


# Bridging the Information Gap in Polycystic Ovary Syndrome: A Narrative Review with Systematic Approach

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## Abstract

Polycystic ovary syndrome (PCOS) is a complex endocrinopathy with wide-ranging implications for affected individuals. Literature has shown that patients with PCOS are dissatisfied with the health information provided to them and that healthcare professionals lack adequate knowledge. In this narrative review with systematic approach, we explored the unmet information needs in PCOS care for both patients and healthcare professionals. A comprehensive search of databases yielded 41 relevant studies, predominantly of observational and qualitative design. Adults and adolescents with PCOS desire wide ranging health information and express a keen desire for weight management guidance. Importantly, discussions surrounding weight should be addressed knowledgeable and without weight bias. Therefore, healthcare professionals should facilitate access to comprehensive evidence-based resources. Lack of information drives PCOS-related online searches. Referral to support groups that promote individual agency in the self-management aspects of PCOS can furthermore guide patient resource acquisition. Patients prefer guidance from professionals that understand the psychosocial complexity of PCOS and can empathize with experiences of stigmatization or even marginalization depending on the cultural context of the individual. The findings informed the 2023 International Evidence-Based PCOS Guideline, recommending patient-centered communication, evidence-based information resources, and culturally sensitive approaches to optimize PCOS care.

## Keywords

- ▶ polycystic ovary syndrome
- ▶ information needs
- ▶ healthcare professionals
- ▶ patient-centered communication

Polycystic ovary syndrome (PCOS) is the most common endocrinopathy affecting females of reproductive age, with an estimated prevalence of 12%.<sup>1</sup> The current PCOS diagnostic criteria from the International Evidence-Based PCOS Guideline have evolved from the Rotterdam criteria.<sup>2</sup> For diagnosis in adults, two or more of the following three

features indicate PCOS after exclusion of other causes: clinical or biochemical hyperandrogenism, ovulatory dysfunction, and ultrasonographic evidence of polycystic ovary morphology.<sup>2,3</sup> Adolescent diagnosis necessitates both hyperandrogenism and ovulatory distinction, but cannot rely on imaging evidence of characteristic polycystic ovarian

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morphology due to similarly appearing ovarian features that are physiologic at this life stage.<sup>2</sup> In addition to hyperandrogenism, insulin resistance is a key endocrine feature that contributes to the cardiometabolic manifestations of PCOS. Beyond reproductive and cardiometabolic complications, PCOS is also linked to psychological comorbidities.<sup>4</sup> The heterogeneous nature of PCOS therefore benefits from long-term and multidisciplinary management, incorporating lifestyle changes, medical intervention, and psychosocial support.<sup>5</sup>

Due to the complex etiology and wide-reaching health impacts of PCOS, providing clear and comprehensive information to patients is paramount. Inadequate education of patients regarding their condition has been shown to result in feelings of frustration, confusion, lack of control,<sup>6</sup> and dissatisfaction with the healthcare professional.<sup>7</sup> Yet, international research has shown that only 15% of individuals with PCOS were satisfied with the information about PCOS provided to them at the time of diagnosis. Satisfactory information provision was experienced by only 12% of patients for lifestyle management, 17% for medical management, 8% for long-term complications, and 3% for emotional support and counseling.<sup>7</sup> On the other hand, many healthcare professionals lack adequate knowledge of PCOS,<sup>8–10</sup> leading to potential misdiagnosis, delayed treatment, and suboptimal management of the condition.<sup>7</sup> International research among physicians and allied health professionals has demonstrated variable knowledge about diagnostic criteria, recommended management strategies, and potential comorbidities, with psychological implications of PCOS being poorly recognized.<sup>8–10</sup> Moreover, a lack of standardized training programs for healthcare professionals has resulted in inconsistent care.<sup>11</sup>

The importance of adequate patient education was recognized by the first International Evidence-Based Guideline for the Assessment and Management of PCOS in 2018.<sup>5</sup> Here, it was recommended that information delivery be person-centered, empathetic, culturally appropriate, and inclusive of biopsychosocial dimensions.<sup>5</sup> With the 2023 update of the guideline, the information, resources, and education needs of patients and healthcare providers have again been identified by key stakeholders as a priority area.<sup>2</sup> As such, this narrative review with a systematic approach aims to establish where PCOS information requirements of patients and healthcare professionals remain unmet. It also seeks to provide expansion into the information needs of culturally and linguistically diverse (CALD) groups and adolescents. The findings of this review directly informed the updated 2023 International Evidence-Based Guideline and translation tools to better support individuals with PCOS and healthcare professionals.

## Methods

This narrative review with a systematic approach was conducted by adhering to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Statement checklist where applicable.<sup>12</sup>

## Information Sources and Search Strategy

The databases Medline (Ovid), PsychInfo (Ovid), All EBM (Ovid), EMBASE, and CINAHL were searched from 1990 until September 13, 2022. The search criteria included key terms and synonyms related to PCOS, patients, healthcare providers, information sources, etc., combined using Boolean operators. The search was limited to human studies published in English. The detailed search strategy is provided in **►Supplementary Table S1**.

## Eligibility Criteria

Detailed inclusion and exclusion criteria were developed based on the Participant, Intervention, Comparison, Outcome, and Study Type (PICOS) framework, by the evidence team members (C.T.T., A.M.) and a clinical expert from the 2023 PCOS Guideline Development Group (T.S.B.) (**►Supplementary Table S2**). Participants were females with PCOS by any definition (including clinician-diagnosed or self-reported) and healthcare professionals who identified as working with individuals with PCOS. Studies were included if they reported the provision of PCOS information and an outcome of information and resource needs, knowledge gaps, or satisfaction levels. All published quantitative observational studies, systematic reviews, and evidence-based guidelines, as well as qualitative studies were included. Interventional studies, non-evidence-based guidelines, conference abstracts, study protocols, and clinical trial registrations were excluded.

## Screening and Study Selection

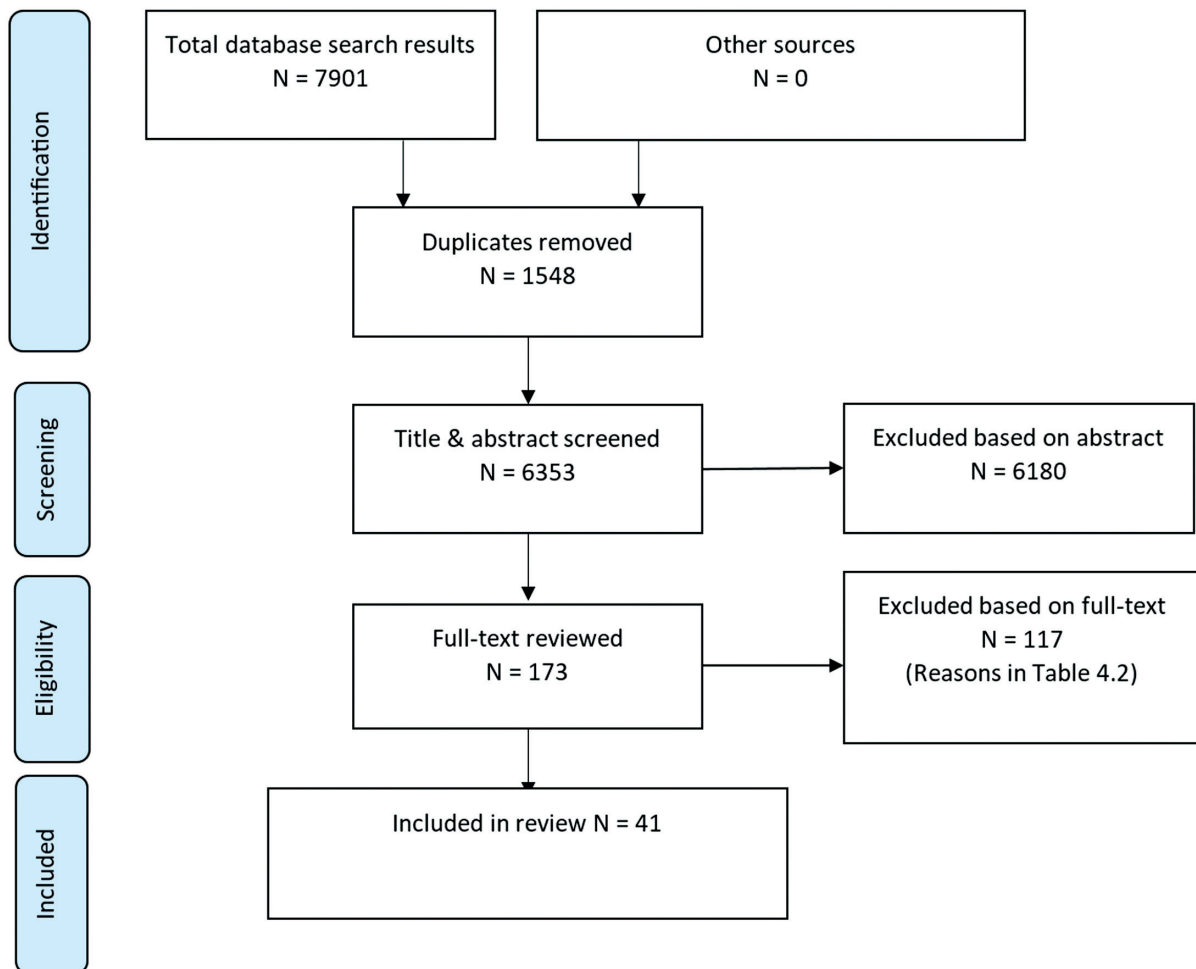
Following the removal of duplicates, articles were imported into Covidence and screened by title and abstract, followed by full-text by a single reviewer (C.T.T.). Articles were included in this review if deemed eligible against the inclusion and exclusion criteria set a priori.

## Quality Appraisal

A critical appraisal was performed by a single researcher (C.T.T.) on all selected studies to assess the risk of bias (RoB). Quantitative studies were appraised using the Monash Centre for Health Research and Implementation (MCHRI) Evidence Synthesis Program Critical Appraisal Tool. This tool gives an overall ranking of low, moderate, or high RoB based on seven domains: selection bias, performance bias, detection bias, attrition bias, report bias, confounding, and other bias.<sup>13</sup> Qualitative and mixed method studies were evaluated using the Critical Appraisal Skills Program (CASP) Qualitative Checklist. This used criteria related to the validity, ethical consideration, rigor, clarity, and local research value of the results, to provide an overall RoB of low, moderate, or high.<sup>14</sup>

## Results

The PRISMA diagram in **►Fig. 1** provides an overview of the search results. The database searches resulted in a total of 6,353 articles after removal of duplication. After screening of titles and abstracts, 173 articles remained for full-text



**Fig. 1** PRISMA flowchart.

review. Finally, 41 articles were included in this review. Of these, 25 addressed information needs in individuals with PCOS, while 14 investigated information needs of healthcare professionals.

Of the 25 included studies addressing information needs of individuals with PCOS, six were cross-sectional studies, another six employed mix-methods design, and the remaining were pure qualitative studies. Majority of the studies exhibited low RoB ( $n = 18$ ), while four studies were ranked as moderate and three studies were ranked as high RoB. Fourteen cross-sectional studies and two qualitative studies investigated the information needs of healthcare professionals. Except for one study which was ranked at high RoB, the rest were ranked as low ( $n = 10$ ) to moderate ( $n = 5$ ) (– **Supplementary Tables S3 and S4**).

### Information Needs in Individuals with PCOS

PCOS is a chronic disease characterized by varied expression from adolescence to post-menopause and therefore tailored informational needs are greatest at the time of diagnosis. Prior to the publication of the 2018 International Evidence-Based PCOS Guideline, an Australian community-based

questionnaire study of 210 participants with PCOS reported that 60% did not receive or were not referred to educational resources for PCOS. Of the 40% that did receive education regarding PCOS, 20% felt that the information was inadequate.<sup>15</sup> Three years later, the authors expanded their online PCOS questionnaire study across Europe and the United States ( $n = 1,385$ ), finding that one-third of participants had a lag time of more than 2 years to diagnosis and nearly half consulted three or more healthcare professionals prior to the establishment of their PCOS diagnosis.<sup>7</sup> The study furthermore reported that most participants (84%) expressed dissatisfaction with the PCOS-related health information received from their healthcare professionals.<sup>7</sup> Specifically, this study and others found that healthcare professional communication lacked recommendations for lifestyle modifications/weight management,<sup>7,16</sup> discussion of long-term complications, extension of emotional support/counseling,<sup>17</sup> and empathy.<sup>18</sup> Indeed, providing comprehensive information in an empathetic, emotionally supportive clinical environment may benefit quality of life in PCOS<sup>19</sup> and satisfy the frequently expressed desire for agency in the self-management of health issues related to PCOS.<sup>6</sup>

### Current Communication Needs in Individuals with PCOS

Due to the lack of comprehensive PCOS information at the time of diagnosis, those affected often search online to enhance understanding. In a Google trends analysis, the frequency of PCOS-related online searches was higher than web interrogations for fibroids, even though fibroids are an equally prevalent gynecological condition.<sup>11</sup> Overall, online searches as well as communication with online PCOS support groups has shown to empower patient self-advocacy and enhance the effectiveness of healthcare visits by allowing for more targeted questions and informed decision-making.<sup>20,21</sup> A survey from Australia also found that a comprehensive question prompt list, if readily available (online or in an App), can further serve as a useful tool to enhance communication with healthcare professionals.<sup>22</sup> Joining online discussion forums and sharing experiences also seem to reduce the psychological burden of PCOS.<sup>23</sup> However, in a recent U.S. survey study ( $n = 759$ ), only 19% of survey respondents had joined a support group after PCOS diagnosis, while 98% reported conducting online searches about PCOS.<sup>11</sup> This study further highlighted that many patients in the United States (57%) continue to be mostly dissatisfied with their PCOS care.<sup>11</sup> Still, the increased engagement with online and virtual chat rooms has broadened opportunities for conducting qualitative studies via communication platforms such as Skype. In a small Skype audio semistructured interview study ( $n = 9$ ) from Great Britain, participants appeared more comfortable communicating from their home environment.<sup>24</sup> While several common themes emerged from this interview study, participants also spoke about how PCOS impacted their sense of identity as a woman and challenged their perception of themselves. Over 50% of participants furthermore opened up about suicide-ideation and self-harm during their interview.<sup>24</sup> A recent Australian focus group and semistructured interview study, similarly, echoed loss of feminine identity as a concern.<sup>25</sup> However, the most fundamental dissatisfaction that united this group of participants with excess body weight was the lack of specific weight management recommendations offered by their healthcare professional.<sup>25</sup>

A recent, post-2018 International PCOS Guideline survey and semistructured interview from the United Kingdom of 323 participants noted that lag time to diagnosis of PCOS was only 6 to 12 months<sup>26</sup> as opposed to previous reports of more than 2 years.<sup>7</sup> However, despite the 2018 International PCOS Guideline recommendations, patients continue to miss comprehensive discussion of comorbidities,<sup>26</sup> weight loss recommendations,<sup>23,26</sup> and enquiry about their mental health.<sup>23,26</sup> In a semistructured interview study from Canada, patients felt PCOS to be stigmatizing, as weight gain, acne, and hirsutism were highly visible, undesirable attributes that separated them from the female ideal of today's society.<sup>27</sup> Furthermore, a lack of empathy and weight bias from health professionals seemed to enhance the feeling of stigmatization of patients in this study.<sup>28</sup> A recent study out of India looking at PCOS treatment seeking pathways in newly diagnosed patients observed that recurrent lack of

clear treatment explanations led to 51% of patients consulting two to three healthcare agencies for treatment recommendations.<sup>29</sup> Even though similar treatment plans were provided at each consultation, a lack of insight into the PCOS-specific medical decision-making left patients unable to accept treatment recommendations.

While the 2018 International PCOS Guideline proposed lifestyle management as first-line treatment for PCOS, specific implementation models still need to be explored. A recent online PCOS survey study out of Australia reported that 95% of those surveyed would attend a lifestyle program if affordable, long-term, and offering PCOS-specific recommendations.<sup>30</sup> A subset of study participants who underwent structured interviews perceived PCOS comorbidities such as anxiety, depression, disordered eating, and poor body image as an impediment to successful lifestyle management and emphasized that addressing barriers to behavior change may greatly enhance effectiveness of PCOS lifestyle counseling.<sup>31</sup>

### Specific Concerns in Adolescents and Culturally Diverse Groups with PCOS

In earlier studies, adolescents often voiced that infertility concerns clouded their life plan. Specifically, adolescents with PCOS were less sexually active and more worried about their ability to conceive later in life than their peers.<sup>32</sup> In a 2011 qualitative study of young adults (age 18–23 years old), worries about future fertility were “ever present.”<sup>33</sup> However, a more recent small qualitative U.S. study from 2019<sup>34</sup> and a larger survey study out of Australia and the United Kingdom<sup>35</sup> from 2022 demonstrated a shift in adolescent priority concern away from worries about looming infertility to more immediate concerns of weight management, menstrual control, and hirsutism/acne treatment. The latter study furthermore reported that time to diagnosis had shortened to < 1 year for most adolescents.<sup>35</sup> While adolescents were overall pleased with their diagnostic experience, they remained dissatisfied with the information received on lifestyle/weight management, psychological aspects of PCOS, and long-term complications—although this varied by expertise and location/setting of care.<sup>35</sup> Another 2022 cross-sectional report examined the diversity of gender identity among adolescents attending a comprehensive multispecialty adolescent PCOS program.<sup>36</sup> During psychosocial assessment, teens that met diagnostic PCOS criteria were more likely to report their gender identity as diverse (trans, fluid, or non-binary) than those that did not meet the PCOS criteria for adolescents. Among those diagnosed with PCOS, gender diversity was associated with higher hirsutism scores but not biochemical hyperandrogenism, suggesting that gender diverse teens might more likely embrace manifestations of hirsutism and choose to forgo common cosmetic treatments. Therefore, the authors concluded that the cultural context in which PCOS is experienced should inform the clinician's approach to care.<sup>36</sup>

An Australian study evaluating health services for Indigenous Aboriginal and Torres Strait Islanders with PCOS noted that group rather than individual consultations were

sometimes preferred.<sup>37</sup> Barriers to accessible and culturally appropriate information provision were identified, such as information not matched to health literacy and unavailability of female physicians. Tribal attitudes, values, and traditions also shaped the impact of PCOS on American Indians in a recent qualitative study ( $n = 13$ ).<sup>38</sup> In this study, lack of predictable menstrual cycles led to abstaining from certain tribal ceremonies, enhancing the sense of social marginalization within the tribe. Interviewees further expressed a loss of feminine identity and status within the tribe, where fertility and procreation are greatly valued.<sup>38</sup> This sense of inadequacy was enhanced by the lack of access to fertility services in the rural contexts of tribal life. Medical care additionally was frequently not sought due to tribal culture of fatalistic acceptance in the setting of little or no PCOS awareness within the community.<sup>38</sup> Like the Aboriginal and Torres Strait Islanders in Australia, American Indians often preferred to include friends and family when diagnostic and treatment information was provided so that they could garner support within the tribe.<sup>38</sup>

### Healthcare Professional Knowledge of PCOS and Professional Practice Patterns

#### Diagnostic Parameters

In 2013, a worldwide survey of in vitro fertility clinics in the United States, South America, Australia, Asia, Europe, and Africa reported that the majority of the clinics (82%) cited the Rotterdam criteria as their PCOS diagnostic tool of choice.<sup>39</sup> Even though the presence of androgen excess is not essential for diagnosing PCOS, 37% of survey responders reported that androgen excess was a prerequisite, pointing to educational opportunities in the application of the Rotterdam criteria.<sup>39</sup> A more recent survey of physicians from North America found that 68% of reproductive endocrinologists and less than half (41%) of general obstetrician–gynecologists knew to apply Rotterdam criteria for diagnosing PCOS.<sup>40</sup> In 2019, a nationwide survey out of China analyzed 2,328 responses from obstetrician–gynecologists (94.5%) and reproductive endocrinologists (5.5%). The study found that despite the 2018 International PCOS Guideline diagnostic criteria, the Androgen Excess and PCOS society (AE-PCOS) criteria were most frequently applied.<sup>41</sup> In this survey, reproductive endocrinologists were less likely to use AE-PCOS criteria and more accurately applied 2018 International PCOS Guideline criteria.<sup>41</sup> Interestingly, a 2020 qualitative study on clinician perspective in Australia demonstrated physicians' concern about the diagnostic accuracy of the 2018 International PCOS Guideline recommendations and the risk for overdiagnosis of PCOS.<sup>42</sup> In a U.S.-based study of obstetrician–gynecologists in training (residents), most (85%) knew that the current guideline for diagnosing PCOS endorses the Rotterdam criteria for adults.<sup>10</sup> However, only 55% correctly identified at least one of the three main diagnostic criteria.

#### Treatment Patterns

According to a survey study from North America, reproductive endocrinologists were more likely to prescribe lifestyle

modification for both fertility and non-fertility-related concerns than general obstetrician–gynecologists.<sup>40</sup> In a similar study examining PCOS-related practice patterns in Nordic countries and Estonia, endocrinologists were more likely to prescribe lifestyle modifications and metformin for patients without fertility concerns compared with obstetrician–gynecologists and older physicians.<sup>9</sup> In a survey analysis regarding PCOS diagnosis, screening, and treatment among varying specialties in India, combined oral contraceptive pills were more commonly prescribed by endocrinologists and gynecologists, whereas metabolic complications were more likely screened for by endocrinologists and general physicians.<sup>43</sup>

#### Comorbidities and Practice

Aligning with patients' experience, surveys of health professionals in Europe/Asia and North America<sup>8</sup> and Nordic European countries<sup>9</sup> confirmed that physician awareness of psychosocial morbidities associated with PCOS is low, while cognizance of insulin resistance and type 2 diabetes is generally high.<sup>8,9,44</sup> A recent study out of India also compared PCOS-related diagnostic and screening practice patterns among different physician specialists.<sup>43</sup> Notably, in this study, depression screening was most often performed by pediatricians when seeing adolescents with PCOS,<sup>43</sup> while laboratory examination to exclude a diagnosis of non-classical–congenital adrenal hyperplasia was rarely performed in any of the compared specialties.

In a small survey study out of Saudi Arabia, endocrinologists reported greater reliance on hyperandrogenism and gynecologists more frequently used ultrasound in application of the Rotterdam criteria.<sup>45</sup> A large physician survey ( $n = 1,318$ ) out of China examined the implementation of metabolic screening recommendations from the 2018 International PCOS Guideline in general obstetrician–gynecologists (85.8%) and reproductive endocrinologists (14.2%).<sup>46</sup> Despite their low representation in this sample, reproductive endocrinologists were significantly more likely to order oral glucose tolerance test and lipid testing and prescribe metformin in patients with fertility demands.<sup>46</sup> A smaller and 2012 survey study out of Germany also noted metabolic screening in PCOS was more commonly performed by reproductive endocrinologists than general obstetrician–gynecologists.<sup>47</sup> A recent qualitative study on physicians' attitude toward PCOS diagnosis and management reported that physicians in Australia were generally very aware of metabolic, cardiovascular, and reproductive risks. In this study, dispelling misconceptions about the risk of infertility was very important to the physicians surveyed.<sup>42</sup>

#### Allied Health Professionals

While around 95% of physicians surveyed in the United States and Europe are aware of type 2 diabetes risk with PCOS,<sup>9,40</sup> examination of rural nurse practitioners in the United States observed that only ~40% of the nurse practitioners recognized PCOS as a risk factor for type 2 diabetes mellitus.<sup>48</sup> Given their common clinical setting in family practice, internal medicine, and women's health, continued education

**Table 1** Summary of the 2023 International PCOS Guideline recommendations on patient and healthcare professional educational needs<sup>2</sup>

<p><b>Evidence-based recommendation</b></p> <ul style="list-style-type: none"> <li>• Tailored information, education, and resources that are high-quality, culturally appropriate, and inclusive should be provided to all with PCOS. (Strong recommendation)</li> <li>• Information, education, and resources are a high priority for patients with PCOS and should be provided in a respectful and empathic manner. (Strong recommendation)</li> </ul> <p><b>Consensus recommendation</b></p> <ul style="list-style-type: none"> <li>• Entities responsible for health professional education should ensure that information and education on PCOS is systemically embedded at all levels of health professional training to address knowledge gaps. (Strong recommendation)</li> </ul> <p><b>Practice points</b></p> <ul style="list-style-type: none"> <li>• The diversity of the population should be considered when adapting practice paradigms</li> <li>• Healthcare professional education opportunities should be optimized at all stages of graduate and postgraduate training, continuing professional development and practice support resources</li> <li>• Counseling on the risk of misinformation and guidance toward evidence-based resources should be provided</li> </ul>
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for nurse practitioners on the diagnosis and comorbidities of PCOS may greatly reduce diagnostic delays and prevent comorbidities of PCOS.<sup>48</sup> A survey of 200 young nurses in Pakistan found that 40% had poor or no knowledge of PCOS.<sup>49</sup> A recent qualitative study in allied health professionals (dietitians, physical therapists, and psychologists) from Australia explored their experience with the implementation of lifestyle recommendations since the 2018 International PCOS Guideline recommendations came into effect.<sup>50</sup> Those interviewed desired more knowledge about the psychological issues associated with PCOS, as these may affect body image, motivation, and increase the risk of disordered eating.<sup>50</sup> Overall, allied health professionals felt that the 2018 International PCOS Guideline lifestyle recommendations were too general and too weight focused. They also desired more communication with the treating clinicians in terms of hand-off and collaboration.<sup>50</sup>

## Conclusions and Implications for Policy and Practice

This review was undertaken to understand the health-related communication needs of those affected by PCOS and to discern if knowledge gaps among healthcare professionals contribute to unmet informational needs in PCOS care. This review informed the 2023 International Evidence-Based PCOS Guideline and consensus recommendations, which are summarized in the ► **Table 1**.<sup>2</sup> Given the descriptive nature of assessing the patient experience, many studies reviewed were observational or qualitative. Still, consistent themes emerged leading to the following recommendations.

To gain agency over PCOS, patients strongly desire comprehensive and evidence-based information from their healthcare professional. Adolescents, while expecting tailored focus on their individual concerns, desire comprehensive disclosure of all risks. Therefore, healthcare professionals should facilitate access to high-quality online or printed resources that are age and culturally appropriate and consider referral to reputable support groups. Misconceptions about PCOS should be explored and addressed, as extensive online searches are not uncommon in those affected by PCOS.

Lifestyle recommendations are prioritized in PCOS care and weight management remains a key concern for patients. There is great need for lifestyle recommendations that take into consideration physiologic and psychological aspects of PCOS. In addition to printed and online resources, referrals to allied health professionals in the field of lifestyle management should be offered. Patients with PCOS prefer that weight management guidance is given by professionals familiar with all aspects of PCOS.

Depending on the cultural circumstances, PCOS can feel stigmatizing and even marginalizing. Patients strongly desire that healthcare professionals address the psychosocial effects of PCOS. Comprehensive health discussions should express empathy and discussions surrounding lifestyle should avoid any weight bias. The development of resources that raise awareness of psychosocial comorbidity such as body image dissatisfaction, anxiety, and depression may further support the provision of effective and holistic care. To assure consumer relevancy of all PCOS resources, patients and patient advocacy groups should co-develop resources with medical societies and guideline committees.

Knowledge gaps among healthcare professionals continue to contribute to unmet informational needs in PCOS care. This lack in knowledge, especially surrounding lifestyle recommendations, negatively impacts consumer satisfaction with PCOS care and education received. Therefore, systemically embedding PCOS education from credible and high-quality resources encompassing best practice information delivery is highly recommended. Furthermore, education opportunities should be sought at all stages of education, from graduate/postgraduate training to continuing professional development. System changes are recommended to enhance and update the PCOS curriculum at all levels of education for physicians, nurse practitioners, physician assistants, and nurses. Knowledge attainment should be monitored through surveys and as part of qualifying examinations.

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