verity
sharing the truth about PMOS

REPORT ON THE NICE PMOS GUIDELINE CONSULTATION

FROM GUIDELINE TO CARE

Community Response to the NICE Guideline on PMOS Consultation

The National Institute for Health and Care Excellence (NICE) sets the national evidence-based clinical guidelines and quality standards for healthcare and social care

78% say the draft guideline improves on the care they receive today. 94% do not believe it will be delivered

September 2026

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About this report

Verity is a registered stakeholder in the NICE guideline for PMOS. During the consultation we surveyed our community on the draft itself. This report sets out what that evidence shows, and what it asks of the organisations that will decide whether the guideline changes care.

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STATUS OF THIS DOCUMENT

This is a Verity report. It is not a NICE document and does not represent NICE, its guideline committee, or the content of the final guideline. It draws solely on Verity's community survey and on the consultation response Verity submitted on 11 August 2026. See section 14 for method, limitations and declarations.

SECTION 01

Executive summary

After more than fifteen years of campaigning, PMOS will soon have national clinical guidance. That is a genuine milestone, and the draft Guideline is welcomed by Verity and the PMOS community. But the same respondents, who have been grossly underserved, have little confidence it will change their care.

PMOS — until recently polycystic ovary syndrome — affects around one in eight women and people assigned female at birth, and has never had a national clinical guideline. The 2026 draft is a significant moment, and the community recognises it as one: **78% say it improves on the care they receive today.**

Asked about the new annual review — endorsed by 97% — **94% doubted it would be delivered in practice.** That gap between approval and expectation is the central finding of this survey: not scepticism about the guideline, but an accurate reading of what happens to recommendations that arrive without funding or accountability.

Underneath it sit barriers that guideline text alone cannot solve. Three carry the strongest consensus.

Eligibility rules that wait for harm. PMOS raises the risk of type 2 diabetes and cardiovascular disease, but the medicines addressing that risk are funded only once one has developed. Of 210 respondents who wanted a GLP-1 medicine, 4 obtained one through NHS criteria.

A classification that overrides clinical need. Hirsutism, hair loss and acne from a diagnosed endocrine condition are treated as cosmetic. 97% disagree, and 79% avoid leaving the house without first removing hair.

Cost displaced rather than avoided. 65% have paid privately, at a median lifetime cost of around £2,000. The spending is already happening — it has simply moved to the household.

78%

say the draft guideline improves on the care they receive now

94%

doubt the new annual review will actually be delivered

65%

have paid privately for PMOS care the NHS would not fund

Median lifetime spend: approximately £2,000

WHAT FOLLOWS FROM THIS

The fourteen recommendations in section 02 are not a ranked shortlist. Respondents endorsed the treatment of skin and hair symptoms, preventative access and a deliverable annual review at almost identical levels, between 92% and 97%.

Together they address one question: what has to be true for a person with PMOS to actually receive what this guideline describes?

> There is no ongoing care. You're diagnosed, then left to Google solutions.
>
> NICE CONSULTATION SURVEY RESPONDENT

SECTION 02

Our asks of NICE

Fourteen asks, grouped by who is able to act on them. Each is drawn directly from the survey evidence in sections 04 to 10. They are listed by audience, not by priority — see the note overleaf.

FOR NICE, IN FINALISING THE GUIDELINE

01 Specify what an annual review must contain, and what is required to deliver it

The most welcomed recommendation in the draft, and the least believed. A defined minimum — metabolic assessment, mental-health enquiry, symptom review and a route to act on findings — makes it auditable rather than aspirational.

02 Recognise PMOS as a basis for preventative metabolic treatment

Rather than requiring a downstream diagnosis of type 2 diabetes or cardiovascular disease before treatment becomes available.

03 Treat hirsutism, hair loss and acne as clinical features, not cosmetic ones

97% of respondents consider each of these a medical symptom — the strongest consensus in the survey. The guideline already identifies hirsutism as a feature of a diagnosed endocrine condition; the recommendations should follow from that.

04 Provide PMOS-specific acne guidance

Acne is deferred to a separate guideline whose endocrine referral trigger requires additional hyperandrogenic features. Acne presenting with irregular cycles may not meet it, leaving a referral gap.

05 Make quality of life an explicit consideration in symptom management

84% report excess hair affecting confidence and body image a lot or severely; 79% avoid leaving the house without first removing hair or covering up; 45% avoid certain jobs or being on camera. Functional impairment of this order belongs in the assessment of clinical need.

06 Strengthen mental-health assessment and support

Two-thirds of respondents consider the draft to give insufficient attention to mental health. Support should be routine and resourced rather than discretionary.

07 Prompt clinicians to explore beliefs, preferences and alternatives

7 respondents in 315 had ever been asked whether their beliefs affect their treatment preferences; 71 had declined hormonal contraception on those grounds. Non-hormonal alternatives should be offered.

08 Address thresholds, ethnicity and compounded risk explicitly

Consider PMOS-specific and ethnicity-adjusted BMI thresholds; guard against local thresholds set below them; recognise PMOS as an indication for an oral glucose tolerance test in pregnancy whatever the BMI; and address compounded metabolic risk in Black, Asian and mixed communities in both the guideline and the equality impact assessment.

FOR NHS ENGLAND AND NATIONAL COMMISSIONERS

09 Make PMOS an eligibility route for preventative weight and metabolic treatment

96% support this. Current rules require a diabetes or cardiovascular diagnosis to develop first. Aligns with recommendation 5 of the 2025 APPG report.

10 End the cosmetic classification for PMOS-related hirsutism

92% consider that effective hair-removal treatment should be funded as a medical treatment; 96% consider the cosmetic label excludes those who cannot pay. The NHS already funds such treatment as a clinical need within certain specialised care pathways, demonstrating that it is not inherently cosmetic. We ask for consistency of principle — levelling up, not down. Aligns with recommendation 6 of the APPG report.

11 Resource the annual review as a commissioned activity

Recommendations relying on existing primary care capacity, with no funding or workforce planning attached, are the ones respondents expect to fail.

12 Provide national backing for established off-label treatments

So that access to treatments such as metformin does not depend on individual clinician confidence or local commissioning decisions.

FOR THOSE WHO PLAN AND FUND CARE IN EACH NATION

13 Commission PMOS care and the services that deliver it

Only 12% of respondents considered their care coordinated between the services they need. Integrated, community-based models — including Women's Health Hubs — align with the shift of care from hospital to community.

FOR PARLIAMENTARIANS AND THE APPG ON PMOS

14 Attach implementation funding and monitoring to the final guideline

A guideline without a funded delivery route reproduces the position respondents already describe. We ask parliamentarians to press for implementation funding, national data collection on PMOS, and a mechanism to report on delivery across all four nations.

THESE ARE NOT COMPETING ASKS

Respondents were separately asked to rank the three greatest barriers to good care, and that exercise produces a hierarchy — reported in full at section 10. A forced ranking is useful for sequencing, but it is not a measure of how much each issue matters, and it should not be read as one.

On strength of support, the picture is markedly flatter. The proposition that excess hair, hair loss and acne are medical rather than cosmetic drew 97% agreement — level with preventative access and with the annual review, and higher than the 78% who consider the guideline an improvement at all. Skin and hair symptoms were ranked sixth as a barrier and first as a matter of consensus. Both readings are set out at section 10 so that neither is taken in isolation.

SECTION 03

The evidence base

Most patient-experience research asks people about the care they have received. This survey asked them to appraise a draft clinical guideline. That distinction is what gives the findings their particular use to the organisations reading this report.

319

people responded during the consultation period

4 responding only in a professional capacity were excluded

315

valid responses form the base for this report

277 with a diagnosis; 20 clinicians who also have PMOS

4

UK nations represented, with responses from every English region

Wales 21, Scotland 16, Northern Ireland 7

What this evidence is good for

It records how the people who will be subject to this guideline read it: which recommendations they consider valuable, which they expect to be undeliverable, and what they identify as the operative barriers. It also quantifies behaviours that are rarely measured — private expenditure, avoidance, treatment declined on grounds of belief — and pairs them with free-text testimony.

What it is not

It is a self-selected sample drawn from an engaged patient community, not a statistically representative sample of the PMOS population. It should be read as strong evidence of consensus, depth and direction, and weak evidence of prevalence. Where subgroups are small we report counts rather than percentages throughout.

CONTEXT FROM THE WIDER EVIDENCE BASE

The 2025 APPG inquiry, informed by Freedom of Information responses from all 42 integrated care boards in England and by Verity's own 2025 consultation of over 2,000 people, found no nationally commissioned pathway, no routine outcome data and no dedicated funding for the condition. Patients rated NHS management of PCOS at 1.9 out of 10, down from 2.2 in 2023.

The findings in this report are consistent with that picture, and add something it could not: a direct patient appraisal of the remedy now on the table.

> What has actually helped me is the things I have accessed privately. Virtually nothing from the NHS has helped.
>
> NICE CONSULTATION SURVEY RESPONDENT

SECTION 04

The delivery gap

The most welcomed recommendation in the draft guideline is also the one respondents least expect to receive. That judgement is evidence about the delivery system, not about the guideline.

97%

consider an annual review for everyone with PMOS **a major step forward**

94%

doubt it **will be delivered** in practice

Respondents were not asked to predict implementation; they volunteered it. The reasoning is concrete: annual blood tests that arrive with no discussion attached, ten-minute appointments that cannot hold a multi-system review, and no clinician holding responsibility between appointments.

> I have yearly blood tests, but the staff never seem to know what or why they are doing them.
>
> SURVEY RESPONDENT

> Everything is disjointed. I have several metabolic conditions, none managed under one umbrella. None are managed at all.
>
> SURVEY RESPONDENT

12%

consider their care coordinated well between the services they need

33%

consider the draft gives sufficient attention to mental health

168

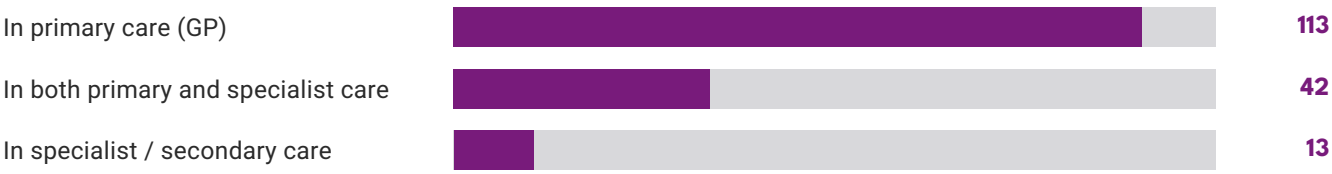
describe their skin or hair symptoms being treated as standalone or cosmetic, against 25 describing joined-up care

WHAT THE EVIDENCE SUPPORTS

A defined minimum content for the annual review — metabolic assessment, mental-health enquiry and a route to act on findings — would make the recommendation auditable and fundable.

Off-label prescribing as an access barrier

PMOS has no dedicated licensed medication in the UK. Established treatments such as metformin are therefore prescribed off-label, and respondents ranked clinician reluctance to do so as the third greatest barrier to good care. Where that reluctance was encountered, it was overwhelmingly in primary care.



Base: respondents who reported that off-label status had affected their access to treatment. Free-text answers describe metformin being characterised as a "grey area", or requiring a secondary-care opinion to authorise a treatment the patient was already established on.

> I have repeatedly been refused metformin. I have been told it is not prescribed for PCOS. This has been at GP practices in Staffordshire and in Essex.
>
> NICE CONSULTATION SURVEY RESPONDENT

> I was refused metformin, and advised they would only put me on it if I wanted to try to have a child. I was 22 at the time.
>
> NICE CONSULTATION SURVEY RESPONDENT

Why this matters to commissioners specifically

Three of the four highest-ranked barriers in this survey are not questions of guideline content. They concern whether the workforce is resourced, permitted and confident enough to act on it. A guideline that is technically sound and operationally unsupported produces exactly the pattern respondents describe: care that varies by practice, by region and by the persistence of the individual patient.

WHAT THE EVIDENCE SUPPORTS

National backing for established off-label use in PMOS — and resourcing attached to the annual review — would address the barriers respondents rank second, third and fourth. None of these requires new evidence; each requires a commissioning decision.

> I have been doing everything I can to lose weight but nothing works. Yet I cannot get any form of GLP-1, and I get refused metformin because it is a "grey area".
>
> NICE CONSULTATION SURVEY RESPONDENT

SECTION 05

Prevention: eligibility rules that wait for harm

PMOS raises the risk of type 2 diabetes and cardiovascular disease. The treatments that address that risk become available only once one of those conditions has developed.

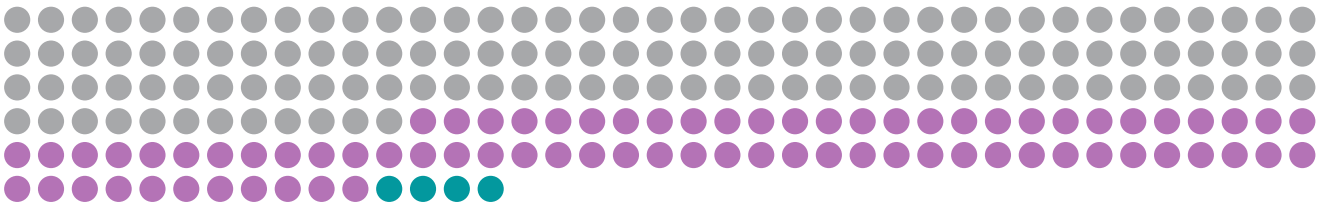
96%

agree PMOS should itself be a route to preventative treatment, rather than requiring a diabetes or cardiovascular diagnosis first

97%

agree that not funding preventative treatment now will cost the NHS more later

Outcomes for the 210 respondents who sought a GLP-1 medicine for PMOS



129 unable to fund private treatment · 77 obtained it privately · 4 obtained it through NHS criteria

Of all respondents who obtained a GLP-1 medicine, **95% funded it themselves.** Existing NHS eligibility criteria reached 2% of those who wanted this treatment.

VERITY NICE CONSULTATION SURVEY, 2026

THIS IS A PREVENTION QUESTION, NOT A WEIGHT-MANAGEMENT ONE

The draft guideline already recognises the elevated metabolic and cardiovascular risk carried by this population. What it does not do is treat that recognised risk as sufficient grounds for preventative action.

THE FOUR NHS CASES ARE THE FINDING

Four qualifying cases among 210 people who sought this treatment is not evidence of limited clinical need. It indicates that the eligibility route is effectively closed to this condition, and that access is determined by household income.

The clinical pattern respondents describe

Free-text responses follow a consistent sequence: self-funded treatment, marked clinical improvement across metabolic and reproductive measures, then cessation on affordability grounds and reversal of those gains. This is reported by respondents, not clinically verified, but its consistency is itself informative.

> I have lost 4.5 stone, my HbA1c has massively reduced, and I have had a period every single month — before, I had two or three a year.
>
> **SURVEY RESPONDENT**

> I started privately and got my period back after 6 years. I had to stop because I could not afford it, and my symptoms have returned.
>
> **SURVEY RESPONDENT**

AN INCENTIVE THAT OPERATES AGAINST THE PREVENTION AGENDA

Because access is gated on BMI, several respondents described the criteria as an instruction to deteriorate before help becomes available. A small number stated that they had considered gaining weight in order to qualify. Whatever the intent of the threshold, this is how it is being understood by the population it governs.

> "I did not meet the eligibility criteria, so I was refused. It feels as though people with PCOS are being forced to struggle until their health deteriorates further."

WHAT THE EVIDENCE SUPPORTS

Recognising PMOS as an eligibility route for preventative metabolic treatment would align the funding rule with the risk the guideline already acknowledges. This was ranked the single greatest barrier to good care by our respondents, and corresponds to recommendation 5 of the 2025 APPG report, which called for such medicines to be accessible regardless of a diabetes diagnosis.

ON THE INVEST-TO-SAVE CASE

We do not present this survey as a health-economic analysis, and it is not one. What it establishes is that substantial expenditure on this condition is already occurring, that it is being met privately by those who can afford it, and that 97% of respondents believe deferring treatment increases eventual cost to the NHS. A formal economic evaluation of preventative treatment in PMOS would test that proposition directly, and we would welcome one.

SECTION 06

The cosmetic classification

Hirsutism, hair loss and acne arising from a diagnosed endocrine condition are administratively classed as cosmetic. The functional consequences reported here are not consistent with that classification.

97%

consider PMOS-related excess hair a medical symptom rather than a cosmetic issue

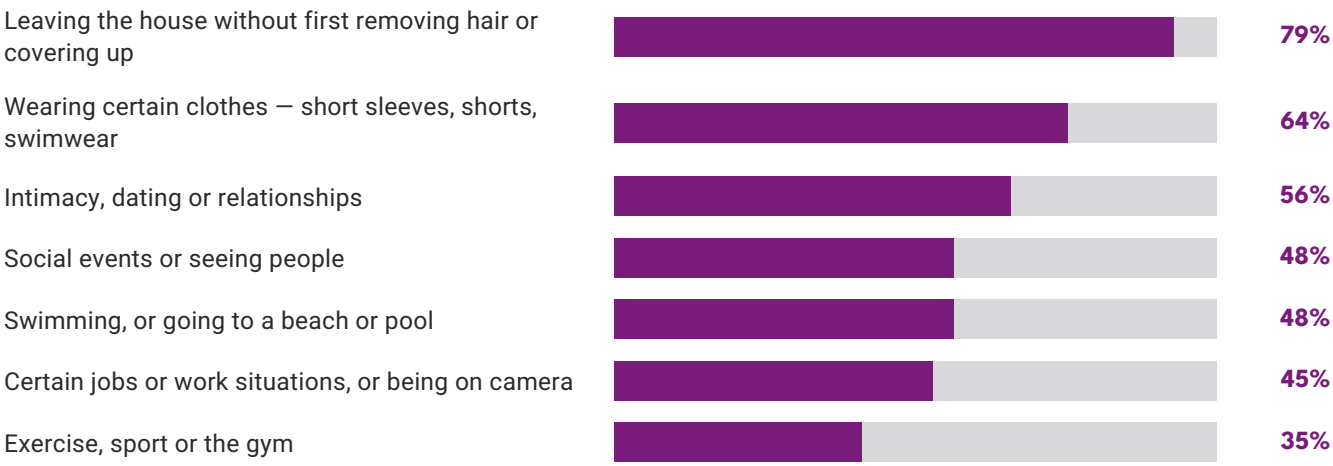
97%

say the same of hair loss

97%

say the same of acne

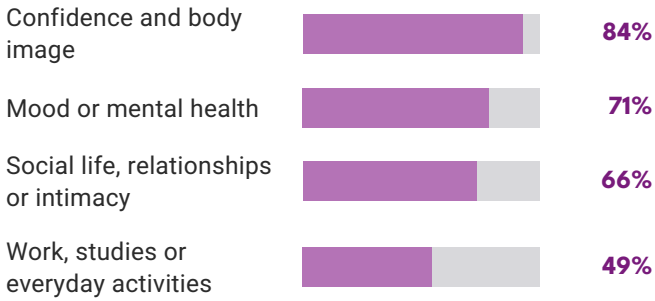
Activities respondents avoid because of these symptoms



Base: 305 respondents answering this question; multiple responses permitted. These are avoidance behaviours rather than distress ratings — the measure is what people stop doing.

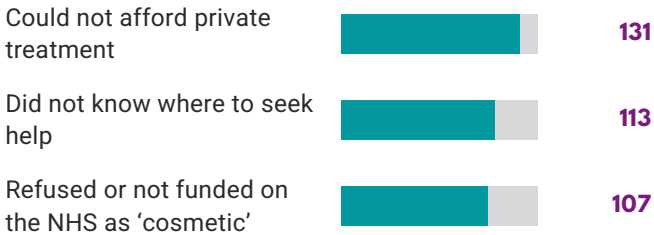
> I have to shave twice a day just to look like a girl. I would not be able to leave the house without doing it.
>
> SURVEY RESPONDENT

Excess hair — affected “a lot” or “severely”



Base: respondents reporting the symptom.

Reasons treatment was not obtained



Base: respondents who sought treatment for skin or hair symptoms and did not obtain it; multiple responses permitted.

92%

consider that effective hair-removal treatment should be recognised as a medical treatment for PMOS and funded accordingly

96%

consider that the cosmetic classification excludes those who cannot pay privately

> I became a recluse for years because of my excess hair and acne. I felt ugly. I wish I could afford laser hair removal.
>
> NICE CONSULTATION SURVEY RESPONDENT

> If I find some at work, I will leave early and take annual leave, to go home and remove it.
>
> NICE CONSULTATION SURVEY RESPONDENT

THE EQUITY ARGUMENT

The NHS already recognises and funds hair-removal treatment as a clinical need within certain specialised care pathways. That establishes the principle that such treatment is not inherently cosmetic, and is appropriately funded where it is judged clinically warranted. Verity's position is one of consistency: we are asking for that principle to be applied to a diagnosed endocrine condition producing the same symptom. We are explicitly not asking for any existing provision to be reduced. This is a levelling-up argument.

WHAT THE EVIDENCE SUPPORTS

Recognising hirsutism management as a clinical need in PMOS would remove income as the determinant of access, and corresponds to recommendation 6 of the 2025 APPG report. Separately, PMOS-specific acne guidance would close a referral gap: acne is currently deferred to NICE's acne guideline, whose endocrine referral trigger requires additional hyperandrogenic features that a patient presenting with acne and irregular cycles may not meet.

SECTION 07

Cost displaced onto patients

This condition is already costing money. The only questions are who pays, and whether that money prevents harm now or treats it later.

65%

have funded PMOS-related care privately because of NHS funding rules

£2,000

median reported lifetime expenditure

Mean approximately £4,000, skewed by a small number of very high figures

£40,000

highest lifetime total reported by a single respondent

Reported expenditure by category

CATEGORY	MEDIAN	RANGE	NOTES
Hair removal & skin	**~£1,000**	**£125 – £40,000**	Laser, electrolysis, waxing, topical treatments, private dermatology. Recurrent and frequently lifelong. 49 figures supplied.
Weight & metabolic medicines	**£1,000+ to date**	**up to £30,000**	A recurring monthly cost of roughly £150–£250, continuing for as long as it remains affordable. 52 figures supplied.
Fertility treatment	**~£3,000**	**£300 – £18,000+**	Private IVF, IUI, ovulation induction and monitoring. 11 figures supplied; indicative only.
Supplements	**~£400**	**£20 – £15,000**	Typically self-directed, in the absence of clinical guidance. 19 figures supplied.

Self-reported lifetime estimates, therefore approximate. Amounts were attributed to the nearest treatment named. 120 respondents supplied a figure.

THE DISTRIBUTIONAL CONSEQUENCE

Private expenditure of this order is available to some households and not others, so clinical outcomes in PMOS are currently stratified by income — counter to the equity commitments in the women's health strategies across all nations.

SECTION 08

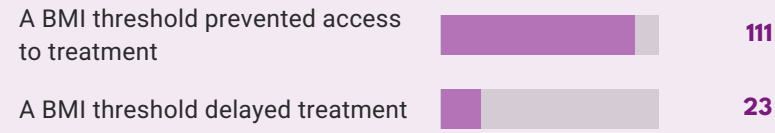
Equity: thresholds, ethnicity and consent

NICE asked stakeholders directly about the BMI values used in the draft. This section answers that question, and raises two further equity issues the consultation did not ask about.

84%

consider the BMI threshold of 40 for ovulation induction a barrier that will continue to exclude people

Reported effect of BMI thresholds on access



Support for ethnicity-adjusted thresholds

NICE already applies lower BMI thresholds by ethnicity elsewhere, to identify diabetes and cardiovascular risk earlier.

29 of 32

respondents from Black, Asian, mixed and other global-majority backgrounds supported ethnicity-adjusted thresholds, against 62% of White respondents. Reported as a count because the subgroup is small.

> "I was refused fertility treatment because my BMI was above 30, and told to lose weight until it was 30. I blamed myself that I could not get pregnant."
>
> SURVEY RESPONDENT

WHAT THE EVIDENCE SUPPORTS

Two related asks follow. First, consider PMOS-specific and ethnicity-adjusted thresholds, and strengthen the guideline against local services applying thresholds below those it sets. Second, the draft recognises higher prevalence in Black, Asian and mixed communities without addressing the compounded metabolic and endometrial risk they carry.

Faith, culture and informed choice about the pill

Combined hormonal contraception is the default treatment offered for PMOS symptoms. The survey identified a gap between the number of people making treatment decisions on the basis of cultural, religious or personal belief and the number ever asked about it. We consider this the most actionable single finding for clinical practice in the whole survey.

7

respondents out of 315 had ever been asked by a clinician whether their beliefs might affect their treatment preferences

278 reported never having been asked

71

had declined hormonal contraception offered as a PMOS treatment on grounds of belief

59

reported that their beliefs affected how they felt about being prescribed it

Substantially more people were making belief-informed decisions than were ever invited to discuss them. Medical contraindications are a separate matter and are handled in the ordinary course of prescribing; what this survey measures is whether the belief conversation happens at all. The consequence is not only a cultural competence issue: it produces silent non-adherence, which is then recorded as treatment failure. Younger, unmarried and religiously observant patients are disproportionately affected.

> I cannot take the contraceptive pill because of my mental health, but also because I am Catholic — and the doctors did not even ask about my religion.
>
> NICE CONSULTATION SURVEY RESPONDENT

> I was told by a doctor there was nothing morally wrong with taking contraceptives. It is against my religion.
>
> NICE CONSULTATION SURVEY RESPONDENT

THE WIDER PATTERN IN FREE-TEXT RESPONSES

Respondents describe hormonal contraception being offered as a means of masking symptoms rather than treating the condition; being offered it while actively trying to conceive; and experiencing mental-health side effects with limited discussion of alternatives. The draft does not set out a non-hormonal option for those who decline it.

WHAT THE EVIDENCE SUPPORTS

A prompt within the guideline for clinicians to explore beliefs and preferences as a routine part of the treatment conversation, and to offer alternatives including non-hormonal options, would address a gap affecting at least 71 people in a sample of 315 at negligible cost.

SECTION 09

Coordination, diagnosis and mental health

Three themes that had no dedicated consultation question, but which dominated the free-text responses.

Diagnostic delay

Of the 281 respondents who reported a timeframe, 31% waited more than five years from first raising symptoms to diagnosis and 50% waited more than two. The reported pattern is consistent: adolescent symptoms attributed to puberty, diagnosis prompted only by attempts to conceive, and presentations overlooked where the patient was not visibly overweight.

> "Took 10 years to get a diagnosis, across a couple of different GP practices and multiple GPs. I was told it was anxiety and depression for a long time. I had 3 out of 3 criteria."

Mental health

Two-thirds of respondents considered the draft to give insufficient attention to mental health. The associated quality-of-life data is severe: 84% report excess hair affecting confidence and body image a lot or severely, 71% report an effect on mood. A small number of respondents disclosed suicidal ideation linked to their symptoms.

> "I suffer with an anxiety disorder and low mood. It has never been mentioned to me that this could be connected. Nor do I get reviewed for it."

31%

waited more than five years for diagnosis

Base: 281 respondents supplying a timeframe

50%

waited more than two years

Base: 281 respondents supplying a timeframe

12%

consider their care coordinated between the services they need

WHAT THE EVIDENCE SUPPORTS

Mental-health assessment and support should be a routine, resourced component of PMOS care rather than a discretionary addition. On diagnosis, respondents consistently describe receiving a diagnosis with a leaflet and no explanation; clearer support for clinicians in communicating what a PMOS diagnosis means would address a recurrent and low-cost failure.

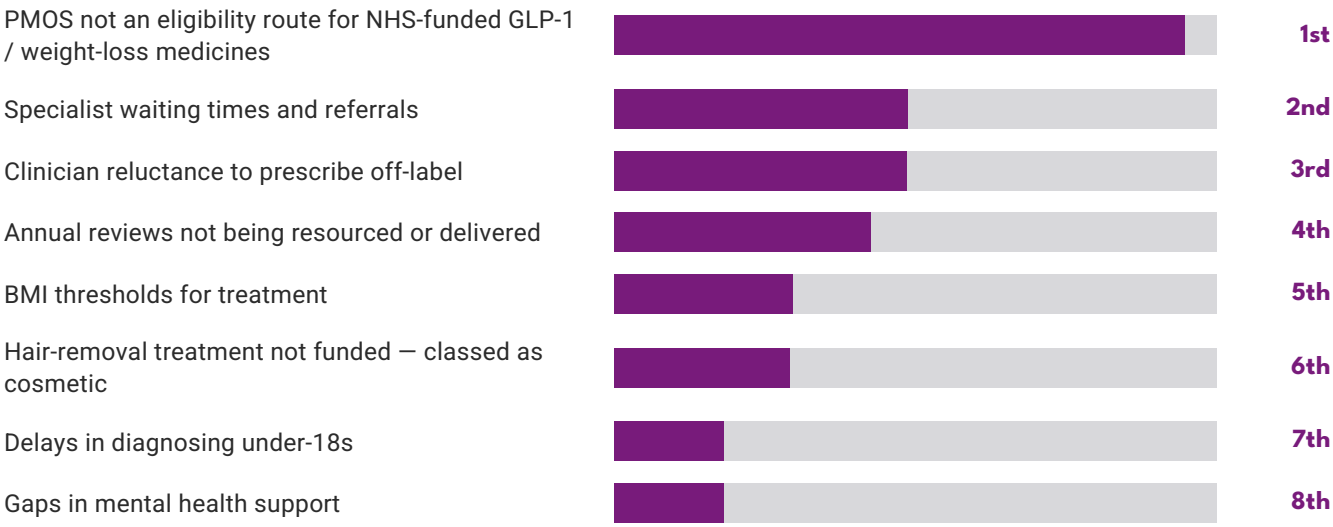
SECTION 10

Priorities and strength of support

The survey measured priority in two different ways, and they do not produce the same order. Both are reported here, because relying on either alone gives a misleading picture of what this population is asking for.

1. Top 3 barriers

Respondents selected the three greatest barriers to good PMOS care and placed them in order. Useful for sequencing: if only one thing can change first, this is what the affected population would choose.



Weighted score: a first choice scores 3, a second 2, a third 1. Base: 315 respondents.

WHY THE RANKING IS NOT A HIERARCHY OF IMPORTANCE

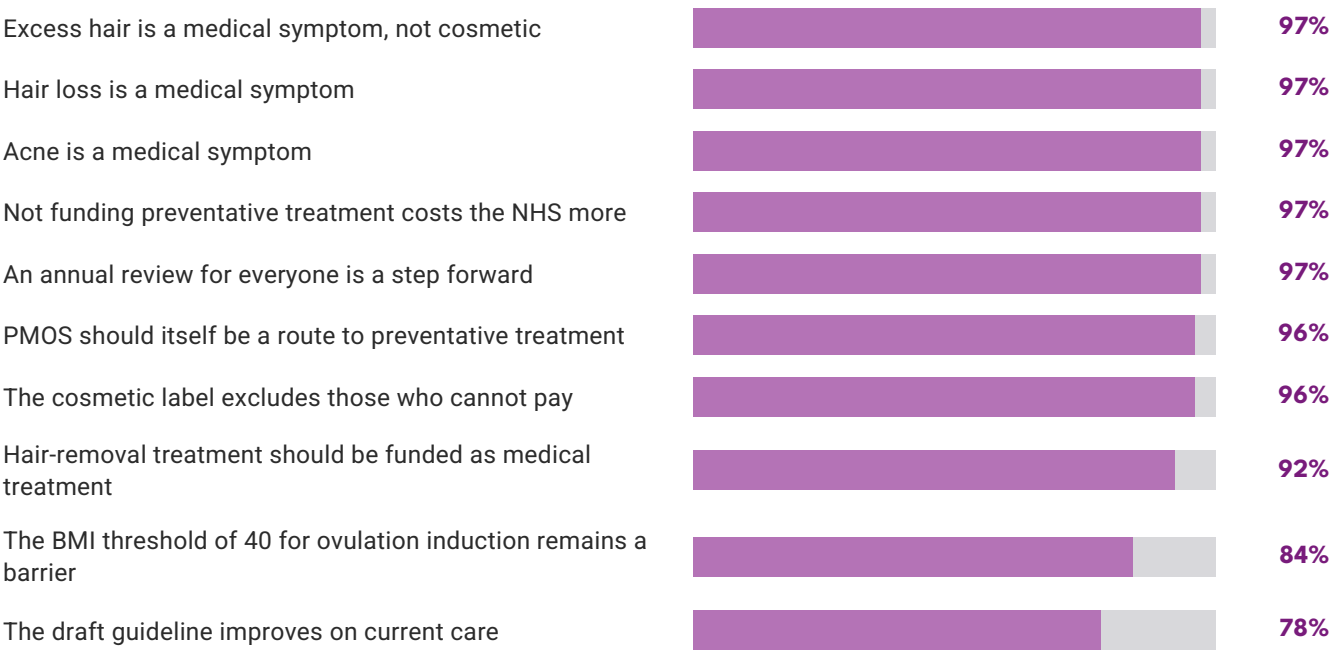
A forced top-three measures which barrier is most acute at the point of asking. It cannot show how strongly each issue is felt, and it systematically disadvantages issues that affect people continuously rather than at a decision point. The second measure overleaf shows a substantially flatter distribution — and a different order.

> BMI alone should not be used as a sole threshold for treatment in PMOS. It is stated that PMOS increases the chance of a higher BMI. Denying treatment because of BMI is unfair.
>
> NICE CONSULTATION SURVEY RESPONDENT

> I have gone private due to long waiting lists and the fear of the postcode lottery — which is wrong.
>
> NICE CONSULTATION SURVEY RESPONDENT

2. Strength of support — how far respondents agree

Proportion agreeing or strongly agreeing with each proposition, excluding "not sure / not applicable". Bases range from 285 to 315.



SKIN AND HAIR RANK SIXTH AS A BARRIER AND FIRST ON CONSENSUS

The proposition that excess hair, hair loss and acne are medical rather than cosmetic drew 97% agreement — the highest recorded in this survey, level with preventative access and the annual review, and above the 78% who consider the guideline an improvement at all. 92% would fund hair-removal treatment as a medical treatment.

WHAT EXPLAINS THE DIFFERENCE

Access to preventative medicines is a barrier encountered at a specific moment, and it is where people feel most acutely blocked. Skin and hair symptoms are experienced daily — 79% avoid leaving the house without first removing hair or covering up. Continuous burden is under-represented by a question that asks what stands in the way.

WHAT THE EVIDENCE SUPPORTS

Both measures should inform the final guideline. The ranked data indicates where a single intervention would have the most immediate effect; the consensus data indicates which propositions command near-unanimous support among the people the guideline governs. On the second measure, the treatment of skin and hair symptoms is not a secondary ask — it is the most strongly held position in the survey.

SECTION 11

Alignment with national policy

The changes sought in this report are not additional to existing NHS priorities. They are applications of them to a condition that has so far sat outside national planning.

POLICY COMMITMENT	SOURCE	WHAT THIS SURVEY CONTRIBUTES
Hospital to community	**NHS 10-Year Plan**	Only 12% of respondents describe coordinated care. Integrated, community-based PMOS pathways — including within Women's Health Hubs — are the model respondents describe wanting, and reduce repeat primary care contacts.
Sickness to prevention	**NHS 10-Year Plan**	96% support PMOS itself being a route to preventative metabolic treatment. Current eligibility rules require a diabetes or cardiovascular diagnosis to develop first, which inverts the prevention principle.
Analogue to digital	**NHS 10-Year Plan**	There is no routine national data on PMOS diagnosis, treatment or outcomes. A national register would make delivery of this guideline measurable rather than assumed.
Ending diagnostic delay	**Women's health strategies, all nations**	31% of respondents waited over five years for diagnosis; 50% over two.
Tackling health inequality	**Women's health strategies, all nations**	Access to effective treatment is currently determined by ability to pay, and BMI thresholds do not reflect ethnic variation in metabolic risk.

CONTINUITY WITH THE APPG INQUIRY

The 2025 APPG report recommended that GLP-1 receptor agonists be made accessible regardless of a diabetes diagnosis (recommendation 5), and that NHS funding be reinstated for hair removal as a clinically justified treatment for PCOS-related hirsutism (recommendation 6). This survey provides direct patient evidence for both.

WHAT IS DIFFERENT ABOUT THIS EVIDENCE

Earlier work established that PMOS care is fragmented. This survey asked the affected population to appraise the proposed remedy — producing a ranked, quantified account of which recommendations they value and which they expect to fail, before the final guideline is published.

SECTION 12

Verity's submission to NICE

Verity submitted fourteen comments on 11 August 2026, covering the four questions NICE posed and ten specific points in the draft. Each was evidenced with survey data and respondent testimony, and concluded with a specific ask.

REFERENCE	SUBJECT	SUBSTANCE OF THE COMMENT
Q1	**Challenges in implementing the guideline**	Annual review, coordinated care and mental-health support identified as most at risk; implementation support requested
Q2	**Cost implications**	65% already paying privately; invest-to-save case and equity impact submitted
Q3	**The AMH blood test**	Outside the scope of a patient survey; clearer clinician support in explaining diagnostic tests noted as welcome
Q4	**BMI values used in the guideline**	84% consider the threshold of 40 for ovulation induction a continuing barrier; 64% support ethnicity-adjusted thresholds; local variation flagged
1.2.3	**The annual review**	Minimum content specified, with implementation guidance and resourcing
1.12.1 / 1.13.3	**Metformin and weight-loss medicines**	PMOS recognised as a basis for preventative metabolic treatment
—	**Acne deferred to the NICE acne guideline**	Referral gap identified; PMOS-specific acne guidance requested
—	**Treatment for hirsutism**	Recognition as clinical need rather than cosmetic provision
1.21.7	**Ovulation induction and BMI**	Strengthened against local thresholds below 40; PMOS-specific and ethnicity-adjusted approach considered
1.22.1–1.22.2	**Pregnancy**	PMOS recognised as an indication for an oral glucose tolerance test, whatever the BMI
1.14	**Mental health**	Assessment and support strengthened and resourced as routine
1.9 / 1.10	**Combined hormonal contraception**	Beliefs and preferences explored routinely; non-hormonal alternatives offered
1.3.4	**Prevalence and long-term risk**	Compounded metabolic risk in Black, Asian and mixed communities addressed in both guideline and equality impact assessment
EIA	**Equality impact assessment**	Equity impact of a system in which effective care depends on private payment

References are to the draft guideline as consulted on.

SECTION 13

How our asks align with the APPG report

In 2025 the All-Party Parliamentary Group on PMOS published *Breaking the Cycle*, making ten recommendations to Government. This survey provides direct patient evidence for eight of them.

#	APPG RECOMMENDATION	ASKS	WHAT THIS SURVEY ADDS
1	Embed the NICE guideline in a commissioned diagnostic pathway	01, 11	Minimum content for the annual review, and funding to deliver it
2	Integrate PMOS care into Women's Health Hubs	13	Only 12% report joined-up care between services
3	Recognise PMOS as a chronic, multisystem condition	06, 13	Mental health resourced as routine; commissioned across systems
4	Address ethnic and socioeconomic disparities	08	Ethnicity-adjusted BMI thresholds; compounded risk in the EIA
5	Make metformin and GLP-1 medicines accessible regardless of diabetes	02, 09, 12	2% of those who wanted a GLP-1 obtained one on the NHS
6	Reinstate NHS funding for hair removal as clinical treatment	03, 10	97% call these symptoms medical; 92% would fund treatment
7	Expand mental health support in primary care	06	Two-thirds say the draft does too little on mental health
8	Mandatory PMOS training for healthcare professionals	12	Off-label reluctance ranked the third greatest barrier
9	Include PMOS in public and school-based education	—	Outside the scope of this survey
10	Mandate a women's health rotation in GP training	—	Outside the scope of this survey

Pictured: Rachel Morman (Chair, Verity), Michelle Welsh MP (Chair, APPG on PMOS), Baroness Merron (Women's Health Minister) and Caroline Andrews (Trustee, Verity).

READ THE FULL APPG REPORT

Breaking the Cycle was published by the All-Party Parliamentary Group on PMOS in 2025. Verity funds the APPG secretariat.

verity-pmos.org.uk/appg

SECTION 14

Method and limitations

Design and fieldwork

An online survey ran during the NICE consultation period, open to people with PMOS, people who believe they may have it, and their families and carers, resident in the UK and aged 18 or over. It used agree/disagree scales, multiple-choice items, a ranked top-three question and free text, structured around the sections of the draft guideline.

319 responses were received. Four respondents answering solely in a professional capacity were excluded, giving a base of 315. Percentages are calculated on those answering each item, excluding "not sure / not applicable"; bases are stated wherever they differ materially.

Testimony

Free-text quotations are anonymous, lightly corrected for spelling, and contain no identifying detail. Respondents were informed that their responses might be shared with NICE and used in Verity's public campaigning.

Data availability

Verity can make further breakdowns available to NICE, NHS England, the devolved administrations and parliamentarians on request, including regional and subgroup analyses not reproduced here.

Limitations

This is a self-selected sample drawn from an engaged patient community. It is not a probability sample and no weighting has been applied. It should be read as evidence of consensus, salience and direction among people sufficiently engaged to appraise a draft clinical guideline — not as an estimate of population prevalence.

283 respondents described themselves as White and 32 as Black, Asian, mixed or another global-majority background. Findings for that group are reported as counts throughout and should be treated as directional.

Expenditure figures derive from a free-text question and are self-reported lifetime estimates, unverified against records. Medians are reported in preference to means, which are skewed by a small number of very high values.

Reported clinical improvements are respondent accounts and are not clinically verified.

The survey item on the BMI threshold of 40 used the wording "fertility treatment". The provision in the draft guideline is for ovulation induction, and it is described that way throughout this report to avoid implying a national threshold for IVF, where access criteria are set locally.

DECLARATIONS

Verity is a registered stakeholder in this NICE guideline. A Verity trustee sits on the NICE guideline committee. This report draws solely on Verity's community survey and on the consultation response Verity submitted. It does not draw on the committee's proceedings, and nothing in it represents NICE or its committee. Verity funds the secretariat of the APPG on PMOS.

A NOTE ON NOMENCLATURE

This report uses PMOS — polyendocrine metabolic ovarian syndrome — the new international name for the condition previously designated polycystic ovary syndrome (PCOS). Quotations and citations retain the terminology used in the original source. Both refer to the same condition.

SECTION 15

What happens next

The consultation has closed, but the decisions that determine whether this guideline reaches patients have not yet been taken.

11 AUGUST 2026

Consultation closed

Verity submitted fourteen comments to NICE, each built on the evidence in this report.

AUTUMN 2026

NICE considers stakeholder comments

The guideline committee reviews every comment and decides what to change. Comments and NICE's responses are normally published alongside the final guideline.

DECEMBER 2026

Final guideline expected

Verity will publish a follow-up comparing what the community asked for with what the final guideline delivers.

2027 ONWARDS

Implementation — where this is decided

A NICE guideline covers the whole UK, but turning it into services is decided locally, by the organisations that plan and fund care in each nation. This is where the 94% who doubt the annual review will be proved right or wrong.

WHAT WE ARE ASKING OF READERS

- Tell us which of the fourteen asks in section 02 fall within your remit
- Consider the eligibility, classification and commissioning decisions that sit outside the guideline text
- Begin implementation planning now, rather than waiting for December — funding and workforce decisions carry their own lead times

WORKING WITH VERITY

We can provide further breakdowns of this survey, including regional and subgroup analyses, and can convene patients willing to speak directly to commissioners and policymakers.

verity-pmos.org.uk

THE ASK

A guideline is a description of good care. It is not delivery of it.

315 people read this draft and told us they recognise it as the right direction — and do not expect it to arrive. Publication in December is the starting point, not the finish. What follows is funding, commissioning, training and implementation, and none of it is decided by the guideline.

Verity stands ready to help with all of it.

Let's make it count.

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Verity is the UK charity for people with PMOS. We provide information and peer support, campaign for better care, and represent the PMOS community to government, the NHS and NICE.

verity
sharing the truth about PMOS

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