

Developing the Premature Ovarian Insufficiency Quality of Life Scale for English Speaking Countries

Background

POI: Common. Serious. Under-researched

POI is associated with increased risks to physical, mental and social health. Despite this, there is little research on interventions - and no validated, culturally relevant quality of life tool for English speaking countries.

POI is not rare:

- Once thought to affect only 1% of women under 40, recent meta-analyses place POI prevalence at 3.5-3.7% - not rare at all (Golezar et al., 2019; Li et al., 2023)

New diagnostic criteria:

- 4+ months irregular/absent cycles + one FSH > 25IU/L for diagnosis. No repeat test needed

Health risks:

- Associated with increased risk to brain, bone, heart and reproductive health (leading to infertility); plus profound psychosocial impacts (Panay et al., 2025; Tian et al., 2024)

Research Gaps:

- Limited research on interventions. Disease specific QOL tool recommended (Hammond & Marczak., 2023; McDonald et al., 2022)

Why it matters:

- Timely diagnosis & Targeted Care improves quality of life (ESHRE 2024)

Methods & Design

Study Design

- Cross-sectional, multi-country scale development
- Following best practice psychometric validation steps

Recruitment

- Social media POI support groups & networks
- Targeted to broaden reach to younger cohorts previously unrepresented

Item Development

- Review of literature & Qualitative Surveys
- Thematic Analysis
- Expert Review (Panel including expert clinicians and women with lived experience)

Data Collection

- Secure online platform
- Demographics, validated scales and new POI items

Analysis

- Pilot Study
- Exploratory & Confirmatory factor analysis
- Reliability & Validity testing

KEY GAPS

Golezar et al (2022) Scale

Why a New Tool is Needed

Lack of Representation

- Excludes younger women & diverse relationships. Item generation- 16 women aged 28 to 47 from a gynaecology clinic (Golezar et al., 2020)
"My intercourse with my husband is out of obligation"

Cultural Limitations

- Assumptions about marriage and motherhood
"It is easier for me to tolerate the disease after I have removed getting married or having children as my goals in life"

Missing Domains

- Omits Health Care Provider (HCP) factors known to influence long-term adjustment.
- Focus on appearance-related HRT effects misses key Physical Health Impacts (cognitive, cardiovascular, bone/joint)

Linguistic Issues

- Double barrelled & Mixed Constructs
"I have become depressed and introverted"
"I feel sad due to some complications of the disease (weight gain, sexual problems, infertility and osteoporosis)"

Methodological

- Unconfirmed Construct Validity
- No convergent or divergent validity testing reported

Unclear Constructs

- Coping strategies included as a QOL measure despite being a mechanism, not an outcome. Blurs construct boundaries and risks cultural bias
"Prayers and trust in God have helped me tolerate the disease"

Emerging Findings

N=192 completed an online open ended survey. Early analysis of qualitative data reveals that POI affects multiple life domains, including identity, relationships and life opportunities

Unmet psychosocial needs were widespread.

Women reported no referral to counselling or support after diagnosis

"there was no help or understanding I was dismissed for several years and then when diagnosed I was left to figure it out on my own"

"I should have gotten into therapy for it right away. I wish more doctors and nurses were educated"

Self-advocacy and supporting others emerged as meaningful,

taking an active role in managing their condition restored a sense of agency and purpose. Some women described involvement in support groups as meaningful and healing.

"I've learnt to trust myself when something feels wrong, advocate for myself, and not make myself feel I'm being selfish or loud for wanting to be heard"

"I also liaise and work with people to raise awareness of this. It has been amazing to advocate for others"

Healthcare experiences shape outcomes.

Women described HCP providers lacking knowledge of POI as compounding distress. Experiences with knowledgeable HCP's described as positive and validating

"I had been going to doctors for years before being diagnosed properly and treated. I hate thinking about it and how hard it has been to get care"

"6 years of being ignored and told everything was fine, switching doctors and having a diagnosis in 3 weeks. After diagnosis treatment has been easy and beneficial for my overall wellbeing."

Age at Diagnosis matters.

Women diagnosed in adolescence or childhood describe persistent impacts on body image, social functioning, and emotional wellbeing, often linked to missed puberty induction treatment — timely treatment may help to prevent decades of distress underscoring the importance of early detection in mitigating long-term harm

"I got POI early on, I didn't develop the way I should've. I struggle with this and body image as a whole to actually feel like a woman"

