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- 1 A systematic review of models of care for polycystic ovary syndrome
- 2 highlights a gap in the literature, especially in developing countries.
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- 22 Keywords: Polycystic ovary syndrome, PCOS, model of care, multidisciplinary care, quality of
- 23 **life.**

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#### 25 Abstract

- 26 Introduction: To identify available polycystic ovary syndrome (PCOS) models of care (MoC) and
- describe their characteristics and alignment with the international PCOS guideline.
- 28 Methods: OVID MEDLINE, All EBM, PsycINFO, EMBASE, and CINAHL were searched from
- 29 inception until 11 July 2022. Any study with a description of a PCOS MoC was included. Non-
- 30 evidence-based guidelines, abstracts, study protocols, and clinical trial registrations were excluded. We
- 31 also excluded MoCs delivered in research settings to minimize care bias. Meta-analysis was not
- 32 performed due to heterogeneity across MoCs. We describe and evaluate each MoC based on the
- recommendations made by the international evidence-based guideline for the assessment and
- 34 management of PCOS.
- 35 **Results:** Of 3671 articles, six articles describing five MoCs were included in our systematic review.
- 36 All MoCs described a multidisciplinary approach including an endocrinologist, dietitian,
- 37 gynaecologist, psychologist, dermatologist, etc. Three MoCs described all aspects of PCOS care
- 38 aligning with the international guideline recommendations. These include providing education on long-
- 39 term risks, lifestyle interventions, screening, and management of emotional well-being,
- 40 cardiometabolic diseases, and dermatological and reproductive elements of PCOS. Three MoCs
- 41 evaluated patients' and healthcare professionals' satisfaction, with generally positive findings. Only
- one MoC explored the impact of their service on patients' health outcomes and showed improvement
- 43 in BMI.

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- 44 **Conclusions:** There is limited literature describing PCOS MoCs in routine practice. Future research
- should explore developing cost-effective co-created multidisciplinary PCOS MoCs globally. This may
- be facilitated by the exchange of best practices between institutions that have an established MoC and
- 47 those who are interested in setting up one.

#### 1 Introduction

- 49 Polycystic ovary syndrome (PCOS) is one of the most common endocrinopathies among women of
- reproductive age with a prevalence of 8-13%, depending on the phenotype and the diagnostic criteria
- used (1). The diagnostic features of the disease are clinical and/or biochemical hyperandrogenism,
- oligo/anovulation, and polycystic morphologic appearance of the ovaries (2,3). PCOS was originally
- 53 perceived as a reproductive disorder. However, mounting evidence suggests that PCOS is also a
- metabolic condition associated with overweight/obesity (4,5), type 2 diabetes mellitus (T2DM) (6,7),
- fatty liver disease (8–10), and cardiovascular disease (CVD) (11,12). It also has a significant
- 56 psychological burden that is more than just a consequence of physical symptoms of PCOS(13–16). We
- 57 proposed an 'iceberg phenomenon' to highlight the neglected and overlooked impact on various
- symptotic and record phenomenant to highlight the neglected and eventorized impact on various aspects of women and individuals with PCOS's health, alongside potential reproductive dysfunction
- 59 (17). However, the original figure did not include the emotional wellbeing concerns associated with
- 60 PCOS. So, we have further adopted this figure to highlight the various additional aspects such as
- anxiety, depression, eating disorders and body image concerns. (**Figure 1**)
- 62 Several studies have shown that women and individuals with PCOS often have a significant delay in
- diagnosis, are dissatisfied with their diagnostic experience, information provision, and the management
- of their PCOS (18–21). Qualitative research has shown women and individuals with PCOS often felt
- 65 they were not taken seriously by their doctors (22) with care falling short of their expectations, due to
- 66 limited evidenced-based treatment options (23). The international PCOS guideline (24) recommends

- patient-centric models of care (MoC) that meet the needs of women and individuals with PCOS across
- the complexity of clinical features.
- An MoC is generally conceptualised as an overarching provision of care that is codesigned with end-
- users, may be shaped by a theoretical basis, and aligns with evidence-based practice and defined
- standards (25,26). A holistic, best-practice PCOS MoC would entail access to primary care,
- endocrinologists, gynaecologists, dermatologists, dieticians, and psychologists as required, to educate
- 73 women and individuals with PCOS about their condition and its long-term consequences, addressing
- 74 cardiometabolic, reproductive, and dermatological issues and providing lifestyle interventions,
- psychological and emotional support (**Figure 2**) (24). In the US and Australia, some MoCs have been
- 76 implemented aligning with the international guideline. The involvement of a psychologist and
- cognitive-behavioural therapy in PCOS resulted in greater weight loss, improved quality of life and
- 78 reduced depression and anxiety (27). However, there is no literature comparing findings across MoCs,
- 79 to advance best practice that can be shared and adopted in other places where women and individuals
- with PCOS are managed.

### 81 **2 Objective**

- 82 To describe the characteristics of available MoCs for PCOS, and their alignment with international
- 83 guidelines and evaluation of outcomes.

#### 84 **3 Methods**

#### 85 3.1 Eligibility criteria, information sources, search strategy

- This systematic review was registered on PROSPERO CRD42022346539. Studies describing MoC
- 87 that have more than one speciality in their PCOS management were identified using a search strategy
- 88 created using MEDLINE limited to English language and human studies. The search strategy was then
- 89 adapted to different electronic databases. OVID MEDLINE, All EBM, PsycINFO, EMBASE, and
- 90 CINAHL were searched from inception until 11 July 2022. We also included articles identified by
- 91 experts (CT) that might be relevant to the study. A full search strategy can be found in **Supplementary**
- 92 1. Studies were included if they described models of care for PCOS. Any study reported in English
- 93 with a detailed description of a PCOS MoC was included. Non-evidence-based guidelines, abstracts,
- 94 study protocols, and clinical trial registrations were excluded. We also excluded MoCs delivered in
- 95 research settings to minimise care bias. Detailed reasons for exclusion can be found in **Supplementary**
- 96 **2**.

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#### 3.2 Study selection

- The process for study selection is summarised in **Figure 3**. Titles and abstracts were independently
- 99 screened by two reviewers (EM, MD) utilizing Covidence software (Covidence systematic review
- software, Veritas Health Innovation, Melbourne, Australia). Following title and abstract screening, full
- texts were obtained and screened by EM and MD against the eligibility criteria. Conflicts were resolved
- following a discussion between the two reviewers and if needed, by a senior reviewer (PK).

#### 3.3 Data extraction

- The data extraction template was developed by the researchers (EM, MD, PK) in partnership with the
- PCOS GDG members (CT, JB, MT) to ensure relevance. Data extracted included the service name, a
- detailed description of the MoC and the service, management, and evaluation.

#### 3.4 Assessment of risk of bias

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- 108 Risk of bias assessments was done using the Monash Centre for Health Research and Implementation
- (MCHRI) evidence synthesis critical appraisal templates, adapted from the relevant Cochrane critical 109
- appraisal tool(s) for mixed-method studies and cross-sectional studies (28). For each study, external 110
- and internal validity were assessed to determine the overall risk of bias for that study. 111
- 112 The findings of this review are reported based on the Preferred Reporting Items for Systematic Reviews
- and Meta-Analyses (PRISMA) guidelines (29). Data are summarised in Table 1 with narrative 113
- 114 synthesis. Meta-analysis was not performed due to heterogeneity across MoCs. We describe and
- evaluate each MoC based on the recommendations made by the international evidence-based guideline 115
- for the assessment and management of PCOS (24). 116

#### 4 **Principal Findings**

- 118 3671 articles were identified for title and abstract screening. Of these, 51 articles underwent full-text
- screening of which six articles describing five MoCs are included in this report (Figure 3). Bekx, 119
- 120 Connor, and Allen (30) and Geier, Bekx, and Connor (31) (MoC A) described an adolescent PCOS
- 121 clinic at the American Family Children's Hospital, United States; Boyle et al. (32) (MoC B) described
- a pilot clinic on Thursday Island, Australia; Torres-Zegarra et al. (33) (MoC C) described a 122
- multidisciplinary clinic for PCOS at Children's Hospital Colorado, United States; Tay et al. (34) (MoC 123
- D) described the Monash Health state-wide integrated PCOS service, Australia; Patil et al. (35) (MoC 124
- 125 E) described an integrated multidisciplinary clinic at Indian Council of Medical Research, India. Two
- were mixed-methods studies and others were cross-sectional. The objectives of the six articles varied. 126
- MoC A, Bekx et al. (30) characterised patients referred to their multidisciplinary clinic, while Geier et 127
- al. (31) aimed to examine the impact of MoC A on weight among adolescents with PCOS. Boyle et al. 128
- 129 (32) evaluated MoC B based on the fidelity to evidenced-based guideline, barriers and enablers to
- women and individuals using their service and MoC's ability to meet the needs of women and 130
- individuals with PCOS. Torres-Zegarra et al. (33) described the characteristics of patients and pattern 131
- of MoC C. Tay et al. (34) evaluated MoC D based on a comprehensive evaluation framework described 132
- by Markiewicz and Patrick (36). MoC E described the process of the models of care including 133
- retrospective chart analysis of profiles of women attending the clinic (35). A summary of these MoCs 134
- is included in Table 1. 135

#### **Characteristics and composition of PCOS MoCs** 4.1

- 137 All included MoCs had a multidisciplinary approach, but their compositions varied. MoC A was one
- of the first published MoCs for women and individuals with PCOS (30,31). Started in 2005, it had a 138
- 139 team of two paediatric endocrinologists, a paediatric gynaecologist, a reproductive endocrinologist, a
- nutritionist, and a psychologist. MoC B, established in 2012, had a general practitioner (GP), women's 140
- health nurse, dietician, and women's health worker (32). Set up in 2012, MoC C included paediatric 141
- endocrinologists, gynaecologists/adolescent medicine specialists, psychologists, nutritionists, and 142
- exercise physiologists (33). A dermatologist was added to the MoC two years later following patient 143
- feedback. MoC D, set up in 2017, was an integrated public multidisciplinary service that comprised 144
- specialties including endocrinology, dermatology, health coaching, and dietetics (34). Patients were 145
- referred to each specialist clinic when required. MoC E described a one-stop MoC involving 146
- gynaecologist, infertility specialist, dermatologist, psychiatrist, nutritionist, yoga expert, and 147
- counsellor; Women were managed in the clinic on a regular basis (once monthly) (35). Detailed 148
- description and characteristics of the MoCs are presented in **Table 1** and **Figure 4**. 149

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#### Services provided in the MoC. 4.2

- 152 Three clinics—MoC C, MoC D, and MoC E—reported all aspects of PCOS care in line with the
- international guideline. All except MoC A had clear information about the criteria they used for 153
- 154 diagnosing PCOS.

#### 4.2.1 Cardiometabolic disease

- 156 All MoCs described some form of cardiometabolic screening, but content varied. MoC A (30,31)
- screened for anthropomorphic effects including height, weight, and body mass index (BMI). They also 157
- monitored the trends in BMI over time to define successful weight loss or weight gain. 2-hour oral 158
- glucose tolerance test, insulin levels and lipid profile were used to screen for dysglycemia, 159
- hyperinsulinemia, and dyslipidemia, respectively. MoC B (32) had all screening done by MoC A with 160
- addition of glycated Haemoglobin (HbA1c) and blood pressure measurements. MoC C (33) evaluated 161
- BMI, blood pressure, lipid profile, and HbA1c. MoC D (34) included screening for long-term 162
- complications. However, the individual components of how this was done were not included in the 163
- 164 study. MoC E (35) included BMI screening, waist-hip ratio, ultrasound to assess for non-alcoholic fatty
- liver disease and screening for metabolic syndrome including 2-hour oral glucose tolerance test, insulin 165
- 166 and lipid profile.

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#### 4.2.2 Lifestyle

- 169 All MoCs provided lifestyle interventions mostly including goal-settings and education. In MoC A
- (30,31), the health psychologist focused on lifestyle changes and helped women and individuals with 170
- PCOS to identify any barriers that might exist and possible solutions. The nutritionist helped provide 171
- education on the role of insulin, meal-planning, goal setting, and exercise. In MoC B (32), patients 172
- were encouraged to set their own lifestyle goals which included reduction of portion sizes and 173
- increasing daily walks. Patients were then asked to attend a follow-up appointment to evaluate their 174
- achievements. MoC C (33) included exercise physiologists and nutritionists who provided lifestyle 175
- interventions. Exercise physiologists described each exercise and helped to set activity goals. 176 Nutritionists helped with monitoring weight trends and provided education regarding healthy eating.
- 177 Further, health nurses provided 30-60 minutes of education for women and individuals with PCOS,
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- covering emotional health, bleeding problems, infertility, endometrial protection, and lifestyle. In MoC 179
- D (34), a dietician and/or health coach conducted group sessions discussing the importance of healthy 180
- diet and physical activity, personal goal setting, and identification of healthcare barriers. All women, 181
- who attended MoC E (35), were advised lifestyle modification with diet and exercise with the help 182
- from nutritionist and yoga expert. 183

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#### 4.2.3 Dermatology

- 186 All MoCs except MoC B (32) described either screening or treatment for dermatological issues
- associated with PCOS. MoC A (30) described screening for hirsutism and acne. The screening tools 187
- used were not specified in the study. MoC C (33) measured hirsutism using the modified Ferriman-188

Gallwey (mFG) score. Screening for presence and severity of acne was done during physical examination. Presence and absence of acanthosis nigricans, androgenic alopecia, and hidradenitis suppurativa were also noted. As for the treatment, MoC C (33) used spironolactone, topical treatments, antibiotics, and isotretinoin to manage hirsutism and acne. The dermal clinic integrated in MoC D (34) used medical grade laser for hirsutism. MoC E (35) had a dermatologist within the MoC to address acne, oily skin, acanthosis nigricans and/or hirsutism however, no specific treatments were described.

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#### 4.2.4 Education on long-term risk

- MoCs C and D were the only MoCs that reported education on long-term risks (33,34). MoC C (33) set up a group education session, where women and individuals with PCOS were taught by endocrinologists and gynaecologists on the pathophysiology and medical treatment of PCOS. Due to the COVID-19 pandemic, they introduced recorded content for these sessions. MoC D (34) educated women and individuals with PCOS regarding clinical features, diagnosis, complications, and management of PCOS via a group session or printed fact sheets during the first appointment. MoC E (35) counselled women on the condition and the need for integrated multidisciplinary management
- 204 following the diagnosis of PCOS.

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### 4.2.5 Emotional wellbeing and reproductive screening and/or management

207 Three clinics described provision of screening for emotional wellbeing and reproduction. It was unclear 208 whether MoC A provided emotional and reproductive screening. However, we note that both included 209 health psychologists and a paediatric gynaecologist in the clinic. At MoC B (32), emotional distress screening was undertaken with the Kessler Psychological Distress Scale (37) which is a global measure 210 211 of distress encompassing anxiety and depression items. A psychologist in MoC C (33) evaluated all 212 patients for mental health symptoms, appetite self-regulation, and emotional eating. In MoC D (34), 213 all women and individuals with PCOS were screened using a modified PCOS questionnaire (PCOSQ) 214 (38) and Hospital Anxiety and Depression Scale (HADS) (39) to evaluate their quality of life and 215 emotional distress, respectively. In MoC B (32), reported infertility treatment by lifestyle intervention, 216 metformin prescription, and/or referral to a specialist. MoC C (33) included screening for endometrial 217 hyperplasia and discussion regarding infertility issues, whereas MoC D (34) included the family 218 planning discussion. Women in MoC E (35) were screened for obvious anxiety and/or depression by 219 counsellors and addressed by psychologist or psychiatrist.

#### 4.3 MoC Evaluation

- 221 MoC evaluation data were organised into three categories: patient outcomes, health professional
- outcomes, and other outcomes. MoCs B (32) and MoC D (34) were the only studies that reported their
- 223 MoCs evaluation. MoC B evaluated outcomes from all three categories while MoC D only evaluated
- 224 patient and other outcomes. Evaluation of patient outcomes was available for MoC A which
- investigated the impact of their service on BMI. No evaluation outcomes were available for MoC C.

#### 4.3.1 Patient health outcomes and satisfaction

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MoC A (31) evaluated patients' health outcomes including improvement in body weight seen in 36% 227 (n=13/36). Having access to both psychologist and dietician was superior in improving weight 228 compared to seeing either alone. MoC B (32) conducted semi-structured interviews and focus-groups 229 with women and individuals with PCOS to assess their satisfaction from the clinic. Women and 230 231 individuals with PCOS found it helpful to have access to this clinic and they found the staff knowledgeable. Patients also found collaboration with a dietician helpful and valuable in goal setting 232 but suggested more tailored plans and ongoing supervision, indicating insufficiency in what was 233 234 provided. Overall, 80% (n=12/15) of patients in MoC D (34) were satisfied with the service. Further semi-structured interviews with women and individuals with PCOS revealed that MoC D covered their 235 236 multifaceted needs and was effective in providing care and communication. Women and individuals with PCOS also reported positive impact of this clinic on medical management, symptom severity, 237 their understanding about PCOS, confidence in managing PCOS, and emotional wellbeing. 238 Suggestions from the interviews included improvements in efficiency, patient communication, 239 resource provision, infrastructure, and awareness on the service availability. Patients also suggested 240 more resources to promote self-management. For MoC E (35), telephone feedback was obtained from 241 155 women who attended the clinic. One year following clinic attendance, 83.8% reported adherence 242 to medication, 52.3% and 46.5% adhered to exercise and dietary interventions, respectively. Sixty-243 eight percent of women were convinced that multidisciplinary clinics were helpful in weight reduction 244 and psychological well being. 245

#### 4.3.2 Health professional satisfaction

- Health professionals' satisfaction was investigated by Boyle et al. (2017) in MoC B (32). A survey
- among service providers found high levels of job satisfaction and professional investment. The service
- providers saw absence of a psychologist as a particular problem. The barriers and enablers to clinic
- sustainability and service delivery were also discussed. Key barriers to sustainability included issues
- 251 that may arise due to lack of cover during leave, administrative support, funding, high staff turnover,
- and system issues. The increased demand for the service, although was a strong reason to continue
- expanding the clinic, was cited as a barrier due to the lack of service providers' availability.
- 254 4.4 Risk of bias of included studies.

#### 25 1 III IIIII OI DIUS OI IIICIUUCU Studies.

- 255 Five studies were deemed low risk of bias by the reviewers. One study [MoC A (30)] had moderate
- 256 risk of bias due to inadequate information on case selection. Furthermore, inclusion and exclusion
- criteria for the study were not described. The detailed risk of bias assessment for each included study
- is presented in **Supplementary 3**.

#### 5 Comparison with Existing Literature

- To date, little progress has been made towards establishing evidence based PCOS MoCs. Existing
- MoCs vary considerably in breadth of multidisciplinary features with few covering all recommended
- aspects of care (cardiology, reproduction, dermatology, emotional wellbeing, lifestyle, and long-term
- 263 risk). Moreover, it is important to note that some of these studies were not designed to evaluate their
- MoC, which accounted for the lack of details of each reported MoC. Lack of progress could be because
- such models exist but are not published, health system constraints hinder development (funding, health
- policy), or there is a lack of know-how about development. Good MoC for PCOS may exist however,
- without their publication, the opportunity to share best practice is lost. We also noted the lack of

systematic reporting and evaluation of MoCs in PCOS, and here we have established a structure for capturing and reporting MoC characteristics to support future work. Future research should concentrate on the evaluation of routine MoC with the focus on patients' experience and satisfaction. This would enable sharing of best practice in the care of women and individuals with PCOS.

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The lack of progress in MoC evaluation in the literature is surprising considering the high prevalence of PCOS as a chronic condition. A systematic review on chronic disease MoC reported that >90% of their included MoCs (n=75/77) reported positive impact on healthcare practices and outcomes (40). Clearly, there is a need and an apparent benefit from multidisciplinary, dedicated one-stop clinics covering all aspects of PCOS, such as the MoCs by Tay et al. (2021) (34) and Torres-Zegarra et al. (2021) (33). This is also in line with the study by Ismayilova and Yaya (2022), where people expressed the need for more PCOS-centric clinics (20). As management of PCOS is largely individualised due to heterogeneity and a broad range of clinical features, having access to multiple disciplines is important (24). However, our results show that the integration of different disciplines varied considerably; yet four out of the five MoCs showed positive patients' and/or healthcare professionals' satisfaction.

Our systematic review showed that none of the peer reviewed MoCs are optimised in line with our suggested MoC structure for women and individuals with PCOS. Despite having all the services for women and individuals with PCOS by Tay et al. (2021) (34), Torres-Zegarra et al. (2021) (33), and Patil et al. (2022) (35), there is currently little evidence on stakeholders' satisfaction of their MoCs. To ensure optimization and sustainability of dedicated MoCs, careful design of components of care is important including a plan for continuous evaluation and monitoring (41). Financial and human resources also play a role in designing such MoC. Despite the high prevalence and long-term consequences of PCOS, as well as the estimated financial impact at \$4.36 billion (42), PCOS receives less than 0.01% of national funding in the US (43). There is a clear need for greater awareness and priority on this condition. This also impacts access to treatment options for PCOS-related symptoms such as expensive laser hair removal and electrolysis for hirsutism (24,42,44). Adequate dermatology management should be provided as hormonal manipulation with contraceptive pills is not always effective and acne can cause significant mental health issues. Women and individuals with PCOS should be educated about sub-fertility due to anovulation and, more importantly, referred to fertility specialists when indicated. As PCOS is also recognized as a metabolic condition, women and individuals with PCOS should be regularly screened for cardiovascular risks and informed of its longterm consequences. Because PCOS is also associated with endometrial cancer, education and public awareness regarding weight loss and progesterone use to reduce endometrial cancer risk is of paramount importance. Emotional wellbeing screening and appropriate referral is also important for women and individuals with PCOS due to high prevalence of anxiety, depression, and reduced quality of life that goes beyond physical manifestations of PCOS. All of these would improve self-management strategies for women and individuals with PCOS coupled with lifestyle interventions that can be provided by healthcare professionals, namely nutritionist, exercise physiologists, and lifestyle coach. Moreover, it is important to ensure race, culture, and tradition are also factored in when designing an MoC as these have been shown to influence the differential services received by women and individuals with PCOS (45-49). This makes it vital to involve women and individuals with PCOS and their families in co-designing services (48).

Many studies have shown that women and individuals with PCOS are generally dissatisfied with their diagnosis experience, information provided, and management of their PCOS (18,19,21,22,50). Patient satisfaction is also an important aspect in healthcare as it has been shown to affect clinical outcomes and patient retention. Furthermore, patient satisfaction also affects time and efficacy of healthcare delivery which is often used as a proxy of quality of healthcare (51). In addition, healthcare professional

314 satisfaction is a key to ensure productivity and sustainability of the service (52). In this context, 315 surprisingly few studies focused on PCOS MoC, and most studies did not assess patients' and healthcare professionals' satisfaction. We have described the satisfaction assessment for two MoCs 316 317 (32,34) with positive results. Our findings are similar to two studies describing an MoC based at the 318 Royal Berkshire Hospital, UK, which were not included in this systematic review due to being 319 published as conference abstracts without details of evaluation methodologies (53). An audit was 320 conducted for their MoC assessing adequacy of investigations and efficacy of treatment for women and individuals with PCOS attending multidisciplinary clinics. Their patient satisfaction survey 321 322 showed that 62/63 women found the clinic useful and were happy with the results. They also reported 323 high satisfaction and improved clinical outcomes such as weight loss, menstruation patterns, hirsutism, 324 and physical activity levels (53,54). A further seven studies that might include PCOS MoC were also 325 excluded from this systematic review because they were abstracts. Hebbar et al. investigated the 326 prevalence of anxiety and body dysmorphia in women and individuals with PCOS attending PCOS 327 specialist clinics in the UK and India (55). The components of their MoC were not described in the 328 abstract (55). Abudu et al. also studied the patient characteristics and subjective improvements in acne 329 for women and individuals attending multidisciplinary PCOS clinics, without description of specialists 330 in the multidisciplinary team (56). Other excluded three studies described either group counselling, self-management, and/or support services for women and individuals with PCOS (57–59). 331

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### 5.1 Strengths and limitations

- The strength of this review includes applying clear definitions of a MoC which enabled the capture of
- studies aligning with the international guideline. We also established a system to report MoCs; it is
- important to note that there might be another system that exists for an "optimal MoC". Our key
- weakness is related to the limited number of MoCs described internationally, and we note the included
- MoCs are from two high-income countries—the US and Australia. Therefore, we are unable to
- generalise our findings to a wider population. Furthermore, due to the design of included studies, not every component of MoCs included are captured in our findings. This does not mean that they did not
- every component of MoCs included are captured in our findings. This does not mean that they did not
- provide the service. Despite only a small number of included studies, this systematic review provides a structured evaluation of the current MoCs of PCOS internationally and further explores their
- 343 effectiveness.

#### **6** Conclusion and implications

- There is a limited number of models of multidisciplinary care currently available in PCOS, with a
- scarcity of data, especially in low- and middle-income countries. Good MoCs may exist but without
- their publications, the opportunities to share best practices are lost. Studies on MoC that evaluated
- patients' and healthcare professionals' satisfaction were generally positive. Future work focusing on
- MoC scale-up should include development of a best-practice MoC framework, co-designed with
- women and individuals affected by PCOS across different countries. Alignment with the updated best
- practice in the 2023 guideline will be important, with adaptation to the range of health systems and
- resource settings, alongside a need for ongoing evaluation and sharing of results to further develop
- 353 the evidence-based on real-world experiences.

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585	8	Conflict of Interest
586 587 588	ovary	systematic review was conducted as part of the international guideline update for polycystic y syndrome ( <b>PROSPERO registration number:</b> CRD42022346539. <b>Date registered</b> : 25 July ). No conflict of interest for all the authors involved in the manuscript.
589		

**Author Contributions** 

- All authors reviewed and edited the manuscript and approved it for publication (as per ICMJE criteria
- for authorship). Both EM and MD were involved in all stages of the study and have contributed equally
- 593 to this work and share first authorship. KM contributed to the design of the study and data analysis.
- 594 CTT, JB, MT supervised the data extraction and finalised the articles included in the study. Members
- of the PCOS SEva working group provided substantial contributions to the conception and design of
- 596 the work and were involved in discussions at all stages of the study. The group included Jameela
- 597 Sheikh, Meghnaa Hebbar, Halimah Khalil, Kashish Malhotra, Tejal Lathia, Helena K. Gleeson, Lynne
- Robinson, and Chitra Selvan. AM and HT were involved in scoping the clinical question and eligibility
- 599 criteria (PICO), overseeing the review methodology in alignment with approved PCOS guideline
- evidence synthesis processes, and reviewing and editing the manuscript. PK conceptualised the study
- and supervised all stages of data collection, analysis, interpretation, and write-up of this study.

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- **608 12 Figures**
- Figure 1. An iceberg phenomenon in polycystic ovary syndrome highlighting the emotional wellbeing
- 610 concerns associated with PCOS.
- Figure 2. (A) outlines 10 recommendations arranged in alphabetical order. The red arrow is the pointer
- for the starting point of reading the hexagon at cardiometabolic screening. (B) Detailed description of
- 613 the best-practice PCOS MoC aligned with the international evidence-based guideline for the
- assessment and management of polycystic ovary syndrome 2018.
- Figure 3: PRISMA chart describing the selection process for our systematic review.
- Figure 4: Graphical representation of the five models of care for polycystic ovary syndrome included
- in this systematic review. Green represents the services that were provided in a model of care. Yellow
- 618 represents that the element of MoC was either not reported or unavailable in their MoC. A to F
- 619 corresponds to the respective models described in this study.

# **12.1 Tables**

622

# **Table 1.** Description of included studies in this study.

	Bekx 2010	Geier 2012	Boyle 2016	Torres-Zegarra 2021	Tay 2021	Patil 2022		
Characteristics and composition of PCOS MoC								
Country of MoC	United States	United States	Australia	United States	Australia	India		
Name of the clinic	Adolescent PCOS clinic at the American Family Children's Hospital (MoC A)	Adolescent PCOS clinic at the American Family Children's Hospital (MoC A)	Pilot clinic on Thursday Island, Australia (MoC B)	Multidisciplinary clinic for PCOS at Children's Hospital Colorado (MoC C)	Monash Health state-wide integrated PCOS service (MoC D)	Integrated multidisci plinary PCOS clinic at Indian Council of Medical Research (ICMR)-National Institute for Research in Reproductive and Child Health (MoC E)		
Year of MoC initiation	2005	2005	2012	2012	2017	2016		
Members of multidisciplinar	Paediatric endocrinologists (x2)	Paediatric endocrinologists	General practitioner (x1)	Paediatric Endocrinologist	Endocrinologist (x1)	Gynaecologist (x1)		
y team		(x2)		(x1)		Infertility specialist		
	Paediatric gynaecologist (x1)	Paediatric	Women's health nurse (x1)	Gynaecologist (x1)	Dermatologist (x1)	(x1)		
	Reproductive	gynaecologist (x1)	Dietitian (x1)	Adolescent Medicine Specialist	Health coach	Dermatologist (x1)		
	endocrinologist (x1)	Reproductive endocrinologist	Women's health	(x1)	(x1)	Psychiatrist (x1)		
	Nutritionist (x1)	(x1)	worker (x1)	Dermatologist (x1) (was added to the	Dietician (x1)	Nutritionist (x1)		
	Health psychologist (x1)	Nutritionist (x1)		MoC in 2014)		Yoga expert (x1)		
						Counsellor (x1)		

		Health psychologist (x1)		Psychologist(x1)  Nutritionist (x1)  Exercise Physiologists (x1)		
Services provide	d in the MoC			<u>I</u>		
Clear diagnosis of PCOS	Unclear	Participants were given a diagnosis of PCOS based on Rotterdam criteria	Evaluated frequency of Rotterdam criteria met	Requirement for a confirmed diagnosis of PCOS prior to the first visit; however, unclear according to which criteria	PCOS diagnosis confirmation; however, unclear according to which criteria	PCOS diagnosis confirmation based on the Rotterdam criteria
Cardiometabolic screening, referral, or management	BMI and BMI trends, 2-h OGTT and insulin levels measured	BMI and BMI trends, 2-h OGTT and insulin levels	BMI and BMI trends, blood pressure, 2-h OGTT and insulin levels, HbA1c and lipid profile	BMI, blood pressure, lipid profile and HbA1c	Included screening for long-term health complications but does not describe the components	BMI, waist-hip ratio, blood pressure, ultrasound for non- alcoholic fatty liver disease, lipid profile, 2-h OGTT
Dermatological screening, referral or management	Hirsutism and acne screening (unspecified screening tool)	Not described	Not described	Hirsutism, acanthosis nigricans and acne screening. Hirsutism with mFG score. Acanthosis and acne were	Medical grade laser for treatment of hirsutism	Acne assessment, Hirsutism with FG score. Dermatologist involved with the management of acne and hirsutism
Education on long-term risk	Not described	Not described	Not described	Group education session on the pathophysiology and medical	Educated attendees regarding the clinical features,	Following diagnosis, women were counselled about the condition and the

Emotional wellbeing screening, referral or management	Unclear	Unclear	Emotional distress screening was with the Kessler Psychological Distress Scale (37)	treatment approaches of PCOS. Educational session by a nutritionist and exercise physiologist on lifestyle recommendations. 30-60 minutes of education to attendees, covering emotional health, bleeding problems, infertility, endometrial protection, and lifestyle factors  Psychologist evaluated all patients for mental health symptoms, appetite self-regulation, and emotional eating.	diagnosis, complications, and management of PCOS via a group session or printed fact sheets during the first appointment.  screened using modified PCOS questionnaire (PCOSQ) (38) and Hospital Anxiety and Depression Scale (HADS) (39)	One stop included psychiatrist and psychological counselling that included screening for emotional, mental health, and QoL
Reproductive screening, referral or management	Unclear	Unclear	lifestyle intervention, metformin prescription, and/or referral to the specialist	screening for endometrial hyperplasia and discussion regarding future infertility issues	Family planning discussion	Has access to gynaecologist and infertility specialist
Lifestyle referral	Psychologist helped	Psychologist	Patients	Exercise	Dietician and/or	All the women were
or management	attendees identify	helped attendees	encouraged to set	physiologist helped	health coach	advised lifestyle

	barriers that might exist and possible solution. Nutritionist helped with education on the role of insulin, meal planning, goal setting, and exercise	identify barriers that might exist and possible solution. Nutritionist helped with education on the role of insulin, meal planning, goal setting, and exercise	own goals including reduction of portion sizes and increasing their walking with follow-up appointments	describe goals for each exercise and set activities and goals at appointments. Nutritionist helped with monitoring weight trends and education regarding healthy eating	conducted lifestyle group sessions discussing the importance of healthy diet and physical activity, personal goal setting, and identification of healthcare barriers	modification with diet and exercise in consultation with a nutritionist and yoga expert. Yoga sessions were held as a group activity on the monthly clinic day and women were taught how to practice the specific asanas at home
<b>Evaluations of M</b>	IoC					
Health professional satisfaction	No	No	Yes	No	No	No
Patient health outcomes	No	Yes	Not described	No	No	Yes
Patient reported outcomes	No	No	Yes	No	Yes	Yes

## 13 Data Availability Statement

No dataset was generated for this study. The search strategies and risk of bias assessments are included in the supplementary materials.

# 626 14 Supplementary Material

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624

627 Supplementary Material is uploaded separately on submission.