through the information they received from their GP or by being referred to a specialist.

In summary, GPs and other HCPs have significant potential to improve the experience of PCOS diagnosis which can enhance patient satisfaction. This finding is important in relation to informing future healthcare practice in relation to PCOS.

Scoping Review Theme 3: Support needs of individuals diagnosed with PCOS

Along with the reported experiences of diagnosis, the literature identified a number of unmet needs of individuals living with PCOS. The most commonly reported support required, which featured in 12 of the 16 papers, was in relation to mental health and wellbeing. It was therefore suggested that individuals diagnosed with PCOS should be screened for mental health issues and provided with opportunities to learn coping strategies to manage the mental and emotional impacts of PCOS. These included worry and anxiety about symptoms and implications, and recognition of the impact of depression on ability to make lifestyle changes.

The next most reported support need was in relation to the lack of knowledge and awareness of HCPs, which led to large gaps in information provision and knowledge of individuals following diagnosis, especially in relation to lifestyle changes and symptom management. The literature suggested that improved GP/HCP training and education from credible and high-quality resources was required. Education should encompass best practice guidelines, and should continue through all stages from graduate and postgraduate to continuing professional development. This was particularly important for HCPs in primary care settings, since they were usually the first point of contact and provided care over the lifespan, but was also necessary throughout the wider healthcare community. Reliable, evidence-based resources and guidelines were deemed imperative to clarify any confusion about diagnostic criteria, to support health literacy and to empower individuals, whilst also recognising that support should be holistic and person-centred to take individual experiences into account.

Another finding was related to the lack of referrals, both to specialist allied health professionals for follow-up care to aid in reaching health goals, and to support groups. The literature suggested that many individuals with PCOS resorted to self-education and discovery, often referring to online resources such as social media and websites and social support (i.e. friends and family). Despite often being the only thing available to individuals with PCOS, there was recognition that online sources were not always reliable and there were questions around validity and trustworthiness of content. Those who accessed peer support groups often found them to beneficial in terms of being part of a wider community and sharing their story. However, Soucie et al (2021) reported some negative experiences of online support groups, such as finding them depressing, comparing experiences to others and frustration. It is therefore important that individuals with PCOS are signposted to credible professionals and valid resources and that a variety of options are available, including patient forums, workshops, websites and email updates.

Scoping review summary

There is a wide perception that GPs and other HCPs lack knowledge and understanding of PCOS and the wide range of associated symptoms. Enhanced education and training in relation to the condition and its wider impact, along with undertaking a holistic and person-centred approach which takes into account the nuances of individual experiences and symptoms, could help mitigate issues such as delays in diagnostic journeys and patient dissatisfaction. Education resources need to be high quality, from credible sources and encompass best practice guidelines. Furthermore, education should continue through all stages from graduate to continuing professional development. Referral to specialist allied health professionals and support groups is important for follow-up care and to aid individuals in making lifestyle changes and reaching health goals.

GPs and other HCPs who come into contact with individuals presenting with symptoms and/or seeking a diagnosis of PCOS have a crucial influential role in relation to the perceptions and experiences of patients. Effective communication skills, a compassionate and empathetic approach and being well informed about the condition can facilitate empowerment of individuals with PCOS and legitimise and validate their experiences, leading to improved patient satisfaction.

It is important for GPs and HCPs to be aware of the potentially wide ranging impact of PCOS on individuals. Personalised approaches, tailored to individual circumstances, are imperative for optimising outcomes in PCOS management (Ghafari et al, 2025). The literature indicates a particular gap in relation to the support needs of individuals diagnosed with PCOS in terms of their mental health and wellbeing. Mental health screening and improved signposting to support services, such as counselling and support groups, could offer outlets for such symptoms of PCOS and improve coping strategies.

It should also be noted that the majority of literature covered in this review was published before the 'International evidence-based guidelines for the assessment and management of PCOS' was issued (Teede et al, 2023) and therefore many GPs and other HCPs will currently be working on outdated diagnostic information, which means diagnoses may not be accurate.

Despite extensive searches, only three published journal articles were found which presented the findings of empirical research in the UK. This limits the extent to which their findings are generalisable and indicates that there are particular gaps in the evidence in relation the lived experiences of individuals in this country. Further research would therefore be valuable, particularly in light of the Women's Health Strategy (DHSC, 2022), the government's new 10-year plan to improve the health and wellbeing of women and girls in England.

Interview Findings

Participants

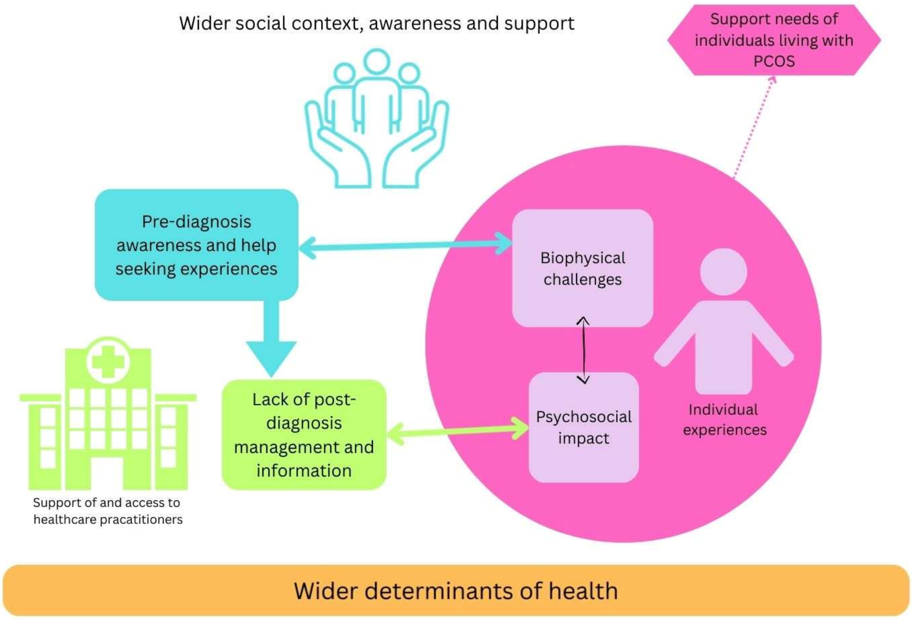
Table 1 shows the demographics and other background information of the participant sample recruited for this study, which comprised 12 individuals living with PCOS.

Table 1. Participant demographics

	N=12
Age	
20-29	5
30-39	5
40-49	1
50+	1
	Mean age = 33
County of diagnosis	
Kent	4
Surrey	4
Sussex	4
Ethnicity (self-reported)	
White British	8
White/Mixed	1
Mixed Black African/White	1
Other	2
Gender (self-reported)	
Woman (she/her)	12
Duration to diagnosis	
10+ years	6
5-10 years	5
<5 years	1

Although experiences of PCOS diagnosis and care were nuanced, there were some common overarching themes highlighted in the interviews. These themes highlight the impact of PCOS diagnosis and the experiences and support needs within Kent, Surrey and Sussex. Figure 1 shows the thematic map developed to illustrate the findings, which are discussed in detail in the following sections.

Figure 1. Thematic map



Theme 1: Pre-diagnosis awareness and help-seeking experiences

Not making the link between symptoms and PCOS

Many participants shared that they simply did not know enough about PCOS to link the symptoms they were experiencing with the condition. Symptoms participants reported experiencing in the lead up to diagnosis were wide and varied, including:

- Irregular menstrual cycle – no periods, missing periods, constant bleeding
- Painful/heavy periods
- Mental health challenges – anxiety, depression, mood swings, disordered eating
- Weight issues – fluctuations, putting on weight easily, difficulty losing weight
- Acne
- Hirsutism
- Fertility issues
- Migraines/headaches
- Fatigue

There were frequent comments along the lines of *"this was just my normal",* reflecting that there is a lack of wider public awareness of how the menstrual cycle should or should not be experienced. This lack of awareness and knowledge across support systems, including school, family and peers, influenced how proactive individuals were in help seeking. Many participants reported that had they known more about PCOS, they might have sought help sooner:

> *"I just had so many absent periods. I guess I just never had a cycle. You know, sometimes I go through phases of it might be a bit normal, but I would just have long stretches without a cycle and nobody ever kind of picked up on it. They just*

> *said, Oh, you know, it could be stress, it could be just your cycle, it could be this, it could be that. And because my blood tests were normal. And they still to this day are saying my hormones they're testing are normal."* [P002]

PCOS messaging focused on select symptoms

Lack of awareness around symptoms was amplified by the existing messaging around PCOS often being focused on a select group of external symptoms, such as issues with fertility, weight and hirsutism, despite the fact that the condition causes a wide variety of additional symptoms which vary in severity between individuals. Therefore, some participants who knew about PCOS felt they did not fit the typical descriptions. This was an additional barrier in initiating contact with healthcare professionals and seeking help:

> *"I have friends with PCOS, so I knew what it was and the markers but I never thought I had it because I just didn't think I had any of the typical symptoms at that point. I didn't have the weight gain. Thinking back to it now It makes more sense as the nurse asked, Do you have any excess hair? I thought about it and I said, No not really. And then afterwards, I realised I do get rid of my moustache every week, but I just didn't think about it because I do that every week all the time for years, since I was a teenager…because it's been going on for so long, you just get used to the symptoms…Even with like acne and spots, I've always had spots. Again, I just thought, I've just always had them. I've had them since being a teenager and I work hard at my skin care routine to stop them coming, but they come…I never thought these are the signs of PCOS. I've always had this."* [P010]
>
> *"I hadn't considered [PCOS] because the symptoms that I knew, that I associated with it, I wasn't really having…like excess hair, that gets lumped in with it the most. And my weight hasn't been a problem…And it was never raised in any of the GP appointments."* [P007]

Repeat visits to HCPs before diagnosis

Participants reported very protracted time periods in seeking and obtaining help, which often necessitated making repeated appointments (one participant reported more than 20 appointments with their GP), repeating themselves to different HCPs and having to push and advocate for themselves to be taken seriously or get further investigation, which felt *"all consuming"*. Additionally, there were reports of trying to access care but being told that their weight was the problem so they just needed to lose weight, which led to further delays and missed diagnoses.

Dismissal of symptoms

There were frequent reports of individuals feeling dismissed by GPs and HCPs and having their experiences disregarded, so by the time they were eventually diagnosed, they had been suffering with symptoms for a considerable time. As shown in Table 1, 50% of the participants spent over 10 years suffering with symptoms before being diagnosed with PCOS, for 42% it took 5-10 years and for 8% of the sample (n=1) it took less than 5 years to be diagnosed:

> *"I've always really struggled with my periods and period management, [since] my first few periods. I have always been really heavy. I have always really struggled with acne...from the age of 12 up until I was 16, it was my mum taking me back and forth to the GP for pain relief for my periods or something for my acne. We never correlated the two together, so around 16 ... I'm at the point of passing out whilst doing my exams...it sort of came to a head of, like, no this is affecting your education now, you can't go on anymore."* [P003]

> *"My whole experience was about managing the symptoms rather than getting a diagnosis. It was a constant battle and countless numbers of internals and prods and pokes."* [P008]

Theme 2: Individual experiences of PCOS

As PCOS is a syndrome, it manifests in individuals in different ways and to varying degrees. Theme 2 sets out reported individual experiences in line with areas of the biopsychosocial model, an approach that expands on the limitations of the narrow but traditional biomedical model and posits that a person's health is not entirely attributed to physiological factors but also psychological processes and social influences (Havelka et al, 2009; Engel, 1977). Application of this model provides a lens through which pre and post-diagnosis experiences can be viewed.

Biophysical challenges

Participants reported feeling dissociated from or out of control of their body as a result of PCOS, which was exacerbated by fluctuating symptoms such as their menstrual cycle, hair growth (hirsutism as well as thinning hair), fatigue, pain, blood sugar spikes, gastrointestinal issues and more:

> *"I didn't understand how my body was working at all. I felt like it was operating on a very separate domain to me."* [P007]

> *"I feel all the time like I don't know my body...really having no idea what was wrong with me. And that's the common theme that stays with me until now - not understanding myself, not knowing what's under the flesh, not knowing why I am the way I am."* [P004]

> *"I felt like my body doesn't work."* [P009]

Participants also felt that there was a lack of recognition from GPs and other HCPs about the nuances of challenges in relation PCOS. This led to participants feeling like they were given *"blanket advice"*, outdated information or led down a path that the professional felt was right, which was not always relevant or did not take into account their individual circumstances. For example, many participants were advised to *"just lose weight"* with no recognition of the challenges presented by PCOS, such as hunger, cravings, emotional and disordered eating, and slow weight loss. Furthermore, some participants felt that incorrect assumptions were made about their diet and physical activity levels, and that their experiences and preferences were not listened to, which, in turn, could potentially be harmful. Many participants described wanting to move away from diet and restriction mentality and working towards a balanced mindset and relationship with physical activity and nutrition, yet this journey was often unsupported by GPs and specialists:

> *"The NHS gynaecologist looked at my ultrasound and said, It's just lose weight…I'd had an eating disorder before and was a size 10 at the time, so this set me back emotionally as I had got to a happy place."* [P003]
>
> *"I'm a vegetarian and [the specialist] said, You can't be, you need to eat meat and fish. I said, I really can't do that. So she had a load of really set recommendations… She said, with this treatment plan it all goes away. And obviously it didn't…She used to make me feel like it was my fault for not eating this or doing that…she was very strict and no nonsense. I used to get upset in those appointments. I was like, I am paying for this and I am crying in your office whilst you have a go at me."* [P007]

Similarly, there were nuanced experiences reported in relation to fertility and starting a family. Many felt that their PCOS diagnosis informed their life choices and behaviours, with most being told *"it will be difficult to conceive"* or even *"you won't be able to have children"*. This misinformation led to distress and feeling under pressure to think about starting a family before they were ready for some. Conversely, others made the decision not to use contraception and this resulted in unplanned pregnancy. As with nutrition and physical activity, there were reports of mixed messages and not feeling heard:

> *"He [gynaecologist] pretty much told me to get pregnant, without discussing with me if I wanted children, not knowing anything about my sexual orientation, my wants, my personal situation, nothing…I kept being told 'tick tock' and that having kids would be difficult but will cure you."* [P008]
>
> *"[The GP] said, You've had children, so why don't you have a hysterectomy? Despite the fact that I was trying to conceive."*[P005]

Psychosocial impact

This sub-theme collates the psychosocial experiences reported by participants before, during and after diagnosis. One of the main impacts of PCOS, reported by the majority of participants was experiencing mental health issues and challenges:

> *"For a while, I wondered if I had depression or something like that because that kind of fitted with it, but not being sure… I went to the doctor's when I was probably about 21 and said, I don't know what's going on. I don't know if I've got depression… you're trying to stick at it, but you know, you're then wondering all the while well, is it just depression? Really having no idea what was wrong with me…"* [P004]

There was recognition that the many and varied symptoms experienced by those living with PCOS could elicit feelings of frustration, helplessness, self-blame, negative body image and feeling out of control of their bodies. Many participants experienced stigma and shame and felt PCOS was a *"taboo"* subject. Others reported experiencing bullying at school because of symptoms. These issues clearly had a significant and ongoing impact on mental health and wellbeing.

In addition, less was known about conditions such as depression and anxiety being the direct result of a biochemical imbalance, which some participants felt was the case, as well as the links with conditions such as Premenstrual Dysphoric Disorder (PMDD). What was clear was that participant felt largely unsupported by GPs and other HCPs in relation to the mental health aspects of living with PCOS.

Mental health was also negatively impacted by the perceived lack of healthcare support, both in primary and secondary care. Feeling dismissed, overlooked, disregarded or not believed were common experiences, which led to participants feeling helpless and despondent about the future.

> *"It feels like this is a very ignored area of women's health and that shows in how we are treated and spoken to. So many people have this condition and there's nothing really for us."* [P010]

Despite the negative impacts of PCOS on mental health and wellbeing, there was recognition from a couple of participants that positive feelings and emotions had developed as a result of managing PCOS and their care around it. Self-reassurance, resilience and confidence to self-advocate were amongst those reported by participants, which were amplified by support from HCPs that was sympathetic, validating and proactive:

> *"You have to be quite resilient if you want to get it sorted."* [P007]

> *"When I was re-diagnosed [with PCOS after back and forth and specialists contradicting each other], he said, Let me help you manage the symptoms. I've got this, you don't need to worry. We will get you there. I was so ready to be in 'fight mode', I just sat there and cried."* [P003]

Psychological aspects of PCOS also interacted with wider social implications, such as the societal pressures on women to have children and beauty standards, which can further impact on issues with self-confidence and self-esteem caused by symptoms. Furthermore, an unpredictable and irregular menstrual cycle and dealing with symptoms of PCOS adversely impacted on social plans, maintaining friendships and romantic relationships, education and work attendance/performance:

> *"From the age of about 18, I started to develop male pattern hair growth on my face, which I was spending anywhere up to three hours a day trying to get rid of...I was so unbelievably self-conscious...I just had a such a fear of anyone touching [me]...it was really having an impact on my self-esteem, especially in any scenarios where you were close up or spending more than one afternoon with somebody, or if there's ever going to be a reason I'd be staying somewhere, or going camping. Things like that that I would enjoy but wouldn't necessarily have access to a torch and a magnifying mirror."* [P004]

Theme 3: Lack of post-diagnosis information and management

Issues with diagnosis delivery – time and approach

Participants reported that when they were diagnosed, appointments were too short, making them feel under pressure and unable to ask questions. There were also numerous reports that GPs/HCPs came across as blunt, dismissive or blasé when delivering the news so they did not feel taken seriously:

> "*[The doctor] said yeah and that was that was it. She didn't give me any information about what PCOS is. She didn't say what type of condition or what it means…there's kind of an awkward silence for a bit…And that's when I had to ask, what do I need to do?"* [P010]

> *"[The gynaecologist] said, it looks like you have PCOS, you're just going to have to live with this. I had been bleeding for a year at this point. It was, try to lose weight, but it's difficult to with PCOS, goodbye…It was, if you want kids have them now. It was very brutal."* [P002]

> *"They said, It's nothing to worry about, it's PCOS…It was kind of, you've got the diagnosis, go away now.""* [P006]

> *"[The specialist said] you've got polycystic ovaries, we can help you with hormones but we can't help you with the pain or any of the other symptoms…these symptoms aren't serious enough, you just have to live with it…the attitude was, well obviously this is the problem. Just being really dismissive of any of the symptoms that actually felt important to me at that time."* [P009]

Conversely, there were a couple of instances in which participants had positive experiences with diagnosis. Positive interactions involved receiving empathy and reassurance, being listened to, feeling like the GP/HCP was thorough, not being rushed and being told *"there are no silly questions"*.

Lack of quality information and resources

Due to a lack of information from GPs and HCPs, participants reported being left to do their own research. They felt that official information on the NHS website was limited, and consequently many had come across charity organisations such as Verity PCOS, however much of their detailed information was behind a paywall, which was off-putting for some. There was also misinformation spready by self-claimed 'PCOS expert' influencers on social media, who often did not have relevant qualifications, were making money through selling people 'cures' and preying on people feeling desperate for symptom relief:

> *"Every time there's something new that I can try, I get this huge sense of hope, like this is going to be the thing that will fix me. Whether that's like I've listened to a podcast and it suggested certain supplements."* [P004]

> *"If I can see that something is kind of backed up by research because, you know, there's people selling all kinds of stuff supplements, you know, 10 steps supplement routines to help balance things. I don't want to buy into this."* [P002]

Two participants mentioned being forwarded the same article in The Guardian [1] newspaper by family or friends which focused on misinformation about the condition, and in which they found out for the first time that International Guidelines for PCOS

---

[1] https://www.theguardian.com/society/2025/jun/22/i-was-diagnosed-with-pcos-and-was-soon-drowning-in-misinformation

(Teede et al, 2023) existed as well as the patient advocacy charity Verity PCOS. The lack of accessible information and misinformation led to participants feeling ill-equipped to manage their condition and significant stress, frustration and fear. Concerningly, one participant heard the word cysts and initially thought the HCP meant tumours and wondered if she had cancer, since it was not clearly explained. Another participant was told categorically that they would not be able to have children, which impacted their mental health and romantic relationships significantly for a long time, and they later found out was not true. Additionally, the lack of information caused participants to feel that the onus was on them to manage their own condition or that the GP could only provide medication, resulting in them taking matters into their own hands and looking elsewhere for support:

> *"I feel the system let me down because there was nothing…most of the information I got was researching it myself, talking to other people, social media."* [P006]
>
> *"I know it's meant to be empowering, but I feel like they don't raise it unless I raise it. It's not proactive in any kind of way…and different healthcare professionals don't talk to each other, it's up to me."* [P005]
>
> *"All the advice you get is, you know, just eat less and move more. And actually, my body doesn't work in that same way, that's not how I'm structured. So, it just feels like a frustrating waste of time. And I think that does lead people to kind of give up on the NHS when it comes to resources and stuff because you're just not given the right information."* [P002]
>
> *"Once we realised that hormonal contraception wasn't something I could take, I was like, I don't think I can get any more help from the doctors now, I'll just have to take it into my own hands."* [P001]

Lack of clarity from HCPs regarding management

For those participants who did receive information regarding lifestyle changes, this was often basic, *"one size fits all"* advice, with little to no direction about how to achieve it within the constraints of the condition:

> "[*The doctor] did also say at the end, The best thing you can do is lose weight. And I was like, well, how am I supposed to do that?"* [P010]
>
> *"They said, You have polycystic ovaries, you need to lose 2 stone and it's going to be very hard for you."* [P001]

Such experiences exacerbated illness burden and also further impacted on widening health inequalities, whereby those who could afford to often sought private healthcare, which was not accessible to everyone. Participants reported seeking help from private clinical specialists, but also working with online pharmacies, nutritionists, personal trainers, mental health professionals, life and wellbeing coaches, women's and hormone health providers and acupuncturists. Often, these people were reportedly more helpful than GPs as they were able to provide more specific information, suggestions on what to eat and how to exercise, and had a non-judgemental approach. However, they required financial investment:

> *"We were lucky because my dad had a bit of health insurance that I could use...which I know is a really privileged thing to be able to do...I'd say the most recent hormone specialist I went to has been the most helpful. But I was having to pay for all those appointments. It was an expensive thing. And that just isn't possible for everyone."* [P007]

> *"My trainer recommended taking Vitamin D and Omega 3...it's a shame that the one I started with was quite expensive. It was £30 a month for just one month supply. So I had to switch to a cheaper brand."* [P011]

Other participants sought support by attending health seminars, which they felt contained varying degrees of useful information and usually carried a cost. Others had accessed Facebook groups, but experiences were mixed: some found them supportive, whereas others found them a negative space where people vented frustration, distress, and anger.

Some participants reported being referred to an NHS weight management education programme where a number of challenges were apparent, including it being scheduled during the day (therefore eliminating those who worked full-time and did not have flexibility), not being PCOS-specific, being aimed at the elderly age group, being patronising and covering information that was too basic.

Reliance on medication to control symptoms

In terms of management, most participants were only prescribed medication including Metformin, the contraceptive pill or coil, usually without explanation of why, and felt that this was a *"sticking plaster"* to alleviate symptoms rather than addressing any underlying issues. Such experiences led to a general distrust of GPs and medications often made symptoms worse, were felt to be prescribed from too young an age further delayed diagnosis of PCOS:

> *"I didn't know what my normal looked like as I'd always been pumped full of hormones."* [P008]

> *"I spent a lot of energy 'putting out fires' [with different PCOS symptoms] for years."* [P011]

Gatekeeping of referrals

Participants reported a lack of appropriate referrals to specialists for those struggling to manage PCOS symptoms. When individuals were able to obtain a referral they often experienced significant waiting times, and also reported other challenges, including being referred to gynaecologists, which was not always sufficient as endocrinologists play an important role supporting PCOS, and also feeling dismissed by specialists, unless they were trying to conceive:

> *"[The gynaecologist] said, Well you're not overweight so what is the problem? He said to come back if I wanted to get pregnant and couldn't, but they wouldn't do anything in the meantime...Because there aren't PCOS specialists, you have to take a punt at what sort of specialist to see. I'm sure if I saw an endocrinologist at that point, the advice would have been very different."* [P007]

Theme 4: Support needs of individuals living with PCOS

Improved awareness, education and training

When participants were asked what support they would have liked when diagnosed with PCOS, one of the most common responses was improving the healthcare workforce and public knowledge and awareness about what PCOS is, how to diagnose it and the impact of symptoms, requiring further training and investment.

> *"I'd like there to be more understanding in GP practices that PCOS is not just you have cysts on your ovaries and it may affect your fertility. It's way more complicated than that and it's much more to do with hormones, not just a gynaecological issue."* [P012]

Many participants felt that improved knowledge of HCPs would result in better care and support. Specific suggestions about the type of knowledge that is required included:

- What PCOS is and its impacts on the body, including insulin resistance
- Nutrition guidance, e.g. suggestions for optimal food/nutrients, recipes
- Specific and targeted physical activity suggestions, e.g. the benefits of strength training versus cardio
- How to treat and manage PCOS holistically
- Clarity about the long-term potential consequences of PCOS, e.g. type 2 diabetes
- Recognition that PCOS impacts an individual's whole life – physically, mentally socially, etc.
- A summary of treatment/approaches are most effective for all the different symptoms of PCOS
- Limitations of treatments, e.g. some laser hair removal is temporary

Additionally, improved knowledge of individuals being diagnosed and their friends, family and supporters was deemed to be valuable by participants. It was suggested that improved knowledge and health literacy result in people being less critical and self-blaming as a result of the symptoms and challenges they experienced.

A multidisciplinary approach to care

It was felt that there was a lack of joined up, multidisciplinary working in relation to treating and managing PCOS. For example, there were instances where advice from GPs and other HCPs was contradictory, such as one participant being put on a lot of medication by a specialist, which their GP refused to continue to prescribe as they felt it was too much. Participants commented on the fragmented approach to care for PCOS:

> *"There's a lot of issues when it comes to women's health in the NHS and, you know, how overlooked and disregarded our experiences are. And I think particularly with something like this, where it affects so many different aspects of your body, it affects your hormones, it affects you physically, your weight and everything...I don't know if GPs need more training or the gynaecologist, or if they could work together better to just say okay this is what we know about this condition, this could help this kind of underlying symptom. Just a little bit more investment in it, I guess, and knowledge about how it presents itself and the ways that the symptoms*

> *can be lessened before it gets to a stage where we have women in their 30s with diabetes and huge weight problems."* [P002]
>
> *"There was no-one connecting the dots."* [P007]

It was felt that the introduction of specialist services with dedicated professionals for PCOS would ensure a holistic approach, continuity of care and consistent communication.

More support for mental health

Another key area in which it was felt there should be more support was mental health and wellbeing. It was clear that PCOS did not happen in isolation and was often linked to challenges including anxiety, depression and eating disorders. Participants who had received mental health support found it very valuable in learning to accept their diagnosis, having their experiences validated, learning coping skills, practicing self-kindness and navigating care pathways and challenges:

> *"I've tried two different antidepressants...it kind of just feels like a crutch more than anything. It's sort of like something to lean on...I then was put on the waiting list for NHS talking therapy, and the wait list was like 2 years so in the end I went to a private therapist, because of how I was feeling so often and how you can't really predict it, but then you could just not want to leave the house, that sort of thing...talking to the therapist, some of that was really helpful, but it's so expensive...It was really helpful at understanding, kind of, which bits were my fault, with the answer being not really any of it a lot of the time. But knowing how to kind of cope, so I would be pushing myself all the time to do stuff that I really didn't want to do. I learned to kind of accept myself in terms of my limitations"* [P004]

In terms of care pathways, alongside mental health screening at the point of diagnosis, it was suggested that people with PCOS should be offered regular check-ups and blood tests, as is the case for other long-term conditions such as diabetes and asthma. Such improvements to care pathways would in turn help alleviate mental and emotional challenges:

> *"There is no plan. I feel like when you're diagnosed with a lifelong condition, there is usually a plan. I have asthma as well and I have an asthma plan. It seems really weird given how destructive PCOS is with your health and how many serious things are associated with it."* [P010]

Enhanced support systems

Many participants expressed the need for better support systems, including an empathetic, sensitive and person-centred approach from GPs and other HCPs. Many also expressed a desire for in person or online peer support, to meet others who are experiencing similar issues, share experiences, put things into perspective and receive advice:

> *"I think everyone seeks [a support group], don't they? Just even, you know, I mentioned like the mentoring earlier and I don't necessarily mean a mentor that can answer my questions because I'm not sure a lot of them will know answers. I*

> *don't even know if there's answers to some of them, but just someone else that's experiencing it, I suppose, would be really useful."* [P005]
>
> *"If I had seen other, older, people living with [PCOS], with kids, I wouldn't have been so scared and would have felt more reassured."* [P007]
>
> *"When I was first diagnosed, I felt like I was the only one and it was going to make my life so much harder…with the friends I have made who have it, I feel lucky as I am aware that I have it the least bad in terms of physical symptoms."* [P012]

Most participants felt they were high functioning despite their ongoing PCOS symptoms, and many worked full-time. Therefore, there were suggestions that peer support needs to take place outside of working hours, or that work places should better enable their attendance, since many experienced stigma about taking time off *"for a bad period"*.

Conclusion

The scoping review and interviews carried out for the purpose of this study highlight themes around delays in diagnosis, dissatisfaction in relation to the knowledge and communication of GPs and other HCPs, and mental distress experienced as a result. Following diagnosis, there was a reported lack of clarity around how to manage PCOS, with participants often receiving 'blanket advice', which further exacerbated illness burden and caused them to feel unheard. There was also felt to be an over reliance of HCPs on medication to alleviate symptoms, with less advice around lifestyle behaviours, and a perceived gatekeeping of referrals to specialists in secondary care. Positive experiences of diagnosis and treatment included experiencing compassion and empathy, feeling listened to and a person-centred and individualised approach.

Individual experiences align with the biopsychosocial model of health, highlighting the interlinked impact of PCOS on the individual's physical health, mental health and wellbeing and social health, including relationships, work and education.

Numerous support needs were uncovered for those diagnosed with or seeking a diagnosis of PCOS, including mental health screening and support, increased knowledge and awareness (of GPs/HCPs and the wider public) to improve health literacy, a multidisciplinary approach to care, referrals to specialists, the provision of evidence-based information resources to those living with the condition and effective peer support.

GPs and other HCPs have significant potential to improve the experiences of PCOS diagnosis which could improve patient satisfaction, in addition to the value of accessible information resource and peer support. These findings are important for informing future healthcare practice in PCOS.

Recommendations

The findings of this study highlight the challenges in relation to diagnosis of PCOS and ongoing support and management. The below recommendations are suggested key priorities to inform future research, practice, policy and care.

1. **Provision of evidence-based PCOS resources**
   Accessible information resources for those living with PCOS and their supporters are imperative to support early diagnosis and ongoing management. Resources should be evidence-based, align with best practice guidelines and cover all associated symptoms of PCOS, not just fertility and weight, to ensure the needs of those living with the condition are met

2. **Improved care pathways and support systems for those living with PCOS**
   Support for those living with the condition could be provided in a variety of ways:
   - Commissioned clinical support, e.g. PCOS specialists linked to Women's Health Hubs who can provide holistic and tailored care
   - Offering those living with the condition regular health checks that include blood tests for early detection of related issues
   - Provision of education programmes (such as those for type 2 diabetes)
   - Mental health support that incorporates relevant approaches, addresses emotional health and improves coping skills
   - Effective peer support, e.g. in-person/online groups facilitated by those with relevant knowledge and skills
   - Accessible support in the community sector. Currently, patient advocacy charity Verity PCOS[2] provides support for those living with PCOS nationally, however they have no government funding so rely on grants and donations, meaning they have to charge for information leaflets. The PCOS Awareness Association[3] (in the USA) provides a similar model of support, which includes free resources and an annual patient conference. Coeliac UK[4] has a model whereby members pay a very minimal annual fee which helps fund support and research, and could be a viable model to consider

3. **Enhanced education and awareness of PCOS**
   Education of allied health and social care professionals should include PCOS, from undergraduate to CPD. Similarly, better awareness is needed across the wider population, including education in schools and on social media, to address misinformation. Education and awareness should include a definition of PCOS and all potential associated symptoms, including currently lesser known issues (such as insulin resistance, psychological symptoms, inflammation, impact of stress, PCOS sub-types, lean PCOS, etc.) and should include outreach and inclusion of diverse communities and those impacted most by health inequalities

---

[2] https://www.verity-pcos.org.uk/

[3] https://www.pcosaa.org/

[4] https://www.coeliac.org.uk/

References

Adshead, C., Sheffield, D., Fido, D., Lagojda, L., Kyrou, I., Randeva, H.S., Williams, S. and Kite, C. (2026) Psychological Interventions for Women with Polycystic Ovary Syndrome (PCOS): A Systematic Review and Meta-Analysis of Randomised and Non-Randomised Controlled Trials. *Psychology International*, *8*(1), 15.

APPG PCOS (2025) *Breaking the Cycle: Addressing Systemic Failures in PCOS Diagnosis and Management. A Report by the All-Party Parliamentary Group on Polycystic Ovary Syndrome (PCOS)*. Available at: https://www.pcosappg.co.uk/2025-report-breaking-the-cycle (Accessed: 18 March 2026).

Arksey, H. & O'Malley, L. (2005) Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology*, *8*(1), 19–32.

Cary, M., Khunti, K. and Davies, M. (2018) Structured education in diabetes: A review of the evidence. *Diabetes & Primary Care*, 14(3), 154-162.

Cleghorn, E. (2021) Unwell Women: A Journey Through Medicine and Myth in a Man-Made World. London: Weidenfield and Nicolson.

DHSC (2022) *Women's Health Strategy for England*. London: Department of Health and Social Care. Available at: https://www.gov.uk/government/publications/womens-health-strategy-for-england/womens-health-strategy-for-england (Accessed: 18 March 2026).

Engel, G. L. (1977) The need for a new medical model: A challenge for biomedicine. *Science*, 196(4286), 129–136.

Havelka, M., Lucanin, J.D. and Lucanin, D. (2009) Biopsychosocial model – the integrated approach to health and disease. *Collegium Antropologicum*, 33(1), 303-310.

JLA (2025) Polycystic Ovary Syndrome: Top 10 priorities. Available at : https://www.jla.nihr.ac.uk/priority-setting-partnerships/polycystic-ovary-syndrome#tab-top-10-priorities (Accessed: 18 March 2026).

Ghafari, A., Maftoohi, M., Samarin, M.E., Barani, S., Banimohammad, M. and Samie, R. (2025) The last update on polycystic ovary syndrome (PCOS), diagnosis criteria, and novel treatment. *Endocrine and Metabolic Science*, 17.

Gibson-Helm, M., Teede, H., Dunaif, A. and Dokras, A. (2017) Delayed Diagnosis and a Lack of Information Associated With Dissatisfaction in Women With Polycystic Ovary Syndrome. *The Journal of Clinical Endocrinology & Metabolism*, 102(2), 604-612.

Gorham, B. and Langham, O. (2024) *Women's health economics: investing in the 51 per cent*. London: NHS Confederation.

Hillman, S., Bryce, C., Caleyachetty, R. and Dale, J. (2020) Women's experiences of diagnosis and management of polycystic ovary syndrome: a mixed-methods study in general practice. *British Journal of General Practice*, e322-e329.

House of Commons (2026) Women and Equalities Committee: Menstrual health of girls and young women. London: House of Commons. Available at: https://committees.parliament.uk/publications/51887/documents/287889/default/ (Accessed: 18 March 2026).

Ismayilova, M. & Yaya, S. (2022) “I felt like she didn’t take me seriously”: a multi-methods study examining patient satisfaction and experiences with polycystic ovary syndrome (PCOS) in Canada. *BMC Women's Health*, 22(47).

Lau, G.M., Elghobashy, M., Thanki, M., Ibegbulam, S., Latthe, P., Gillett, C.D.T., O'Reilly, M.W., Arlt, W., Lindenmeyer, A., Kempegowda, P. and PCOS SEva Working Group (2022) A systematic review of lived experiences of people with polycystic ovary syndrome highlights the need for holistic care and co-creation of educational resources. *Frontiers in Endocrinology*.

Mani, H., Chudasama, Y., Hadjiconstantinou, M., Bodicoat, D.H., Edwardson, C., Levy, M.J., Gray, L.J., Barnett, J., Daly, H., Howlett, T.A., Khunti, K. and Davies, M.J. (2018) Structured education programme for women with polycystic ovary syndrome: a randomised controlled trial. *Endocrine Connections*, 7(1), 26-35.

NICE (2026) Polycystic ovary syndrome: assessment and management. Available at : https://www.nice.org.uk/guidance/indevelopment/gid-ng10436 (Accessed: 18 March m2026).

Ogden, J. & Bridge, L. (2022) How communicating a diagnosis of polycystic ovarian syndrome (PCOS) impacts wellbeing: a retrospective community survey. *BJGP Open*, 6(3).

Peña, A.S., Teede, H., Hewawasam, E., Hull, M.L. and Gibson-Helm, M. (2022) Diagnosis experiences of adolescents with polycystic ovary syndrome: cross-sectional study. *Clinical Endocrinology,* 96, 62-69.

Percy, C., Turner, A., Aphramor, L., Broom, D., Clark, C., Martin, F. and Wark, P. (2024) A Feasibility Trial Of A Co-created Digital Self-management Programme For Adults With Polycystic Ovary Syndrome (Hope PCOS). [Poster]. The Annual Conference of The Endocrine Society, 1-4 June 2024, Boston, United States.

Presswala, B. & De Souza, L.R. (2023) The diagnostic experience of polycystic ovary syndrome: A scoping review of patient perspectives. *Patient Education and Counseling*, 113.

Ritchie, J. and Spencer, L. (2004) Qualitative data analysis for applied policy research. In Bryman A. and Burgess R.G. (eds.) Analyzing Qualitative Data. London: Routledge.

Sharma, S. & Mahajan, N. (2021) Polycystic Ovarian Syndrome and Menopause in Forty Plus Women. *Journal of Mid-Life Health*, 12(1), 3-7.

Shukla, A., Rasquin, L.I. and Anastasopoulou, C. (2025) *Polycystic Ovarian Syndrome*. Treasure Island (FL): StatPearls Publishing.

Soucie, K., Samardzic, T., Schramer, K., Ly, C. and Katzman, R. (2021) The Diagnostic Experiences of Women With Polycystic Ovary Syndrome (PCOS) in Ontario, Canada. *Qualitative Health Research*, 31(3), 523-534.

Teede, H., Tay, C. T., Laven, J., Dokras, A., Moran, L., Piltonen, T., Costello, M., Boivin, J., Redman, L., and Boyle, J. (2023) *International Evidence-based Guideline for the assessment and management of polycystic ovary syndrome*. Australia: Monash University.

WHO (2023) Polycystic ovary syndrome: Key facts. Available at: https://www.who.int/news-room/fact-sheets/detail/polycystic-ovary-syndrome (Accessed: 13 February 2026).