PMOS Survey for Women / trans men / AFAB Individuals — iGEM Lund
The "" Marks mandatory questions.*

About the Survey
This survey is run by iGEM Lund 2026, a student research project at Lund University, to better understand the experiences and treatment preferences of people affected by PMOS (formerly PCOS). Some questions ask about your health, symptoms, and diagnosis.
This survey takes approximately 10-15 minutes to complete (28 questions).

Eligibility check

- ☐ I confirm that I am 18 years of age or older.*
- ☐ I confirm that I am a woman, trans man, or an individual assigned female at birth.*

If either is unchecked, the survey closes and this text pops up: "Thank you for your interest, this survey is only open to women, trans men, or individuals assigned female at birth, aged 18+. Contact us at information@igemlund.org with questions."

Your data and privacy
Participation is voluntary, your answers will be kept confidential, and you can withdraw at any time without giving a reason.
Read our full privacy notice here *[Expandable privacy notice]*

- ☐ I have read the privacy notice and give my explicit consent to the processing of my health-related data as described above (**mandatory**).*
- ☐ I agree that anonymized quotes from my open-text answers may be shared publicly on our project website (**optional**).

Section 1 – Demographics

1. How old are you?*

- ☐ 18–24
- ☐ 25–34
- ☐ 35–44
- ☐ 45 or older
- ☐ Prefer not to say

2. Which region are you currently based in?*

- ☐ Europe
- ☐ North America
- ☐ Latin America & Caribbean
- ☐ Sub-Saharan Africa
- ☐ Middle East & North Africa
- ☐ South Asia
- ☐ East & Southeast Asia
- ☐ Oceania
- ☐ Prefer not to say

3. What is your PMOS status?*

- ☐ Formally diagnosed with PMOS
- ☐ Suspected but not formally diagnosed
- ☐ Not diagnosed (taking survey on behalf of someone / general interest)
- ☐ Other (please specify) _____

4. Which region are you currently receiving PMOS treatment in, if any? Select “Non applicable” if you are not currently receiving care.*

- ☐ Europe
- ☐ North America
- ☐ Latin America & Caribbean
- ☐ Sub-Saharan Africa
- ☐ Middle East & North Africa
- ☐ South Asia
- ☐ East & Southeast Asia
- ☐ Oceania
- ☐ Prefer not to say
- ☐ Not applicable (not currently receiving care)

5. Do you know which phenotype of PMOS you have been diagnosed with?*

- ☐ Hyperandrogenic PMOS (HA-PMOS)
- ☐ Overweight-obesity phenotype (OB-PMOS)
- ☐ High level of sex hormone-binding globulin (SHBG-PMOS)
- ☐ Elevated luteinizing hormone and antimüllerian hormone, AMH (LH-PMOS)
- ☐ I have been formally diagnosed, but I am unsure of my subtype
- ☐ I have not been formally diagnosed, so I am unsure of my subtype
- ☐ Other (please specify) _____

6. How long did it take to receive your diagnosis?*

- ☐ Less than 6 months
- ☐ 6–12 months
- ☐ 1–3 years
- ☐ More than 3 years
- ☐ Not applicable (I have not been formally diagnosed)
- ☐ Other (please specify) _____

Section 2 – Symptom severity

7. How severe are the following symptoms for you?*

1 = not experiencing this, 5 = severely affected

Symptom	1	2	3	4	5
Acne	○	○	○	○	○
Excess hair growth (hirsutism) e.g. on face, back or chest	○	○	○	○	○
Hair loss or thinning (alopecia)	○	○	○	○	○
Weight gain / difficulty losing weight	○	○	○	○	○
Blood sugar / insulin-related issues	○	○	○	○	○

8. How much does PMOS affect the following areas of your life?*

1 = not at all, 5 = extremely

Area	1	2	3	4	5
Self-esteem and body image	○	○	○	○	○
Social confidence and interactions	○	○	○	○	○
Academic or work performance	○	○	○	○	○
Mood and mental health	○	○	○	○	○
Energy and daily tasks	○	○	○	○	○

9. In the last 90 days (3 months), how many periods have you had?*

- ☐ None
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4 or more
- ☐ Unsure
- ☐ Not applicable (I do not get a period)

10. How would you describe your cycle regularity in the last 90 days (3 months) compared to your usual?*

- ☐ More regular than usual
- ☐ About the same as usual
- ☐ Less regular than usual
- ☐ Unsure
- ☐ Not applicable (I do not get a period)

11. Overall, how much does PMOS affect your daily life?*

1 = not at all, 5 = extremely

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5

Section 3 – Healthcare and treatment experience

12. Which treatments have you tried or are currently using for PMOS? Select all that apply.*

- ☐ Combined oral contraceptive pill
- ☐ Progesterone-only pill or other progestogen
- ☐ Spironolactone
- ☐ Metformin
- ☐ Diet and lifestyle changes
- ☐ Supplements (e.g. inositol, spearmint)
- ☐ Other (please specify) _____

13. Are you currently receiving treatment for PMOS?*

- ☐ Yes - hormonal (e.g. combined pill, progesterone-only pill)
- ☐ Yes - non-hormonal (e.g. metformin, lifestyle changes only)
- ☐ Yes - both hormonal and non-hormonal
- ☐ No - tried treatments but stopped
- ☐ No - never been treated
- ☐ Other (please specify) _____

14. How satisfied are you with currently available treatment or management options? Skip if untreated.

1 = very dissatisfied, 5 = very satisfied

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5

15. Have you experienced any negative side effects from hormonal treatments? Select all that apply. Skip if untreated.

- ☐ Mood changes or depression
- ☐ Nausea or digestive issues
- ☐ Weight gain
- ☐ Reduced libido
- ☐ Headaches or migraines
- ☐ Breakthrough bleeding
- ☐ I did not experience notable side effects
- ☐ Other (please specify) _____

16. Have you experienced any positive effects or symptom improvement from hormonal treatments? Select all that apply. Skip if untreated.

- ☐ More regular menstrual cycles
- ☐ Reduced acne or clearer skin
- ☐ Decreased excess facial or body hair growth (hirsutism)
- ☐ Reduced pelvic pain or lighter periods
- ☐ Improved mood or stabilized emotions
- ☐ Weight management or loss
- ☐ I did not experience noticeable positive effects
- ☐ Other (please specify) _____

Section 4 – Gut health symptoms

17. How often do you experience bloating or digestive discomfort?*

- ☐ Never
- ☐ Rarely (less than once a week)
- ☐ Regularly (1–2 times a week)
- ☐ Frequently (3–5 times a week)
- ☐ Daily or almost daily
- ☐ Unsure

18. Have you ever been diagnosed with IBS (Irritable Bowel Syndrome)?*

- ☐ Yes
- ☐ No
- ☐ Unsure

19. Do you currently take or have you taken probiotics?*

- ☐ Yes, currently regularly
- ☐ Yes, in the past
- ☐ No, but open to it
- ☐ No, not comfortable
- ☐ Unsure

Section 5 – Treatment preferences and product concept

The remaining questions are about a hypothetical product that **does not exist yet**. Imagine a daily oral **probiotic** tablet containing a **genetically engineered** (living, beneficial) bacterium, without synthetic hormones. It does not treat the root cause of PMOS, but is designed to reduce symptoms of hyperandrogenism (elevated levels of male sex hormones) by breaking down excess androgens in the gut.

20. How important is it to you that a PMOS treatment does not introduce synthetic hormones into the body?*

1 = not important, 5 = very important

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5

21. How interested are you in **non-hormonal probiotic based** treatments for PMOS?*

1 = not interested, 5 = very interested

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5

22. If this oral probiotic tablet product were available, proven safe, and prescribed by a doctor, how likely would you be to try it?*

1 = very unlikely, 5 = very likely

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5

23. Compared to **hormonal treatments,** how would you rate your interest in this probiotic approach?*

- ☐ Strongly prefer probiotic
- ☐ Somewhat prefer probiotic
- ☐ No preference
- ☐ Somewhat prefer hormonal
- ☐ Strongly prefer hormonal

24. If this probiotic treatment cost more out-of-pocket than your current hormonal treatment, how would that affect your interest in trying it?*

- ☐ Still very interested regardless of cost
- ☐ Interested if extra cost is modest
- ☐ Only interested if same or less
- ☐ Cost not a barrier (e.g. insurance/subsidized)
- ☐ Unsure

25. Which aspects of this approach appeal to you most? Select all that apply.

- ☐ No systemic hormone exposure
- ☐ Likely fewer side effects
- ☐ Targeted — acts only where the problem occurs
- ☐ Could be used alongside existing treatments
- ☐ Feels more natural
- ☐ Nothing in particular appeals to me
- ☐ Other (please specify) _____

26. What would be your biggest concern about a probiotic-based treatment? Select all that apply.*

- ☐ Uncertainty about long-term safety
- ☐ Whether it would be effective enough
- ☐ The use of a genetically engineered bacterium
- ☐ Cost or availability
- ☐ Having to take it every day
- ☐ No significant concerns
- ☐ Other (please specify) _____

Section 6 – Open responses (Optional)

27. What is the biggest challenge you face due to PMOS?

_____

28. Is there anything else you would like researchers to know, about your experience with PMOS or what you would want from future treatments?

_____

Thank you for completing this survey. As agreed at the start, your anonymized responses will be used for this research project.

Any questions? Contact us at: information@igemlund.org.