# Polyendocrine metabolic ovarian syndrome, the new name for polycystic ovary syndrome: a multistep global consensus process

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**Polyendocrine metabolic ovarian syndrome (PMOS), previously named polycystic ovary syndrome (PCOS), affects one in eight women. However, the term PCOS is inaccurate, implying pathological ovarian cysts, obscuring diverse endocrine and metabolic features, and contributing to delayed diagnosis, fragmented care, and stigma, while curtailing research and policy framing. Building on an international mandate for change, we outline an unprecedented, rigorous, multistep global consensus process for the name change. Funding and governance were established with engagement of 56 leading academic, clinical, and patient organisations. Using iterative global surveys (with responses from 14 360 people with PCOS and multidisciplinary health professionals from all world regions), modified Delphi methods, nominal group technique workshops, and marketing and implementation analyses, we identified principles prioritising scientific accuracy, clarity, stigma avoidance, cultural appropriateness, and implementation feasibility. An accurate new name was prioritised over retaining the PCOS acronym or a generic name. Implementation approaches prioritised evolution rather than transformation. Preferred terms were polyendocrine, metabolic, and ovarian, reflecting the condition's multisystem pathophysiology, and polyendocrine metabolic ovarian syndrome was the consensus new name. Accuracy was improved by omitting cysts and by capturing endocrine, metabolic, and ovarian dysfunction. A co-designed global implementation strategy, including a transition period, education, and alignment with health systems and disease classification, is under way.**

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## Background and rationale

Polycystic ovary syndrome (PCOS) affects 170 million women during their reproductive years alone.[1] Following exclusion of other disorders, the condition is diagnosed based on adults (aged ≥20 years) meeting at least two of the following International Guideline criteria: (1) oligo-anovulation, (2) clinical or biochemical hyperandrogenism, and (3) polycystic ovaries on ultrasound or elevated anti-Müllerian hormone (AMH).[2,3] Adolescents (aged 10–19 years) require the presence of the first two criteria.[4] PCOS has long been primarily perceived as a gynaecological or ovarian disorder; however, mounting research, evidence synthesis, and International Guidelines have shown that PCOS is underpinned by endocrine disturbances in insulin, androgens, and neuroendocrine and ovarian hormones.[2–5] Features can be metabolic (ie, obesity, dysglycaemia, type 2 diabetes, hypertension, dyslipidaemia, metabolic dysfunction-associated steatotic liver disease, cardiovascular disease, and sleep apnoea), reproductive (ovulatory disturbances, irregular menstrual cycles, infertility, pregnancy complications, and endometrial cancer), psychological (depression, anxiety, poor quality of life, and eating disorders), and dermatological (acne, alopecia, and hirsutism).[2–5] BMI is generally higher in people with PCOS than in those without the condition, and contributes to its severity.[6] Overall, PCOS has multisystem health impacts and represents a growing health and economic burden.[1,7]

However, the broad clinical features of the condition are not captured in its current name, as although arrested follicular development is common, pathological ovarian cysts are not increased.[8–10] These factors delay diagnosis—with up to 70% of affected individuals remaining undiagnosed—and also contribute to widespread knowledge gaps and patient dissatisfaction.[11–13] In 2012, the US National Institutes of Health Office of Disease Prevention Evidence-based Methodology Workshop on

### Key messages

- Polycystic ovary syndrome affects more than 170 million women globally, yet its current name is inaccurate and misleading, obscuring the condition's multisystem endocrine and metabolic features, reinforcing stigma, delaying diagnosis, and hindering effective clinical care, research, and policy alignment.
- Through an unprecedented, rigorous global consensus process engaging patients, multidisciplinary health professionals, and organisations across world regions, a new name—polyendocrine metabolic ovarian syndrome—was agreed, omitting the misleading reference to ovarian cysts and accurately reflecting the diverse features of the condition.
- Consensus for the new name was built by use of robust, transparent methods, including modified Delphi survey processes, nominal group technique workshops, and implementation and marketing analyses, ensuring scientific accuracy, cultural appropriateness, stigma avoidance, and feasibility of adoption. These processes optimised representativeness, legitimacy, and transparency, and served to enhance engagement to underpin implementation.
- Coordinated implementation is under way in health systems, research institutions, funding bodies, education providers, clinical guidelines, and disease classification systems (including ICD coding), and is supported by a global transition period and continuous evaluation.
- Aligning nomenclature with scientific evolution and improving accuracy will enhance awareness, diagnosis, care quality, research coherence, and patient experience, strengthening policy, advocacy, and health outcomes globally.

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PCOS highlighted the challenges and inaccuracy of the current name, and recommended a change to better reflect the condition.[14] Despite the strong rationale (panel 1) and long-standing recognition that PCOS is an inaccurate and misleading term, efforts to change the name have repeatedly stalled. Patient groups, alongside leaders in the field of reproductive medicine, such as Dr Ricardo Azziz, Prof Andrea Dunaif, Prof Bart CJM Fauser, Prof Robert J Norman, and Prof Helena J Teede, have persistently advocated for change.[8,9,15,16] Expert commentaries, guidelines, and surveys have reaffirmed the limitations of the narrow reproductive focus and inaccuracies, noting ongoing confusion among people with PCOS and clinicians, fragmented policy and advocacy efforts, and downstream consequences for diagnosis, care, outcomes, and research.[2,8,9,15] However, previous renaming efforts failed to gain traction, with barriers including a lack of inclusive global leadership and the need for a coordinated international consensus process, alignment between patient advocacy groups, agreement on an alternative name, and a comprehensive implementation strategy.[8,9] The need for greater awareness, advocacy, education, and implementation, alongside international collaboration and resourcing, was also recognised.[9] A longitudinal global study engaged people with PCOS and health professionals in serial surveys and workshops and highlighted ongoing confusion around the name.[9] Overall, 84% of respondents endorsed a global consensus process to identify and implement a new name, alongside education and implementation strategies. An accompanying impact assessment indicated that the perceived benefits of a name change outweighed the risks.[9] As a result of these data, the compelling evidence base, and strong patient advocacy and leadership by Verity, a UK-based charity and advocacy organisation, Monash University's Centre for Research Excellence in Women's Health in Reproductive Life and the Androgen Excess and PCOS Society launched a global initiative with a clear mandate for a name change.[9]

Throughout this process, we sought to obtain funding; establish governance; further engage people with PCOS, multidisciplinary health professionals, and their member organisations across world regions; and undertake global surveys and workshops through modified Delphi and nominal group techniques. We aimed to establish principles, approaches, preferred terms, a new name, and implementation priorities.[9] Ultimately, this Health Policy initiative outlines both the consensus process and a pragmatic global implementation strategy to correct inaccuracies, recognise diverse clinical features of the condition, and strengthen research, education, and clinical care to improve health outcomes globally for people with polyendocrine metabolic ovarian syndrome (PMOS).

***Panel 1*: Context and the case for a new name**

The term polycystic ovary syndrome (PCOS) has long been recognised as inaccurate and potentially harmful. The following evidence-based considerations informed the need for a new name:

- The term polycystic ovary implies the presence of pathological ovarian cysts, which are not a feature of the condition. This misnomer contributes to misunderstandings among patients, clinicians, policy makers, and the public.
- PCOS encompasses diverse endocrine, metabolic, reproductive, psychological, and dermatological features. The current name reflects only one organ and fails to capture the disorder's multisystem nature.
- Confusion arising from the current name can delay diagnosis and hinder effective communication between patients and health professionals, contributing to patient dissatisfaction with care.
- The reproductive focus of the name can reinforce stigma, particularly in sociocultural contexts where fertility carries high value. Many individuals report distress associated with the name itself.
- The misnomer complicates epidemiological classification, research comparability, and health system coding. A more accurate name is expected to improve scientific coherence, research funding, and policy alignment.
- International guidelines, expert groups, and patient organisations have repeatedly called for renaming, with serial surveys and workshops culminating in a mandate to change the name through a rigorous, global consensus process.
- A new name must support long-term clinical care, research, and global adoption, and enable a smooth transition from existing terminology.

## Global engagement and processes

The Australian National Health and Medical Research Council awarded funding to the Centre for Research Excellence in Women's Health in Reproductive Life, which provided leadership alongside the Androgen Excess and PCOS Society, an international multidisciplinary society focused on advancing education and awareness, and Verity, a leading patient charity and advocacy group. We established an international steering group with members from across lead agencies, and identified and engaged patient groups and professional societies from the International PCOS Guideline Network, with purposive extension to broader disciplines and world regions.[2] In April, 2025, letters to organisation members were distributed to encourage participation in tasks such as survey dissemination, workshop representative nomination, and contribution to implementation and dissemination of the new name. Building on previous survey results, global surveys were co-designed and disseminated, and international consensus workshops were convened by use of robust methods aligned with the James Lind Alliance processes (panel 2).[17–19]

### Delphi surveys

The new surveys built on the results of two previously published surveys and workshops in 2017 and 2023, and were informed by literature review and consultation with health professionals and people with PCOS.[9] We used a purposive, stratified non-probability sampling approach, recruiting participants via partnering professional societies and patient organisations, with targeted

sampling to achieve multidisciplinary representation across world regions. Extended recruitment timelines and dissemination strategies aimed to maximise reach, including engagement with harder-to-reach populations through language translation and use of multiple online platforms. No formal sample size calculation was done; the sample size was guided by our aim of achieving broad global representation across regions and disciplines.

Survey A (appendix p 1) included a historical introduction and rationale, an outline of the mandate for a name change, a linked explanatory statement, ethics approval, and implied consent details. Demographic data included age, country, and participant type (ie, people with PCOS or health professionals). Questions were largely similar across patient and health professional surveys, other than the use of plain language and explanation of technical terms for people with PCOS. Likert scales and free text response options were provided. Additional naming principles included scientific accuracy, ease of communication, stigma avoidance, and cultural appropriateness. Approaches presented included adopting a generic name, an accurate name reflecting features of the condition, or a name that retained the acronym PCOS with different terms. Each proposed approach included a list of terms and name options. The principles, preferred approach, and related options for this approach were carried forward to subsequent stages. Participants could opt to leave their email addresses for future involvement.

Survey A was provided on multiple online platforms (ie, Qualtrics, Google Forms, and WeChat) in English, Chinese, German, Persian, and Malaysian to optimise global reach. These languages were pragmatically selected and provided based on the most common spoken languages globally and the availability of workshop participants for translation, validation, and dissemination. For many other world regions, English proficiency was considered sufficient. All languages were accepted in free text comments. The survey link was disseminated via engaged societies and patient groups (through newsletters, dedicated email communication, and conference announcements), social media (ie, X and LinkedIn), and steering committee networks, and was open from April 1 to Oct 1, 2025. Survey results guided preparatory work for the workshops, including background research on naming options.

Survey B was generated to address specific controversies emerging from workshop A, including the reproductive term and final preferred name (appendix p 15). This survey was disseminated by email to survey A participants who had provided their email address, and to workshop A attendees, and was open from Jan 20 to Jan 31, 2026.

### Workshops

Recruitment of attendees was rigorous and purposive, as we aimed for engagement across world regions. People with PCOS included leaders in patient advocacy organisations and community-based participants. Health professionals included representatives from key disciplines and leading world experts. Recruitment sources included members of the steering committee, lead agency governing bodies, and single nominees from each engaged society or patient advocacy group. To engage broadly across world regions and disciplines, additional representatives were identified via networks and self-nomination in survey A. All participants were invited to complete an online expression of interest form on workshop availability, country, ethnicity, nominating organisation, and disciplines; health professionals were also asked about their experience in clinical care for PCOS, and people with PCOS were asked for their time since diagnosis. The steering committee approved the final workshop invitation list, with invitations then sent by email. No financial incentives were offered for participation, other than reimbursement for time and

***Panel 2:* Overview of the consensus process**

We conducted a structured, multistep global process to establish a new name for polycystic ovary syndrome, incorporating patient and professional perspectives across all world regions. Key stages included:

- Funding: we obtained resources for the name change process and translation (in September, 2024)
- Governance and stakeholder engagement: we established an international governance framework and recruited patient organisations, professional societies, and lived experience and multidisciplinary health professional experts (in December, 2024)
- Delphi surveys: building on 7708 previous survey responses, two further global surveys (launched in April, 2025, and January, 2026,) generated a further 14 360 responses from 10 411 patients and 3949 health professionals, that identified principles, approaches, terminology, and combinations for a new name
- Nominal group workshops: in November, 2025, and February, 2026, we held serial online workshops with participants from all world regions for systematic iterative testing of endocrine, metabolic, and reproductive terms, combinations, and acronyms, with prioritisation based on accuracy, acceptability, and cultural appropriateness
- Marketing and communication analysis: we applied branding and communication frameworks to assess feasibility, clarity, and transition strategies for candidate names in December, 2025
- Prioritised outcome: agreement among patients and health professionals on the new name (polyendocrine metabolic ovarian syndrome) occurred in February, 2026
- Implementation strategy: in 2025 and 2026, we developed a transition roadmap to support adoption across clinical practice, research, education, and public communication

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See Online for appendix

contribution from lead patient representatives on the steering committee. Independent observers were recruited and trained to facilitate.

Before workshop A, participants had to complete a code of conduct (appendix p 20) covering expected behaviours, confidentiality, and agreement to respect publication embargo and streamlined communication and messaging with signed agreement. The workshop agenda and a 15-min video presentation on the history of the name change, purpose, workshop processes (including transparent participant recruitment), consensus methods, and participants' roles and responsibilities, were disseminated to all participants. Principles and approaches generated from survey A were presented to underpin the workshop's structure and activities. Preparatory sessions and guiding documents were provided for breakout group chairs (ie, people with PCOS), co-chairs (health professionals), and independent observers. The workshop was conducted via Zoom with dedicated IT support provided by Monash University. Workshop A involved a brief introduction, outline of the code of conduct, presentation of survey results on principles and approaches, and presentations of the most accurate and supported terminology. Participants then engaged in breakout discussions, followed by individual online voting on preferred terms. The process was repeated after combining the terms to form the new name. Breakout groups were preassigned to ensure balanced representation across people with PCOS, disciplines, and world regions. All groups included participants from three to five world regions, three to four people with PCOS, and at least three disciplines. Each group was co-chaired by a patient and a health professional, with independent observers present to oversee adherence to the code of conduct. Each participant had a timed opportunity to raise any clarifications, concerns, or considerations. After breakout discussions, feedback was shared broadly by co-chairs and confidential online individual voting was conducted to rank priorities.

| | Survey A (n=3656) | Workshop registrations* (n=60) | Survey B (n=293) |
|---|---|---|---|
| Obstetrics and gynaecology | 1183 | 16 | 117 |
| Reproductive endocrinology | 664 | 15 | 94 |
| Endocrinology | 366 | 13 | 50 |
| Primary care | 267 | 3 | 36 |
| Nutrition or exercise | 215 | 2 | 64 |
| Nursing or midwifery | 136 | 2 | 39 |
| Paediatrics | 62 | 5 | 17 |
| Dermatology | 8 | 1 | 2 |
| Psychology | 34 | 1 | 24 |
| Academia or laboratory work | 292 | 2 | 81 |

Questions in surveys A and B were not mandatory, and multiple responses were allowed. Totals therefore might not equal the number of respondents.
*Five participants who attended workshop A were unable to attend workshop B.

*Table 1:* **Health professional disciplines represented across workshops and surveys A and B**

### Patient involvement

Verity, a UK patient charity and advocacy group, led the reinvigoration of the renaming initiative in 2023. The Australian Health Research Alliance guidance on patient involvement was followed throughout the name change process, supporting an active, respectful partnership in which people with PCOS were valued for their lived experience, and were involved as active contributors with shared power.[20] This involvement captured patients' real-world needs and values from global and multicultural perspectives to foster relevant, inclusive, and impactful outcomes. People with PCOS were integrally involved in all stages of governance, survey co-design, workshop development, presentations, dissemination, and communication. Survey results were disaggregated by participant group.

The implementation strategy was co-designed by implementation science experts in partnership with people with PCOS. These were based on the principles derived from survey A, the previous survey's impact assessment,[9] the Consolidated Framework for Implementation Research[21] and the Expert Recommendations for Implementing Change strategies,[22] professional marketing input, and workshop feedback. Ethics approval was obtained from the Monash Health Ethics Committee (project numbers 07070C and 78892).

## Outcomes and consensus

The steering group comprised a Chair (ie, author HJT), two people with PCOS (authors RM and LB), and seven multidisciplinary health professionals (authors HJT, JSEL, AEJ, MFC, RJN, AD, and TP) from three continents, and an academic project lead (MBK). The Androgen Excess and PCOS Society Board was an advisory body and included health professionals and academic leaders from multiple world regions and disciplines. Organisations were from across world regions and diverse health professional disciplines, including obstetrics and gynaecology, fertility, endocrinology, paediatrics, dermatology, imaging, primary care, nutrition science, and psychology (appendix p 23).

### Survey and workshop reach and participant characteristics

Survey A included responses from 9358 people with PCOS and 3656 health professionals. 27 people with PCOS and 63 health professionals participated in the workshops, and 1053 people with PCOS and 293 health professionals in survey B, with broad global representation (appendix p 24). Given the extensive, multichannel dissemination strategy, a response rate for survey A could not be determined. Health professionals represented a wide range of disciplines (table 1).

Workshop A was held in November, 2025, with 90 attendees from multiple world regions (table 1). Survey B was distributed to participants who had consented to recontact (n=2733), with 1346 responses received (response rate 49%). Participant characteristics for surveys A and B, including age distribution, duration of PCOS in patients, and years of PCOS-related experience among health professionals, are shown in table 2.

| | Survey A | | Survey B | |
|---|---|---|---|---|
| | Patients (n=9358) | Health professionals (n=3656) | Patients (n=1053) | Health professionals (n=293) |
| **Age, years** | | | | |
| 18–25 | 1563 (19%) | 103 (3%) | 116 (11%) | 3 (1%) |
| 26–35 | 4230 (50%) | 724 (24%) | 461 (44%) | 38 (13%) |
| 36–45 | 1866 (22%) | 866 (28%) | 292 (28%) | 82 (28%) |
| 46–55 | 523 (6%) | 696 (23%) | 112 (11%) | 93 (32%) |
| ≥56 | 187 (2%) | 612 (20%) | 57 (5%) | 74 (25%) |
| Prefer not to say | 75 (1%) | 47 (2%) | 6 (1%) | 2 (1%) |
| **Duration of PCOS, years** | | | | |
| <1 | 1052 (14%) | NA | 43 (4%) | NA |
| 1–5 | 2450 (31%) | NA | 299 (31%) | NA |
| 6–10 | 1564 (20%) | NA | 199 (20%) | NA |
| ≥11 | 2736 (35%) | NA | 440 (45%) | NA |
| **PCOS care, years** | | | | |
| ≤5 | NA | 812 (27%) | NA | 105 (24%) |
| 6–10 | NA | 624 (21%) | NA | 84 (19%) |
| 11–20 | NA | 716 (24%) | NA | 118 (27%) |
| >20 | NA | 845 (28%) | NA | 134 (30%) |

Percentages are calculated based on available responses for each variable; denominators therefore vary due to non-response. NA=not applicable. PCOS=polycystic ovary syndrome.

*Table 2:* **Participant characteristics across surveys**

## Principles

The guiding principles presented in panel 3 were affirmed in the survey results and endorsed at workshop A (table 3), with most people with PCOS and health professionals supporting the principles. Patient support was strongest for stigma avoidance, and health professionals for accuracy. These principles were carried forward throughout the consensus process (table 3).

## Approaches

The approach prioritised on survey was to adopt a new, symptom-based name (as voted for by 86% of people with PCOS and 71% of health professionals). The second ranked approach was adoption of a generic name, such as diabetes or asthma (favoured by 45% of people with PCOS and 54% of health professionals), and the third was retaining PCOS as the acronym (20% of people with PCOS and 40% of health professionals; table 3). This approach was endorsed in workshop A. Prominent themes in the free text comments highlighted long-held patient frustrations over the need for a name that was accurate, enhanced understanding of broader features, and included a focus on recognition that this was a female condition. Some responses noted the need to be aware of implications for individuals of diverse genders. Concerns were also expressed that if no change to the PCOS acronym occurred, the consensus process's impact would be diminished. Based on these results, only the approach for a new, accurate, symptom-based name was explored in the workshops and carried forward in subsequent steps.

## Key terms

Survey A's results, presented in table 3, show that endocrine and polyendocrine, metabolic and cardiometabolic, and ovulatory, ovary, and reproductive were terms supported by most participants. In workshop A, after presentation of the survey results, preferred approach, principles, and evidence summaries for accuracy, breakout groups confirmed support for a name change. Only two workshop participants were unsupportive of a name change, citing evolving science related to the genetic component of PCOS, the potential for a male phenotype, and concerns around rebranding and marketing.

Endocrine and metabolic terms were supported; however, consistent concerns arose around the reproductive term. Although accurately aligned to genetics, pathophysiology, and clinical features, the potential for the reproductive term to cause social stigmatisation and harm in some cultures or world regions was recognised. Alternative terms such as ovulatory were felt to be less stigmatising but did not encompass broader reproductive features or extend beyond menopause. Workshop A voting largely aligned with survey A's results, prioritising endocrine and metabolic terms. After discussions, ovulatory was preferred over reproductive, despite concerns that the term could be too narrow.

### *Panel 3:* Summary of naming principles

Principles guiding the development of a new name for polycystic ovary syndrome were established through global Delphi surveys and multistakeholder workshops.

- Support for clinical care, research, and improved health outcomes: the name should facilitate diagnosis, improve awareness, optimise care, and enhance research and understanding of the condition to improve health outcomes
- Scientific and medical accuracy: the name must reflect the underlying endocrine and metabolic pathophysiology and avoid inaccurately including ovarian cysts.
- Clarity and communication: the terminology should be readily understood by patients, clinicians, researchers, and the public
- Avoidance of stigma: terms perceived as potentially stigmatising—particularly those linked directly to reproduction or fertility—should be avoided
- Cultural and linguistic appropriateness: the name must be acceptable and interpretable across diverse cultural, linguistic, and regional contexts.
- Feasibility of implementation: the name should allow for a practical transition in clinical, research, and policy environments

### Potential names

In workshop A, the preferred terms were combined into candidate names (table 3) and assessed for duplication, pronunciation, stigma, and cultural implications. Some terms were excluded (eg, metabolic endocrine reproductive syndrome, as its acronym would duplicate that of Middle East respiratory syndrome). Endocrine metabolic ovulatory syndrome, although ranked top initially, was found to overlap with the so-called emo youth subculture, in which emotional expression—particularly melancholy, alienation, romantic despair, and anxiety—was central to identity formation. These issues, along with concerns on the most appropriate reproductive term, precluded consensus on a final new name and highlighted the need for further engagement processes.

| | Survey A (April to October, 2025; support %) | Workshop A (November, 2025; ranked first %)* | Survey B (January, 2026; ranked first %) | Workshop B (February, 2026; ranked first %) |
|---|---|---|---|---|
| **Naming principles** | | | | |
| Scientific accuracy | 67% | ✓ | ✓ | ✓ |
| Patients | 60% | .. | .. | .. |
| Health professionals | 86% | .. | .. | .. |
| Ease of communication | 68% | ✓ | ✓ | ✓ |
| Patients | 62% | .. | .. | .. |
| Health professionals | 85% | .. | .. | .. |
| Avoidance of stigma | 71% | ✓ | ✓ | ✓ |
| Patients | 66% | .. | .. | .. |
| Health professionals | 85% | .. | .. | .. |
| Cultural appropriateness | 60% | ✓ | ✓ | ✓ |
| Patients | 53% | .. | .. | .. |
| Health professionals | 80% | .. | .. | .. |
| **Naming approaches** | | | | |
| Generic name | 48% | NA | NA | NA |
| Patients | 46% | NA | NA | NA |
| Health professionals | 54% | NA | NA | NA |
| Unchanged PCOS acronym, new terms | 25% | NA | NA | NA |
| Patients | 20% | NA | NA | NA |
| Health professionals | 39% | NA | NA | NA |
| Accurate name | 82% | ✓ | ✓ | ✓ |
| Patients | 86% | .. | .. | .. |
| Health professionals | 70% | .. | .. | .. |
| **Key terms** | | | | |
| Endocrine features | | | | |
| Endocrine | 85% | 65% | ✓ | NA |
| Patients | 89% | NA | .. | NA |
| Health professionals | 74% | NA | .. | NA |
| Polyendocrine | 81% | 35% | NA | ✓ |
| Patients | 88% | NA | NA | .. |
| Health professionals | 60% | NA | NA | .. |
| Metabolic features | | | | |
| Cardiometabolic | 52% | 21% | NA | NA |
| Patients | 52% | NA | NA | NA |

(Table 3 continues on next page)

### Additional steps

Review of all survey responses and breakout discussions, and reconsideration of alternative terms with majority support, highlighted polyendocrine and ovarian as potential alternative terms. Pro bono assessment from leading experts in a global marketing agency, including the use of artificial intelligence marketing, did not identify any additional terms or names beyond those already considered. The recommendation was for evolutionary rebranding—which supports some continuity with an existing name or acronym and is framed as an update—rather than revolutionary rebranding, which implies a new condition. Survey B in January, 2026, yielded 1346 responses (from 1053 people with PCOS and 293 health professionals) from across all world regions. Terms presented included ovary and ovulatory, with ovulatory ranking the highest on surveys (table 3); thematic analysis of free text responses confirmed limitations of these terms, with incomplete representation of ovarian, endocrine, and follicular disturbances, and irrelevance after menopause. Polyendocrine was included as an option, alongside endocrine, based on majority support from survey A, workshop concerns on the cultural implications of the acronym EMOS, and because it offered an evolutionary marketing approach with similarity to the current acronym, PCOS. Workshop B presentations and breakout groups reviewed all survey results and free text comments for ovary-related terms (ie, ovulatory and ovary from survey A, and ovarian from previous surveys, with 62% of people with PCOS and 67% of health professionals supporting the latter on surveys). Ultimately, workshop voting prioritised ovarian (encompassing endocrine, follicular, and ovulatory disturbances), over ovary or ovulatory.

### New name

The top ranked name on survey B was polyendocrine metabolic ovulatory syndrome. Workshop B revised this to polyendocrine metabolic ovarian syndrome. All participants supported the new name, except for two participants who also did not support a name change. The need for careful attention in language translation was also captured.

### Implementation

The co-designed implementation strategy was presented and discussed in workshop breakout groups. Individual feedback was collected from breakout groups and in live online surveys to finalise the strategy (panel 4).

## Implications

This unprecedented and comprehensive international health policy initiative was ultimately focused on

implementation for global-level impact. The robust process generated representativeness, legitimacy, and transparency, with engagement of people with PCOS, health professionals, and 56 organisations across world regions. Building on a mandate for change, 14 360 survey responses and multiple workshops with around 90 representatives generated agreed principles, supporting better outcomes for people with PCOS, scientific accuracy, ease of communication, avoidance of stigma, cultural appropriateness, and optimising implementation. The preferred approach was evolution to a new accurate name that retained some similarity to PCOS to enable its implementation. Ultimately, prioritised terms were polyendocrine, metabolic, and ovarian, and the preferred name for the condition formerly known as PCOS was polyendocrine metabolic ovarian syndrome (PMOS). An implementation strategy was codeveloped and is under way.

A clear rationale and mandate for change underpinned this consensus process.[9] The need to correct the inaccurate polycystic term (which implies pathological ovarian cysts)[10] and recognise the multisystem features of the condition[2] were prioritised by patient and health professional groups. and government agencies.[14] Widespread delayed diagnosis, knowledge gaps, and patient dissatisfaction with information provision and care, are well documented.[9,12,13] Although International Guidelines, evidence-based resources, and ongoing patient and health professional advocacy have contributed to improved awareness, confusion associated with the name has persisted, reinforcing the mandate for change (panel 1).[9] Renaming a medical condition is a complex process that requires funding, governance, broad engagement, and adherence to robust methods and processes. Such a change also necessitates stakeholder engagement to ensure representativeness, legitimacy, and transparency, and to optimise implementation.[9] Throughout this process, we built on a clear mandate for change, secured funding, established leadership and governance, delivered a coordinated global consensus process, obtained broad and inclusive engagement between people with PCOS and multidisciplinary health professionals, and achieved agreement on principles and approaches. We applied iterative Delphi surveys and nominal group workshop techniques that were linked to a robust implementation strategy.[17,18,20–22] This approach addressed barriers and surpassed previous stalled renaming attempts to exemplify an inclusive, iterative process that could help guide future name change initiatives.

PMOS encompasses multiple interacting endocrine abnormalities, rather than an isolated ovarian disorder.[5,23–25] Meta-analyses of large-scale genomic analyses and recent definitive studies confirm that PMOS has polygenic origins across neuroendocrine, metabolic, and reproductive pathways.[26,27] Hyperandrogenism is a defining endocrine and diagnostic feature, with elevated ovarian—and often adrenal—androgens contributing to hirsutism, acne, alopecia, and metabolic features.[2,28,29] Central neuroendocrine abnormalities include increased gonadotropin-releasing hormone pulsatility, with consequent elevations in luteinising hormone that drive

| | Survey A (April to October, 2025; support %) | Workshop A (November, 2025; ranked first %)* | Survey B (January, 2026; ranked first %) | Workshop B (February, 2026; ranked first %) |
|---|---|---|---|---|
| (Continued from previous page) | | | | |
| Health professionals | 52% | NA | NA | NA |
| Metabolic | 76% | 79% | ✓ | ✓ |
| Patients | 74% | NA | .. | .. |
| Health professionals | 80% | NA | .. | .. |
| Reproductive features | | | | |
| Reproductive | 54% | 40% | NA | NA |
| Patients | 52% | NA | NA | NA |
| Health professionals | 63% | NA | NA | NA |
| Ovary | 42% | NA | NA | 25% |
| Patients | 38% | NA | NA | 8% |
| Health professionals | 53% | NA | NA | 30% |
| Ovulatory | 54% | 60% | 51% | 5% |
| Patients | 51% | NA | 49% | 8% |
| Health professionals | 64% | NA | 64% | 5% |
| Gynaecological | NA | NA | 37% | NA |
| Patients | NA | NA | 40% | NA |
| Health professionals | NA | NA | 27% | NA |
| Repro† | NA | NA | 13% | NA |
| Patients | NA | NA | 11% | NA |
| Health professionals | NA | NA | 9% | NA |
| Ovarian | NA | NA | NA | 70% |
| Patients | NA | NA | NA | 85% |
| Health professionals | NA | NA | NA | 65% |
| **Names and acronyms for combination of terms** | | | | |
| Endocrine metabolic ovulatory syndrome | NA | NA | 22% | NA |
| Patients | NA | NA | 22% | NA |
| Health professionals | NA | NA | 24% | NA |
| Ovulatory metabolic endocrine syndrome | NA | NA | 11% | NA |
| Patients | NA | NA | 10% | NA |
| Health professionals | NA | NA | 19% | NA |
| Polyendocrine metabolic ovarian syndrome‡ | NA | NA | 66% | ✓ |
| Patients | NA | NA | 69% | .. |
| Health professionals | NA | NA | 57% | .. |

Tick marks indicate the option was prioritised and carried forward to the next stage of the consensus process. NA=not assessed. *Ranked first indicates the percentage of respondents who selected the option as their highest-ranked (most preferred) choice. †Repro was provided as an option for reproductive, with examples including repro-endocrine or repro-metabolic. ‡Polyendocrine metabolic ovarian syndrome was substituted for endocrine metabolic ovulatory syndrome given its majority support in survey A workshop A, marketing recommendations and cultural considerations, and to address challenges associated with the acronym of endocrine metabolic ovulatory syndrome (EMOS). PCOS=polycystic ovary syndrome.

***Table 3:*** **Iterative development of naming components across surveys and workshops**

***Panel 4:*** **Eight stages for global implementation of the new name for polycystic ovary syndrome, polyendocrine metabolic ovarian syndrome**

The implementation strategy was informed by considerations highlighted in survey responses, and was co-designed with consumers, marketing and implementation experts, and governance bodies (including health professional experts), and was based on implementation science frameworks.

**Stage 1: publication and academic dissemination**
Publication of this Health Policy, supported by accompanying commentaries, clinical reviews, editorial correspondence, and updates to textbooks and educational materials.

**Stage 2: resource development**
Co-design of patient and health professional resources in multiple languages and for diverse platforms and delivery modes.

**Stage 3: global communication and engagement**
Implementation of a structured communication strategy, including society toolkits, multilingual patient and clinician resources, multimedia dissemination, professional education programmes, and coordinated events for patients and health professionals worldwide.

**Stage 4: integration within health care and health information systems**
Incorporation of the new terminology into electronic health records, including within Systematized Nomenclature of Medicine—Clinical Terms, and engagement with major electronic medical record vendors and key stakeholders in health-care provider education (eg, universities and textbook publishers).

**Stage 5: policy and research alignment**
Engagement with governments, research funders, journal editors, regulators, and the health-care industry (including the pharmaceutical industry), to support adoption across research classifications, publication processes, and funding systems.

**Stage 6: international classification and global bodies**
Formal engagement with international bodies, including WHO, to progress integration into disease classification systems, including the ICD.

**Stage 7: transition and future refinement**
A managed transition period of 3 years with monitoring and evaluation, consideration of emerging evidence on subtypes, and refinement of terminology as scientific understanding evolves.

**Stage 8: guidelines**
Integration into the International Guideline, which is already used in 195 countries and will next be updated in 2028.

excessive ovarian androgen.[24] Insulin resistance and compensatory hyperinsulinaemia, present in 85% of affected individuals (75% of lean women [with BMI ≤25 kg/m²] with PMOS),[30,31] amplify androgen secretion and disrupt steroidogenesis, highlighting the metabolic–endocrine interplay.[30,31] Altered AMH concentrations, ovarian endocrine function, adipokine signalling, and gut–hormone interactions influence clinical features, including reproductive and metabolic manifestations.[5,32] Furthermore, the combination of endocrine disturbances underpin pregnancy risks, which are compounded by metabolic features.[33,34] Collectively, these complex endocrine abnormalities underscore the multisystem manifestations of PMOS and support reframing it as a polyendocrine condition that extends beyond ovarian pathology.

Metabolic abnormalities underpin PMOS, from genetic origins to clinical manifestations.[2,5,26,35] Insulin resistance affects the majority of people with PMOS and contributes to androgen excess, which, together with low-grade inflammation and dysfunctions in adipokine signalling and the sympathetic nervous system, drives metabolic dysfunction.[5,36] Obesity—particularly central adiposity—is increased in people with PMOS, implicated as causal on mendelian randomisation studies, and exacerbates symptom severity.[2,37] Lifestyle, pharmacological, and surgical weight management interventions have shown clinical benefit.[37–40] Cardiometabolic complications, such as impaired glucose tolerance, gestational diabetes, metabolic dysfunction-associated steatotic liver disease, type 2 diabetes, dyslipidaemia, hypertension, and vascular dysfunction are increased in PMOS, exacerbated by obesity, and drive cardiovascular disease risk.[2,5,35,41,42] Evidence from women who are predominantly premenopausal shows that the odds ratios of composite cardiovascular disease (1·68), myocardial infarction (2·50), and stroke (1·71) are increased in those with PMOS compared with those without PMOS.[43] Collectively, this evidence shows that metabolic features are inherent in PMOS, which firmly endorses incorporation of the metabolic term in the revised nomenclature.

Ovarian dysfunction is a defining feature of PMOS, with genetic origins and disturbances in endocrine and paracrine function during and beyond reproductive life stages.[5] Neuroendocrine abnormalities disrupt ovarian steroidogenesis and impair follicular maturation. Such dysfunction is exacerbated by hyperinsulinaemia-driven dysregulation of granulosa and theca cells, which worsens hyperandrogenism.[5] These abnormalities disrupt folliculogenesis and result in accumulation of small antral follicles, as seen in the classic ultrasonographic appearance of this condition.[44] Elevated AMH occurs with disordered folliculogenesis, and is now included in adult diagnostic criteria.[2,32] Clinically, these abnormalities manifest as ovulatory dysfunction, menstrual irregularity, and infertility, endorsing the explicit inclusion of ovarian in the new nomenclature. Other features of the condition, such as psychological and dermatological changes, are important but are largely secondary to endocrine changes, and these terms were not supported for inclusion in the new name.[9]

The implementation strategy for the new name was generated through use of a structured, co-designed process grounded in the Consolidated Framework for Implementation Research and Expert Recommendations for Implementing Change.[21,22] Led by implementation experts and informed by implementation priorities identified from the surveys and workshops outlined here,[9] patients' and health professionals' input, and marketing specialists, the multistage global implementation strategy aids transition to the new name

and incorporates evaluation (panel 4). This strategy includes: publication and academic dissemination; development of multilingual resources for people with PCOS and clinicians; coordinated global communication and engagement; integration into electronic health records and health-care education systems; alignment with policy agencies, research funders, and journal processes; formal engagement with international classification bodies, including WHO, for adoption in the ICD; and a managed 3-year transition and planned integration into the 2028 update of the International Guidelines, which are already used in 195 countries.[2] This implementation strategy is supported by an embedded evaluation plan. Key considerations include meaningful language translation and cultural appropriateness, especially where reproductive implications and infertility can be linked to the supposed value or worth of an affected individual. This approach creates the implementation architecture to support consistent global uptake of the new name for sustainable change across policy, research, health systems, practice, and outcomes.

This Health Policy initiative has both strengths and limitations. A major strength is the unprecedented partnership and involvement with stakeholders (ie, people with PCOS and health professionals) across all stages, including governance, conceptualisation, co-design, recruitment, interpretation of results, participation in consensus workshops, and implementation. Robust consensus methods were applied. The consensus process presents an exemplar to overcome barriers in name change processes as scientific understanding evolves. Limitations of this Health Policy initiative include disproportionate representation across world regions and disciplines, with lower participation from middle-income and low-income countries, and from Asia, Africa, and South America. Furthermore, the use of a purposive, non-probability sampling approach and voluntary participation could introduce selection bias and hinder generalisability. In addition, response rates could not be determined for survey A due to broad dissemination. Despite these limitations, analysis of survey results by region did not identify major differences in the final terms or name preferences. The overwhelming majority of participants in earlier surveys and workshops supported a name change, and the principles, approach, and terms used.

## Conclusion

In this common yet historically neglected female condition affecting more than 170 million individuals worldwide, we led global engagement of people with PCOS and health professionals through a structured, multistep, robust process to generate a new name that avoids misleading references to ovarian cysts and accurately reflects the condition's diverse and multisystem features. The condition formerly known as PCOS now has a new name: polyendocrine metabolic ovarian syndrome. This change has global implications for health-care systems, policy, and research, and for advancing understanding and treatment of the condition. Transition to the new name will occur over 3 years, supported by a multifaceted implementation strategy. Overall goals include greater awareness, enhanced diagnosis, improved care quality and patient satisfaction, and optimised outcomes across the broad features of the condition. The transition is underpinned by a global implementation and embedded evaluation strategy.

#### Contributors

HJT is the lead investigator and led this Health Policy initiative from funding to conception, engagement, analysis, interpretation, and drafting the publication. AEJ, RJN, and MFC are investigators of the Centre for Research Excellence in Women's Health in Reproductive Life. Authors included members of the Steering Committee and Androgen Excess and Polycystic Ovary Syndrome Society Board who contributed to the concept, design, governance, and completion of this Health Policy. HJT, MBK, and RM led survey development, dissemination, and analysis, and workshop design and analysis. All named authors and those in the international network (appendix pp 25–27) engaged in the surveys and workshops, could access the data on request, and contributed to data interpretation in the workshops, and to editing and revising the manuscript. All authors had final responsibility for the decision to submit for publication, and all provided their approval for submission.

#### Declaration of interests

HJT is the primary investigator of the Australian National Health and Medical Research Council (NHMRC)-funded Centre for Research Excellence in Women's Health in Reproductive Life (APP number 1171592), and is supported by an NHMRC Fellowship (APP number 2009326). She is the unpaid President of the International Society of Endocrinology and lead on the International Polycystic Ovary Syndrome Guidelines and the National Institute for Health and Care Excellence (NICE) Guidelines Committee. RM has received grants from Waterloo Foundation and Verity for administrative support, the James Lind Alliance Priority Setting Partnership, and the All-Party Parliamentary Group. She has received support from Roche Pharmaceutical for travel and time to film patient story videos. She is an unpaid Trustee of Verity and a member of the International Guidelines Steering Group and the NICE Guidelines Committee (honoraria). JSEL has received grants and personal fees from Astellas, Ferring, Gedeon Richter, and Siemens. He is a member of the Androgen Excess and Polycystic Ovary Syndrome (AE-PCOS) Society Board and a member of the Data Safety Monitoring Board of the LOCI trial. He is the Chief Executive Officer and owner of JSEL Consultancy. AEJ has received honoraria from Amgen, Novo Nordisk, and Eli Lilly for presentations. She served on the Board of Directors of the AE-PCOS Society and has received free continuous glucose monitoring devices (ie, Freestyle Libre, Dexcom G7, and OnePlus) for research or clinical purposes. DAR is the Chair of the steering committee for the LOCI trial, a topic adviser for the NICE Guideline Committee, a board member of the AE-PCOS Society, and participates in the All-Party Parliamentary Group on Polycystic Ovary Syndrome. RJN reports support from the Centre for Research Excellence in Women's Health in Reproductive Life, consulting fees from Westmead Fertility and VinMec Hospital, is Chair of the Data Safety Monitoring Board for a Chinese natural therapies and miscarriage study (NCT02633878), and is Chair of the Clinical Advisory Committee at Westmead Fertility. AD serves as Executive Director of the AE-PCOS Society. TP has received project grants from Novo Nordisk, the Research Council of Finland, and the Sigrid Juselius Foundation; consulting fees from Exeltis and Astellas; honoraria from Exeltis, Gedeon Richter, Stragen, and Bayer; and travel support from Gedeon Richter. She is the unpaid President of the AE-PCOS Society. All other authors declare no competing interests.

#### Data sharing

We can share de-identified, individual participant-level survey data once all analyses are completed and after receipt of a request detailing the study hypothesis and statistical analysis plan. All requests should be sent

to the corresponding author (helena.teede@monash.edu). The steering committee of this study will discuss all requests and decide, based on the scientific rigour of the proposal, whether data sharing is appropriate. All applicants will be asked to sign a data access agreement.

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## Supplementary appendix

This appendix formed part of the original submission and has been peer reviewed. We post it as supplied by the authors.

Supplement to: Teede HJ, Khomami MB, Morman R, et al. Polyendocrine metabolic ovarian syndrome, the new name for polycystic ovary syndrome: a multistep global consensus process. *Lancet* 2026; published online May 12. https://doi.org/10.1016/S0140-6736(26)00717-8.

# Supplementary appendices

## Table of Contents

## Supplementary Box 1. Survey A: questions and response options

### Polycystic Ovary Syndrome (PCOS) Consultation – Renaming the Condition

**Summary**

***What's Been Done?***

In 2018 and 2023, global guidelines confirmed PCOS is a complex condition with hormonal, reproductive, metabolic, and mental health features. Previous surveys and discussions with over 7,700 people showed interest in re-evaluating the name, though views were mixed.

***What's Happening Now?***

An international group of patients, healthcare professionals, and researchers is gathering input to improve understanding, care, and communication about PCOS.

***Why This Survey?***

Polycystic Ovary Syndrome (PCOS) is a common condition that affects around 1 in 8 women globally. Some feel the current name does not fully reflect what the condition involves or may lead to confusion.

***Why Your Input Matters?***

We're now inviting a broader range of people to share their thoughts on:

- What matters most in a name
- Possible naming ideas or terms
- Reactions to names suggested so far
-

***Want more information?***

**Further details on the background work, naming considerations, and objectives of this consultation are provided in the following section after you indicate your role.**

We value your input via this international 5-10 minute voluntary survey which is fully anonymous, with no obligation to answer any specific questions. Ethics approval has been obtained. For further information on the survey contact Helena.Teede@monash.edu.

This survey can only be completed once by each participant.

***By clicking the next option below, you acknowledge that you understand the purpose of this survey and you consent to participate.***

Q1 Are you? (Tick one)

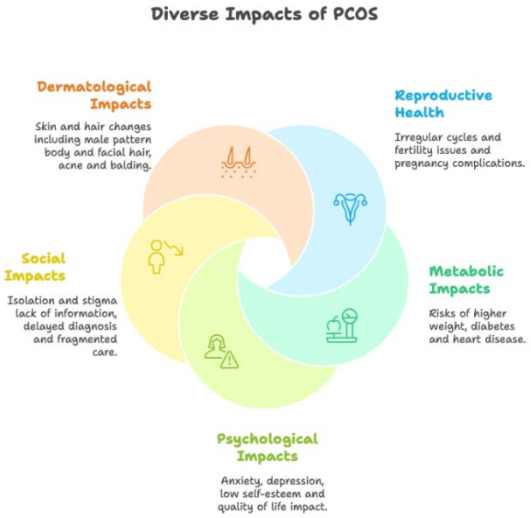
- ○ An individual with PCOS, a family member and support person/group
- ○ A healthcare professional/ researcher

PCOS affects 1 in 8 women globally, yet limited research and health professional education has led to underdiagnosis, under treatment, and few dedicated models of care. Patients worldwide report delayed diagnosis, insufficient provider knowledge, dissatisfaction with care, and misinformation, especially through social media. These challenges are partly due to the misleading name 'polycystic ovary syndrome'.

With growing evidence synthesised for the 2023 international PCOS Guideline, we now understand that:

- PCOS does not involve pathological ovarian cysts and is not an isolated ovarian or gynaecological disease.

- It is a chronic, genetic, and lifestyle-related condition underpinned by endocrine (hormonal) changes, including insulin resistance and hyperandrogenism.




- Its broad clinical features span reproductive, psychological, cardiometabolic, and dermatological (skin) health.
- The name is not fit for purpose and there is global consensus that it has caused confusion and adversely impacted research, education, and patient care.

### *What Has Been Done So Far?*

The Australian Centre for Research Excellence in Women's Health in Reproductive Life partnered with the European Society of Human Reproduction and Embryology, The American Society for Reproductive Medicine, Endocrine Society, European Society for Endocrinology, Androgen Excess and Polycystic Ovary Syndrome Society and 34 other Societies and consumer groups from six continents in the International PCOS Guideline in 2018, updated in 2023. Leveraging insights from the Guideline and assembled evidence on cause and clinical features, global engagement explored **whether** a name change was warranted and to understand the impact of a potential name change. We conducted global surveys and workshops with 7,708 health professionals and patients confirming overwhelming support for a name change (76-86%), generating a consensus that the name will be changed, with perception that benefits outweighed disadvantages. Key preferred terms were identified during this process.

### *Delivering that change together - What's Next?*

We are now delivering a global consensus process across patients and diverse health professionals to establish the most acceptable name to all stakeholders, recognising that any name change must engage stakeholders, avoid stigma, retain historical links and be culturally appropriate. The process follows best practice building on the 7,708 perspectives to date and will include:

- a global survey across broader world regions and societies in April - August 2025 (what you are doing now)
- an international forum with robust and embedded voting in September 2025
- formal International Classification of Diseases change processes implementation and education with a five-year transition period (whereby the condition will be referenced as “new name” formerly known as PCOS)

***How Can You Contribute?***

The name will be changed, and we invite you to engage in this global effort by sharing your perspectives on:

- Principles that should guide the new name.
- Naming preferences, including previously proposed options from the literature and international surveys and any new options that best reflect the nature of the condition.

## About You

Display this question:

*A patient*

Q2 What is your current age range (years)?

- ○ <18
- ○ 18 - 25
- ○ 26 - 35
- ○ 36 - 45
- ○ 46 - 55
- ○ ≥ 56
- ○ Prefer not to say

*A healthcare professional/ researcher*

Q2_1 What is your current age (years)?

- ○ 18 - 25
- ○ 26 - 35
- ○ 36 - 45
- ○ 46 - 55
- ○ >56
- ○ Prefer not to say

*A patient*

Q3 Are you?

- ○ A person with PCOS (diagnosed by a health professional)
- ○ A person who thinks they may have PCOS
- ○ A family member of someone who has PCOS
- ○ A support person of someone who has PCOS
- ○ Other (please specify) _____

*A healthcare professional/ researcher*

Q3_1 Are you? (Tick all that apply)

- ☐ A medical endocrinologist
- ☐ A reproductive endocrinologist
- ☐ An obstetrician/gynecologist

- [ ] A pediatrician
- [ ] A dermatologist
- [ ] A general practitioner/internist/general physician
- [ ] A nurse or midwife
- [ ] A dietitian
- [ ] Other allied health professional (exercise physiologist/health coach)
- [ ] A psychologist or psychiatrist
- [ ] A researcher (academic)
- [ ] Other (please specify) _____

Q4 What country do you live in?

▼ Afghanistan ... Zimbabwe

Your country is not listed above?

Q5 Please specify your current country of residence:

_____

*A patient*

Q6 What country do you consider your ethnic origin or family came from?

▼ Afghanistan ... Zimbabwe

*A patient*

Q7 Your country of ethnic or family origin is not listed above? Please specify:

_____

*A patient*

Q8 How long have you been diagnosed with PCOS?

- ○ <1 year
- ○ 1-5 years
- ○ 6-10 years
- ○ 11 years or more

*A healthcare professional/ researcher*

Q8_1 How long have you been involved in PCOS care or research?

- ○ 5 years or less
- ○ 6-10 years
- ○ 11-20 years

○ More than 20 years

## Naming ideas and what is important to you

*A healthcare professional/ researcher*

Q9 How much do you support each of the following principles in renaming PCOS?
(Please rate each option on a scale of 1 to 5, where 1 = Strongly oppose and 5 = Strongly support.)

| | Strongly oppose | Oppose | Neither support nor oppose | Support | Strongly support | I am unsure |
|---|---|---|---|---|---|---|
| Scientific and medical accuracy (ensuring the name reflects the condition's underlying mechanisms and clinical features) | ○ | ○ | ○ | ○ | ○ | ○ |
| Ease of pronunciation and communication (accessible for both healthcare professionals and patients) | ○ | ○ | ○ | ○ | ○ | ○ |
| Avoiding stigma and negative connotations (ensuring the name does not reinforce misconceptions or harmful stereotypes) | ○ | ○ | ○ | ○ | ○ | ○ |
| Cultural and linguistic appropriateness (ensuring the name is respectful, culturally safe, and linguistically appropriate for all communities) | ○ | ○ | ○ | ○ | ○ | ○ |

*A patient*

Q9_1 How much do you support each of the following in a new name for PCOS? (Please rate each option on a scale of 1 to 5, where 1 = Strongly oppose and 5 = Strongly support.)

| | Strongly oppose | Oppose | Neither support nor oppose | Support | Strongly support | I am unsure |
|---|---|---|---|---|---|---|
| The name matches current science and facts about PCOS. | ○ | ○ | ○ | ○ | ○ | ○ |

| | | | | | | |
|---|---|---|---|---|---|---|
| The name is easy to say and understand. | ○ | ○ | ○ | ○ | ○ | ○ |
| The name does not feel negative or hurtful. | ○ | ○ | ○ | ○ | ○ | ○ |
| The name makes sense in different cultures and languages. | ○ | ○ | ○ | ○ | ○ | ○ |

*A healthcare professional/ researcher*

Q10 Any other principles you believe should be considered in renaming PCOS?

_____

*A patient*

Q10_1 Any other things you believe should be considered when choosing a new name?

_____

*A healthcare professional/ researcher*

Q11 How much do you support each of the following approaches for renaming PCOS?
Please rate each option on a scale of 1 to 5, where 1 = Strongly oppose and 5 = Strongly support.)

| | Strongly oppose | Oppose | Neither support nor oppose | Support | Strongly support | I am unsure |
|---|---|---|---|---|---|---|
| Adopt a neutral or generic name not tied to specific symptoms (similar to 'diabetes', which is widely accepted but not a literal description of symptoms) | ○ | ○ | ○ | ○ | ○ | ○ |
| Adopt a new name based on symptoms and clinical presentation (as proposed in literature or by stakeholders) | ○ | ○ | ○ | ○ | ○ | ○ |
| Keep the current acronym (PCOS) but with different and more accurate words for each letter | ○ | ○ | ○ | ○ | ○ | ○ |

*A patient*

Q11_1 How much do you support each of the following approaches for renaming PCOS?
Please rate each option on a scale of 1 to 5, where 1 = Strongly oppose and 5 = Strongly support.)

| | Strongly oppose | Oppose | Neither support nor oppose | Support | Strongly support | I am unsure |
|---|---|---|---|---|---|---|
| Pick a simple and general name, like “diabetes” or “asthma.” | ○ | ○ | ○ | ○ | ○ | ○ |

| | | | | | | |
|---|---|---|---|---|---|---|
| Choose a brand-new name based on what the condition is now known to be. | ○ | ○ | ○ | ○ | ○ | ○ |
| Keep the letters "PCOS" but change what the letters stand for. | ○ | ○ | ○ | ○ | ○ | ○ |

*A healthcare professional/ researcher*

Q12 Any additional approaches to renaming PCOS?

_____

*A patient*

Q12_1 Do you have other ideas about how the name should be chosen?

_____

*A healthcare professional/ researcher*

Q13 If a neutral or generic name were to be chosen (like how diabetes is named), what name do you think would be suitable for this condition?

_____

*A patient*

Q13_1 Some people think the condition should have a general name that does not focus on body parts or symptoms (like how 'diabetes' is named).
Do you have ideas for a more general or neutral name?

_____

Q14 If a neutral or generic name were to be adopted, how much do you support each of these name options?

| | Strongly oppose | Oppose | Neither support nor oppose | Support | Strongly support | I am unsure |
|---|---|---|---|---|---|---|
| Endorina | ○ | ○ | ○ | ○ | ○ | ○ |
| Crinora | ○ | ○ | ○ | ○ | ○ | ○ |
| Endira | ○ | ○ | ○ | ○ | ○ | ○ |
| Crisa | ○ | ○ | ○ | ○ | ○ | ○ |
| PCOS | ○ | ○ | ○ | ○ | ○ | ○ |

*A healthcare professional/ researcher*

Q15 In previous surveys of healthcare professionals and patients, we explored potential terms for a new name for this condition. Healthcare professionals supported Androgens, Cardiometabolic and Reproductive
(However, it is important to note that the terms 'Reproductive' and 'Androgens' raised concerns about potential stigma in certain cultures
Healthcare professionals and patients supported Endocrine and Metabolic.

Considering this, please indicate the extent to which you support the inclusion of each of the following terms in a new name.

*A healthcare professional/ researcher*

| | Strongly oppose | Oppose | Neither support nor oppose | Support | Strongly support | I am unsure |
|---|---|---|---|---|---|---|
| Endocrine | ○ | ○ | ○ | ○ | ○ | ○ |
| Polyendocrine | ○ | ○ | ○ | ○ | ○ | ○ |
| Hormonal | ○ | ○ | ○ | ○ | ○ | ○ |
| Insulin resistance | ○ | ○ | ○ | ○ | ○ | ○ |
| Androgens | ○ | ○ | ○ | ○ | ○ | ○ |
| Cardiometabolic | ○ | ○ | ○ | ○ | ○ | ○ |
| Metabolic | ○ | ○ | ○ | ○ | ○ | ○ |
| Reproductive | ○ | ○ | ○ | ○ | ○ | ○ |
| Ovary | ○ | ○ | ○ | ○ | ○ | ○ |
| Syndrome | ○ | ○ | ○ | ○ | ○ | ○ |
| Spectrum (A range of symptoms that can vary in severity, type, and how they appear (presentation) in different people) | ○ | ○ | ○ | ○ | ○ | ○ |
| None (I prefer a neutral or generic name not tied to specific symptoms) | ○ | ○ | ○ | ○ | ○ | ○ |

*A patient*

Q15_1 In previous surveys of healthcare professionals and patients, we explored potential terms for a new name for this condition.

- **Healthcare professionals** supported **Androgens**, **Cardiometabolic** and **Reproductive** (However, it is important to note that the terms 'Reproductive' and 'Androgens' raised concerns about potential stigma in certain cultures).
- **Healthcare professionals and patients** supported **Endocrine** and **Metabolic**.

Considering this, how much do you support including these words in a future name for PCOS.

| | Strongly oppose | Oppose | Neither support nor oppose | Support | Strongly support | I am unsure |
|---|---|---|---|---|---|---|
| Endocrine (about hormones) | ○ | ○ | ○ | ○ | ○ | ○ |
| Polyendocrine (affects many hormone systems) | ○ | ○ | ○ | ○ | ○ | ○ |
| Hormonal | ○ | ○ | ○ | ○ | ○ | ○ |
| Insulin resistance | ○ | ○ | ○ | ○ | ○ | ○ |
| Androgens | ○ | ○ | ○ | ○ | ○ | ○ |
| Cardiometabolic (about heart and metabolism) | ○ | ○ | ○ | ○ | ○ | ○ |
| Metabolic (about how the body uses energy) | ○ | ○ | ○ | ○ | ○ | ○ |
| Reproductive (about periods, ovary function and ability to have children) | ○ | ○ | ○ | ○ | ○ | ○ |
| Ovary | ○ | ○ | ○ | ○ | ○ | ○ |
| Syndrome (a group of symptoms) | ○ | ○ | ○ | ○ | ○ | ○ |
| Spectrum (a range of symptoms or experiences) | ○ | ○ | ○ | ○ | ○ | ○ |
| None (I prefer a neutral or generic name not tied to specific symptoms) | ○ | ○ | ○ | ○ | ○ | ○ |

*A healthcare professional/ researcher*

Q16 Any other terms to be included in a new name?

_____

*A patient*

Q16_1 Are there other words you think should be included in a new name?

_____

*A healthcare professional/ researcher*

Q17 If a new name were to be adopted based on symptoms and clinical characteristics, please indicate your level of support for each of the following options:

| | Strongly oppose | Oppose | Neither support nor oppose | Support | Strongly support | I am unsure |
|---|---|---|---|---|---|---|

| | | | | | | |
|---|---|---|---|---|---|---|
| Polyendocrine Cardiometabolic Ovulatory syndrome (PCOS) | ○ | ○ | ○ | ○ | ○ | ○ |
| Metabolic Reproductive Syndrome (MeRS) | ○ | ○ | ○ | ○ | ○ | ○ |
| Reproductive Metabolic Syndrome (RMS) | ○ | ○ | ○ | ○ | ○ | ○ |
| Metabolic Reproductive Endocrine Syndrome (MRES) | ○ | ○ | ○ | ○ | ○ | ○ |
| Chronic Polyendocrine Syndrome (CPS) | ○ | ○ | ○ | ○ | ○ | ○ |
| Polyendocrine Complex Ovulatory syndrome (PCOS) | ○ | ○ | ○ | ○ | ○ | ○ |
| Polyendocrine Chronic Ovulatory syndrome (PCOS) | ○ | ○ | ○ | ○ | ○ | ○ |
| Endocrine Metabolic Reproductive Syndrome (EMRS) | ○ | ○ | ○ | ○ | ○ | ○ |
| Endocrine Reproductive Metabolic Syndrome (ERMS) | ○ | ○ | ○ | ○ | ○ | ○ |

*A patient*

Q17_1 If a new name were to be adopted based on symptoms and clinical characteristics, how much do you support each of these name options?

| | Strongly oppose | Oppose | Neither support nor oppose | Support | Strongly support | I am unsure |
|---|---|---|---|---|---|---|
| Polyendocrine Cardiometabolic Ovulatory syndrome (PCOS) | ○ | ○ | ○ | ○ | ○ | ○ |
| Metabolic Reproductive Syndrome (MeRS) | ○ | ○ | ○ | ○ | ○ | ○ |
| Reproductive Metabolic Syndrome (RMS) | ○ | ○ | ○ | ○ | ○ | ○ |
| Metabolic Reproductive Endocrine Syndrome (MRES) | ○ | ○ | ○ | ○ | ○ | ○ |
| Chronic Polyendocrine Syndrome (CPS) | ○ | ○ | ○ | ○ | ○ | ○ |
| Polyendocrine Complex Ovulatory syndrome (PCOS) | ○ | ○ | ○ | ○ | ○ | ○ |

| | | | | | | |
|---|---|---|---|---|---|---|
| Polyendocrine Chronic Ovulatory syndrome (PCOS) | ○ | ○ | ○ | ○ | ○ | ○ |
| Endocrine Metabolic Reproductive Syndrome (EMRS) | ○ | ○ | ○ | ○ | ○ | ○ |
| Endocrine Reproductive Metabolic Syndrome (ERMS) | ○ | ○ | ○ | ○ | ○ | ○ |

*A healthcare professional/ researcher*

Q18 Any other name?

_____

*A patient*

Q18_1 Do you have any other name ideas you want to share?

_____

*A healthcare professional/ researcher*

Q19 We have explored whether retaining the acronym PCOS with more accurate terms for P, C and O should be considered.

Health professionals indicated stronger support for this option.

If **considered,** the results showed that:

- **Healthcare professionals** did not have a clear preference for specific words.
- **Patients** supported **Complex** and **Chronic**.
- **Healthcare professionals and patients** supported **Polyendocrine**, **Cardiometabolic**, **Ovulatory** and **Ovarian**.

Considering this, please indicate how much you support the inclusion of each of the following terms in a new name.

| | Strongly oppose | Oppose | Neither support nor oppose | Support | Strongly support | I am unsure |
|---|---|---|---|---|---|---|
| Polyendocrine | ○ | ○ | ○ | ○ | ○ | ○ |
| Polymetabolic | ○ | ○ | ○ | ○ | ○ | ○ |
| Cardiometabolic | ○ | ○ | ○ | ○ | ○ | ○ |
| Complex | ○ | ○ | ○ | ○ | ○ | ○ |
| Chronic | ○ | ○ | ○ | ○ | ○ | ○ |
| Ovary | ○ | ○ | ○ | ○ | ○ | ○ |
| Ovulatory | ○ | ○ | ○ | ○ | ○ | ○ |

| | | | | | | |
|---|---|---|---|---|---|---|
| Syndrome | ○ | ○ | ○ | ○ | ○ | ○ |
| Spectrum | ○ | ○ | ○ | ○ | ○ | ○ |
| None<br>I prefer a neutral or generic name not tied to specific symptoms | ○ | ○ | ○ | ○ | ○ | ○ |

*A patient*

Q19_1 We have explored whether retaining the acronym PCOS with more accurate terms for P, C and O should be considered.

Health professionals indicated stronger support for this option.

If **considered,** the results showed that:

- **Healthcare professionals** did not have a clear preference for specific words.
- **Patients** supported **Complex** and **Chronic**.
- **Healthcare professionals and patients** supported **Polyendocrine**, **Cardiometabolic**, **Ovulatory** and **Ovarian**.

Considering this, if we use the same short name (PCOS), how much do you support these words being part of it?

| | Strongly oppose | Oppose | Neither support nor oppose | Support | Strongly support | I am unsure |
|---|---|---|---|---|---|---|
| Polyendocrine | ○ | ○ | ○ | ○ | ○ | ○ |
| Polymetabolic | ○ | ○ | ○ | ○ | ○ | ○ |
| Cardiometabolic | ○ | ○ | ○ | ○ | ○ | ○ |
| Complex | ○ | ○ | ○ | ○ | ○ | ○ |
| Chronic | ○ | ○ | ○ | ○ | ○ | ○ |
| Ovary | ○ | ○ | ○ | ○ | ○ | ○ |
| Ovulatory | ○ | ○ | ○ | ○ | ○ | ○ |
| Syndrome | ○ | ○ | ○ | ○ | ○ | ○ |
| Spectrum | ○ | ○ | ○ | ○ | ○ | ○ |
| None | ○ | ○ | ○ | ○ | ○ | ○ |

| | |
|---|---|
| I prefer a neutral or generic name not tied to specific symptoms | |

*A healthcare professional/ researcher*

Q20 Any other terms for the 'P', 'C', 'O' and 'S'?

_____

*A patient*

Q20_1 Do you have other suggestions for what 'P', 'C', 'O' and 'S' could stand for?

_____

*A healthcare professional/ researcher*

Q21 Any other advice or comments you would like the global team of patient and health professional leaders to consider and/ or monitor in the name change process?

_____

*A patient*

Q21_1 Do you have any other ideas, concerns, or messages you want to share with the teams working on the new name for PCOS?

_____

**Want to stay involved or be notified about the international workshop in November 2025? This survey is anonymous, but if you would like to receive updates or express interest in participating further, you can opt in by providing your email address below. This is entirely optional and will not be linked to your survey responses.**

_____

## Supplementary Box 2. Survey B: questions and response options

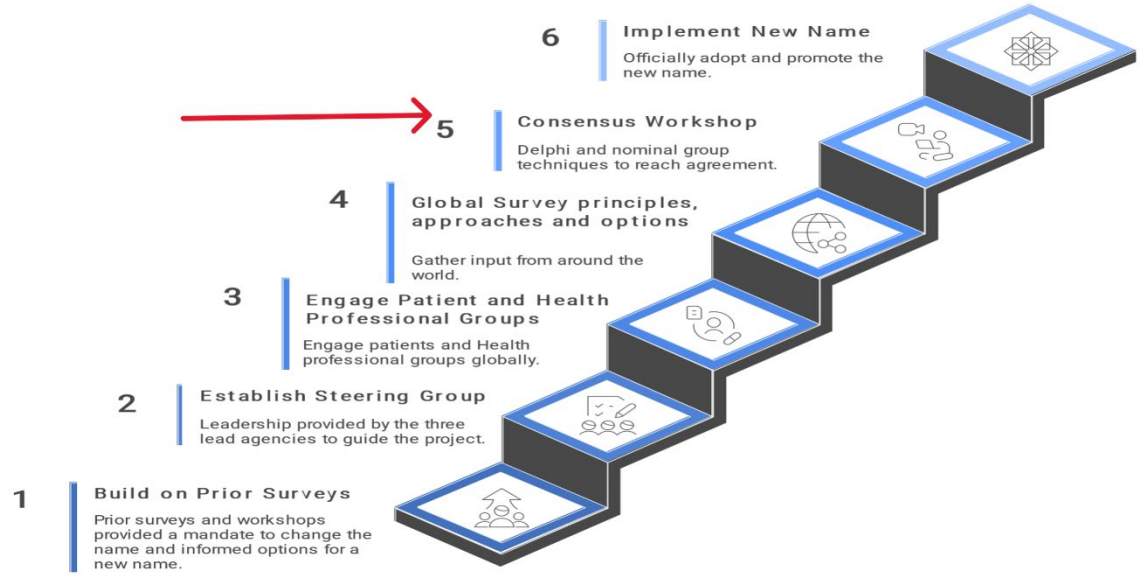
### Polycystic Ovary Syndrome (PCOS) Consultation – Renaming the Condition

Dear respondent,
Thank you for engaging in the previous international PCOS name change survey. We are contacting you because you previously provided your email address OR you are a member of our key partner societies. So far, over 20,000 people have responded to our surveys.

We have generated four agreed principles to guide the new name:

1. Scientific and medical accuracy
2. Ease of pronunciation and communication
3. Avoiding stigma and negative connotations
4. Cultural and linguistic appropriateness

We have also defined the approach with a **new name based on features of the condition,** reflecting clinical understanding.




Three features will be reflected in the new name:
• **Endocrine/Hormonal**
• **Reproductive**
• **Metabolic**

This short follow-up survey takes 5 minutes and aims to guide the final expert health professional and lived experience workshop in February 2026. Here, we are seeking input on the specific options for the **'Reproductive'** features of PCOS.
Participation is voluntary, responses will be analysed in aggregate without identifying individuals and we thank-you for your continued contribution to this global initiative.

Q1 Are you? (Tick one)

- ○ An individual with PCOS, family member and/ or support person/group
- ○ A healthcare professional/ researcher
- ○ Both

## About You

*A healthcare professional/ researcher*

Q2_1 What is your current age (years)?

- ○ 18 - 25
- ○ 26 - 35
- ○ 36 - 45
- ○ 46 - 55
- ○ >56
- ○ Prefer not to say

*A patient*

Q3 Are you?

- ○ A person with PCOS (diagnosed by a health professional)
- ○ A person who thinks they may have PCOS
- ○ A family member of someone who has PCOS
- ○ A support person of someone who has PCOS
- ○ Other (please specify) _____

*A healthcare professional/ researcher*

Q3_1 Are you? (Tick all that apply)

- ☐ A medical endocrinologist
- ☐ A reproductive endocrinologist
- ☐ An obstetrician/gynecologist
- ☐ A pediatrician

- ☐ A dermatologist
- ☐ A general practitioner/internist/general physician
- ☐ A nurse or midwife
- ☐ A dietitian
- ☐ Other allied health professional (exercise physiologist/health coach)
- ☐ A psychologist or psychiatrist
- ☐ A researcher (academic)
- ☐ Other (please specify) _____

Q4 What country do you live in?

▼ Afghanistan ... Zimbabwe

Your country is not listed above?

Q5 Please specify your current country of residence:

_____

*A patient*

Q6 What country do you consider your ethnic origin or family came from?

▼ Afghanistan ... Zimbabwe

*A patient*

Q7 Your country of ethnic or family origin is not listed above? Please specify:

_____

*A patient*

Q8 How long have you been diagnosed with PCOS?

- ○ <1 year
- ○ 1-5 years
- ○ 6-10 years
- ○ 11 years or more

*A healthcare professional/ researcher*

Q8_1 How long have you been involved in PCOS care or research?

- ○ 5 years or less
- ○ 6-10 years

○ 11-20 years

○ More than 20 years

## Naming ideas and what is important to you

Q9 **"Endocrine or Polyendocrine" and " Metabolic" have been prioritised and we are now seeking additional guidance on options for reproductive features.**
Below are some of the options for reproductive term, considerations and potential names and acronyms.
**Please consider the following principles:**

- scientific and medical accuracy
- ease of pronunciation and communication
- avoiding stigma or negative meanings
- cultural and linguistic appropriateness

We recognise that no term is perfect. Please keep an open and balanced perspective when reviewing the options, then click and drag them into your preferred order from 1 to 3, with 1 indicating the option that best reflects the reproductive features AND agreed principles.

_____ Ovulatory
Considerations: The term 'Ovulatory' is accurate and has been voted as less stigmatising and preferred to 'Reproductive'. However, it may not cover all reproductive features.

_____ Gynae, Gynaecological (spelling may vary in different world regions)

Considerations: These terms are accurate and used in medical practice- Gynae-endocrinology, is a specialty in obstetrics and gynaecology, focused on endocrine and reproductive health overall, where PCOS is the main condition. These terms are broad and cover all reproductive aspects of PCOS. They are female sex specific but are not gendered.

_____ Repro (e.g. Repro-endocrine or Repro-metabolic)
Considerations: In some cultures, the term 'Reproductive' is highly stigmatised, may lead to adverse social consequences, heighten the risk of domestic violence, and was voted on two rounds in the workshop as being less preferred than 'Ovulatory'. An alternative is to use the abbreviation "Repro" which is accurate but may be less stigmatising.

*A healthcare professional/ researcher*

Q10 Any other terms for the reproductive aspect to be included in a new name?

_____

_____

*A patient*

Q10_1 Are there other words you think should be included in a new name to reflect the reproductive aspect of the condition?

_____

Q11 If the term "Ovulatory" is adopted, please rank the following possible names and acronyms: (only options with minimal risk of confusion with existing acronyms or negative connotations are provided)
_____ Polyendocrine Metabolic Ovulatory Syndrome (PMOS)

Note: 'Endocrine' when used here, results in 'EMOS', with unacceptable cultural implications, hence 'Polyendocrine' and 'PMOS' were preferred and have marketing advantages in implementing a new name given some similarity to the current name while aligning to all principles.

_____ Endocrine Metabolic Ovulatory Syndrome (EnMOS)

_____ Ovulatory Metabolic Endocrine Syndrome (OMES)

Q12 If either of the terms Gynae or Gynaecological is adopted, please rank the following possible names and acronyms:
(only options with minimal risk of confusion with existing acronyms or negative connotations are provided)

_____ Gynae-endocrine Metabolic Syndrome (GEMS)

_____ Metabolic Gynae-endocrine Syndrome (MGES)

_____ Gynaecological Endocrine Metabolic Syndrome (GEMS)

_____ Gynaecological Metabolic Endocrine Syndrome (GMES)

_____ Endocrine Metabolic Gynaecological Syndrome (EMGS)

_____ Endocrine Gynaecological Metabolic Syndrome (EGMS)

_____ Metabolic Endocrine Gynaecological Syndrome (MEGS)

_____ Metabolic Gynaecological Endocrine Syndrome (MGES)

Q13 If the term Repro is adopted, please rank the following possible names and acronyms:
(only options with minimal risk of confusion with existing acronyms or negative connotations are provided)

_____ Repro-metabolic Endocrine Syndrome (RMES)

_____ Metabolic Repro-endocrine Syndrome (MRES)

*A healthcare professional/ researcher*

Q14 Any other advice or comments you would like the global team of patient and health professional leaders to consider and/ or monitor in the name change process?

_____

*A patient*

Q14_1 Do you have any other ideas, concerns, or messages you want to share about the reproductive aspect with the teams working on the new name for PCOS?

_____

## Supplementary Box 3. Code of conduct for workshop participants

### Code of Conduct –
### PCOS Name Change Workshop

***Purpose of the workshop***

This workshop is to decide on the new name for Polycystic Ovary Syndrome (PCOS). It is the final step in a long process and builds on past surveys (with over 20,000 responses) and prior workshops and will definitively change the name of PCOS. We are here to work together respectfully and kindly. All are welcome and valued — no matter your gender, age, culture, language, religion, or whether you are a patient or a health professional. During the workshop people will share confidential results, lived experience, personal perspectives and professional knowledge. To keep trust and respect the process, all who wish to participate must agree beforehand to follow this code of conduct.

**Attendance**
Attendees are required to attend for the full workshop, to be held on Thursday 6 November 2025 10:00 pm to 12:30 am AEDT

I am able to attend for the full workshop.
☐ Yes

**Acknowledgement**
Results will be published in a medical journal (being finalised) and after this on the official websites of the partnering societies and attendees will be acknowledged.

I agree to be acknowledged by name on the publication and websites.
☐ Yes

**Confidentiality (Keeping Things Private)**

- **Keep all workshop information private**

Anything shared in this workshop must stay private or confidential— spoken or written — including pre reading, discussions, documents and the new name (the latter until the embargo date - which you will be advised on via email after the meeting). Do not share any of the above outside the workshop unless you have written permission from the project lead helena.teede@monash.edu.

- **No recording or sharing**

Do not record, take screenshots, photos, or share slides, messages, or anything in relation to the workshop.

- **Your responsibility**

Each person has an individual responsibility to protect privacy and confidentiality.

- **If there is a privacy breech**

You will be removed from the workshop and not included in future publications or acknowledgements.

- **Media and communication**

The new name will be under embargo, until it is published in a key journal. Breaking this embargo will compromise the reach and impact of the announcement. A media team has created a plan for sharing the new name and workshop results. All participants are asked to follow the agreed messages and timelines to ensure global reach and impact is achieved. All participants will be notified via email of the date that the new name can be shared. We will welcome spokespersons who wish to assist in the process in their local regions.

I agree with these privacy and confidentiality requirements and to follow the media plan.
☐ Yes

**Behaviour (How we treat each other)**

Who Leads the Workshop?

Breakout groups will be led by a patient (consumer) chair and a clinical co-chair. Independent helper (called scrutineers) will make sure everyone follows the agreed processes/ rules.

**Required behaviour**

- Be respectful, kind, and professional.
- Listen carefully and let others speak.
- Don't interrupt or talk too much.
- Use language that includes everyone.
- Respect different opinions and cultures.
- Follow instructions from the chairs and scrutineers.
- Respect the global survey results and consensus and focus on resolving areas of controversy.
- Endeavour to represent your group, region, or culture over personal opinion.
- Respect the final consensus decision, even if this differs to your personal views.

**Unacceptable behaviour**

- Harassment, bullying or discrimination of any kind.
- Aggressive, dismissive or sarcastic communication.
- Talking over others, interrupting, or silencing contributions.
- Gatekeeping participation or preventing others from joining in — especially patients.
- Ignoring agreed evidence and process, including the global surveys with 20,000+ participants which take precedence in informing workshop discussions

- This is a democratic process- there should be no canvassing or lobbying to influence others votes, coordinating responses, off-platform soliciting during or between sessions (if you are approached in this manner, please message or WhatsApp on +61 xxx xxx xxx.

**Inclusive language notes**

This is a global workshop with patient and professional participants from many regions. The sessions will be conducted in English. Please remember that English may not be the first language for all participants, so people may use different terms for the same concept, need a little extra time to find the right words, or feel less confident expressing complex ideas. Be patient, listen actively, and assume good intent while seeking clarity.

**Process integrity**

- Follow the facilitation and voting steps as instructed.
- Respect time limits and the decision to move on.
- Declare any conflicts of interest relevant to agenda items.

I agree to follow the behaviour requirements:

☐ Yes

**Reporting concerns**

If you see or experience unacceptable behaviour:

- Communicate privately to a scrutineer or chair via the private zoom chat function or send a message to the lead facilitator at +61 xxx xxx xxx.
- You will not be identified in any subsequent actions, and your points will be taken seriously.
- Action will be taken quickly — this may include a warning or removal from the workshop.

**Support for patients**

If you feel upset or triggered by the discussion, a support person is available. A debriefing session will be held online after the workshop for anyone who wants to talk further about any personal concerns.

Signature

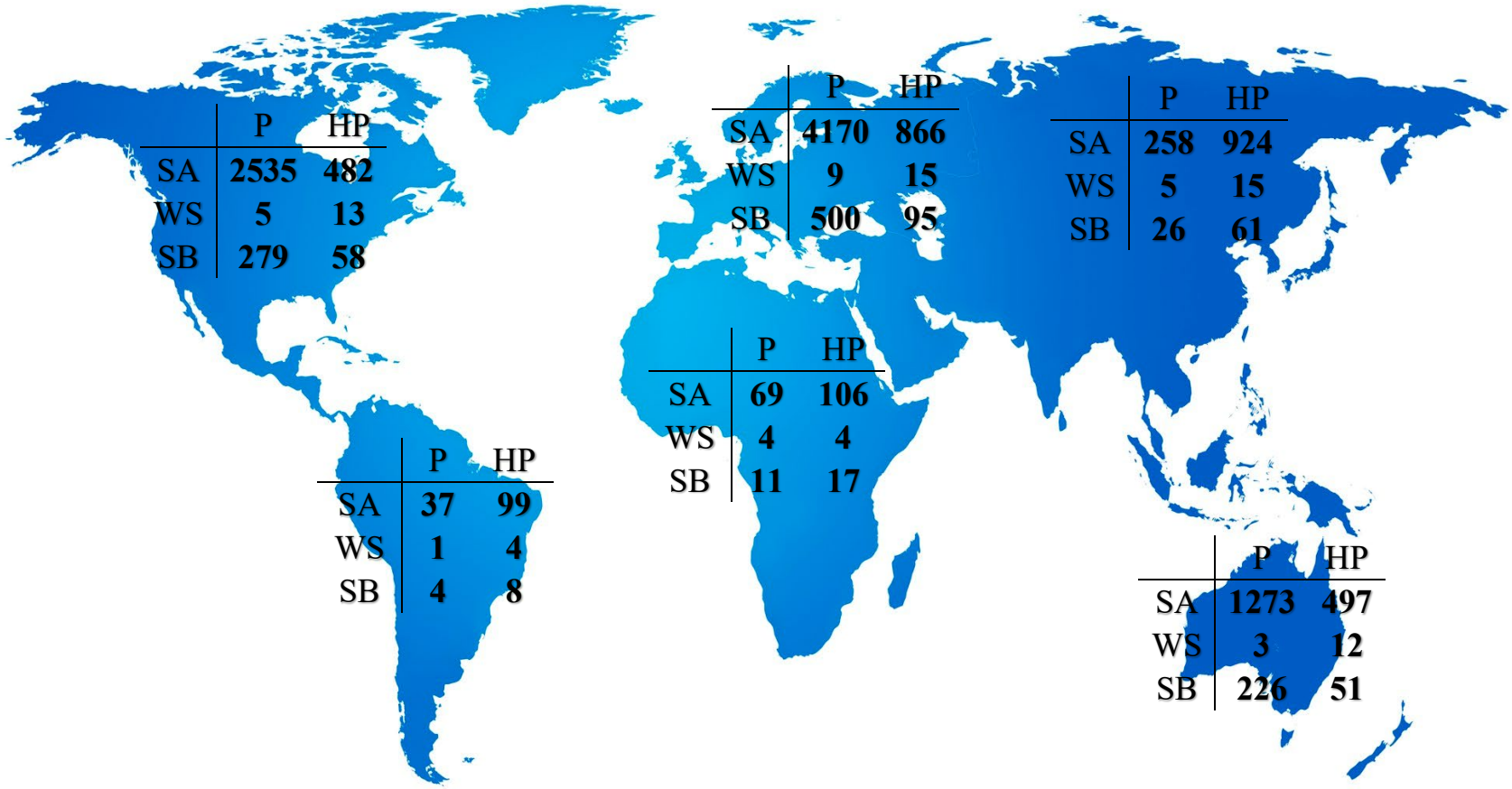
X_____

Please enter your full name: ----------

## Supplementary Box 4: Organisations engaged

- American Gynaecological & Obstetrical Society
- American Society of Reproductive Medicine
- Androgen Excess and Polycystic Ovary Syndrome Society
- Asia Pacific Initiative on Reproduction
- Asia Pacific Paediatric Endocrine Society
- Australia and New Zealand Society for Paediatric Endocrinology and Diabetes
- Australasian College of Dermatologists
- Australian College of Midwives
- Brazilian Society of Endocrinology and Metabolism
- British Fertility Society
- Canadian Society of Endocrinology and Metabolism
- Chilean Society of Endocrinology and Diabetes
- Chinese Society of Reproductive Medicine
- DAISy-PCOS
- Endocrine Society
- Endocrine Society Australia
- European Society of Endocrinology
- European Society of Gynaecology
- European Society of Human Reproduction and Embryology
- Federation of Obstetric and Gynaecological Societies of India
- Fertility Society Australia and New Zealand
- Finnish Korento
- Indian Society for Assisted Reproduction
- International Federation of Fertility Societies
- International Federation of Gynaecology and Obstetrics
- International Federation for the Surgery of Obesity and Metabolic Disorders
- International Society of Endocrinology
- International Society of Ultrasound in Obstetrics and Gynaecology
- The International Federation of Gynecology and Obstetrics
- Iran Endocrine Society
- Italian Society of Gynaecology and Obstetrics
- Japan Endocrine Society
- Latin American Federation of Endocrinology
- Latin American Network of Assisted Reproduction
- Latin American Society for Paediatric Endocrinology
- Nordic Federation of Societies of Obstetrics and Gynaecology
- PCOS Challenge Inc: The National Polycystic Ovary Syndrome Association
- PCOS Conquerors
- PCOS Norge
- PCOS Society of India
- PCOS Support Association (Malaysia)
- PCOS Vitality
- Paediatric Endocrine Society
- Polycystic Ovary Syndrome Association Australia
- PCOS awareness association
- PCOS Association
- Royal Australian and New Zealand College of Obstetricians and Gynaecologists
- Royal Australian College of General Practitioners
- Royal College of Obstetricians and Gynaecologists
- Society for Endocrinology
- Society for Endocrinology, Metabolism and Diabetes of South Africa
- Society for Reproductive Endocrinology and Infertility
- Society of Obstetricians and Gynaecologists of Canada
- SOPK Europe
- South African Society of Obstetricians and Gynaecologists
- Thai Society for Reproductive Medicine (TSRM)
- Verity

**Supplementary Figure 1. Global distribution of participants across surveys and workshops**




HP: health professional; P: patient; SA: survey A; SB: survey B; WS: workshop

## PCOS name change consortium co-authors

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## Research in Context

### Evidence before this study

Polycystic Ovary Syndrome (PCOS) is a common multisystem disorder affecting 10-13% of women globally. Research, systematic reviews and International Guidelines have updated diagnostic criteria and defined diverse endocrine, metabolic, dermatological, psychological, and reproductive features. Yet, the name implies a primary gynaecological condition inaccurately focusing on ovarian cysts and ignoring diverse features. The 2012 National Institute of Health Evidence-based Workshop on PCOS, noted the misleading name and recommended a new name to improve education, research, and healthcare. Prior renaming attempts have stalled, yet recent international surveys and workshops generated a mandate for a name change.

### Added value of this study

In the largest engagement of patients, multi-disciplinary health professionals, and relevant organisations across world regions in a medical name change process, robust consensus methods generated agreed principles, an approach and preferred terms (endocrine/polyendocrine, metabolic/cardiometabolic and ovulatory/ovarian). From this, the name Polyendocrine Metabolic Ovarian Syndrome (PMOS) was prioritised, omitting the inaccurate term ‘cystic’ and highlighting diverse clinical features. The implementation strategy includes engaged organisations, dissemination, education, and changes to medical and research database terminology and International Classification of Disease (ICD) codes.

### Implications of all available evidence

Extensive research, evidence synthesis, and International Guidelines have demonstrated the diverse features of this condition. Inaccuracy and narrow reproductive framing of the name PCOS delayed diagnosis, compromised patient-centred care, and limited research, underpinning a mandate for change. A multistep international consensus process generated a new accurate name

‘Polyendocrine Metabolic Ovarian Syndrome (PMOS)’ for the condition formerly known as PCOS, with a transition period and comprehensive implementation strategy.