

Supplementary File 1.

Semi-structured interview guide

Opening statement

Thank you for agreeing to participate in this interview. This study aims to understand the health management experiences of women with polycystic ovary syndrome (PCOS). Your participation is voluntary, and you may withdraw at any time without any impact on your care. The interview will be audio-recorded to ensure accuracy, and all information will be kept confidential and anonymized. Only the research team will have access to the recordings. Do you have any questions before we begin?

(1) Could you walk me through the changes you noticed in your body before diagnosis, what you did about them, and what finally prompted you to seek medical help? When did you first notice these changes? (e.g., menstruation, weight, skin) Did you take any measures on your own? (e.g., dieting, seeing a dermatologist) How did these changes affect your daily life, emotions, or social interactions? Did you discuss them with family or friends? How did you describe them? What finally made you decide to go to the hospital? How did you describe your symptoms to the doctor during your first visit? Probes: Which department did you visit first? Were you ever misdiagnosed or told “there is nothing wrong”? How satisfied were you with that first encounter?

(2) How was the diagnosis communicated to you, and what did you do to understand your condition afterward? How did the doctor explain PCOS to you? What was your first thought and strongest emotion when you heard the diagnosis? When you left the hospital, how much did you feel you understood about PCOS? Through which channels did you start learning about the disease? (e.g., internet, books, patient peers)

What made you feel most helpless during the information-seeking process?

Probes: Did the doctor mention “chronic condition” or “lifelong management”? What were you most worried about (fertility, appearance, health)? Did the initial information ease or worsen your anxiety? What help did you most wish healthcare professionals had provided?

(3) What management plan were you given, and what has it been like trying to follow it while balancing work, social life, and personal plans?

What initial management plan did the doctor give you? (e.g., medication, lifestyle modification)

What was the easiest part and what was the most difficult part of following the plan?

Did following the plan conflict with your work, social life, or life plans (e.g., marriage, childbearing, career)?

How did you view and balance these conflicts?

Probes: Can you give a specific example of a conflict and how you handled it?

(4) In your ongoing care, what has your relationship with healthcare providers been like? What kind of communication best supports you?

During follow-up visits, did you feel the doctor addressed all the concerns you had as a young woman?

Did you feel listened to or dismissed?

Did you feel involved in treatment decisions?

Can you describe a memorable experience of being supported or neglected?

What kind of doctor–patient communication would be most helpful for your long-term management?

(5) Can you share moments of both success and struggle in your self-management?

What has sustained you, and what support do you still need?

Please describe a moment when you felt “in control” of your self-management.

Please describe a moment when you felt “exhausted” or even wanted to give up.

What sustained you through those difficult times?

What support did your family, friends, or patient peers provide?

What additional support do you still hope to receive?

(6) Looking back on this whole journey, how has PCOS shaped the way you see yourself and plan for the future? Has it brought any unexpected growth?

To what extent has PCOS changed the way you see yourself, manage your health, and plan for the future?

How would you describe your relationship with PCOS today?

Beyond the challenges, has this journey brought you any unexpected gains or growth?

Probes: How has your attitude toward the illness evolved? Have you redefined your self-worth? Have you adjusted future plans (e.g., fertility)? What would you most like to say to women with similar experiences?

Closing

Thank you for sharing your experiences with me. Is there anything else you would like to add that we haven’t covered? If you have any questions later, please feel free to contact the research team. Your contribution is greatly appreciated.