

EP 14.08: Exploring individuals' preferences for endometriosis diagnostic tests (IPEdT): a mixed methods study



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Introduction

- Endometriosis affects ~10% of individuals of reproductive age.
- Diagnosis is often delayed 8–12 years due to symptom overlap and limited provider awareness.
- Current diagnostic methods: clinical assessments, imaging, histology, biomarkers, surgery.

Objective:

- Explore patient preferences for diagnostic methods.
- Inform patient-centered care and best practices.

Methods

- Mixed-methods across 4 phases.
- Focus groups:
 - Confirmed diagnosis (imaging/surgery)
 - Presumptive diagnosis (clinical only)
- Grounded theory analysis.
- Five focus groups with 25 participants (24 diagnosed, 1 referred; aged 21–56) revealed eight key themes:

Table 1: Patient Demographics

Characteristics	Value <i>n</i> = 25 (%)
Age (years)	
<30	11 (44)
30-39	9 (36)
40-49	3 (12)
≥50	1 (4)
Not disclosed	1 (4)
Ethnicity	
African	1 (4)
Asian	1 (4)
Latin	2 (8)
Middle Eastern	1 (4)
Mixed Race	2 (8)
White	17 (68)
Not disclosed	1 (4)
Highest level of schooling	
High school	3 (12)
College or University	14 (56)
Postgraduate education	6 (24)
Not disclosed	2 (8)
Employment status	
Unemployed	6 (24)
Employed part-time	1 (4)
Employed full-time	16 (64)
Not disclosed	2 (8)



Results

Theme	Key Findings
Diagnostic Challenges & Delays	Dismissal of symptoms, inconsistent outcomes, limited access.
Patient Advocacy & Self-Advocacy	Self-directed research, independent referrals.
Provider Expertise & Trust	Specialized ultrasound, continuity, transparency
Visual Confirmation & Validation	Need for diagnostic images, visual validation.
Emotional & Psychological Impact	Relief with diagnosis, toll of delays, mental health effects.
Preferences & Risk Tolerance	Non-invasive preferred, invasive if needed.
Practical & Institutional Needs	Formal diagnosis vital for insurance and workplace support.
Educational Needs & Gaps	Limited provider awareness, need for education. Quote:

Conclusion

- Patient voices highlight diagnostic preferences and unmet needs.
- Findings inform patient-centered diagnostic practices.
- Next step: discrete choice experiment aligning diagnostic options with patient priorities
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