

Co-designing a patient-led AI research agenda for endometriosis

Schor B.G.S., Buter M., Neal D., Dusseljee-Peute L., De Leeuw R., Huirne J. with EndoFrance (FR), Endometriosis Stichting (NTL), AI for Women’s Health (UK), University of Cambridge - CRASSH (UK), Amsterdam UMC (NTL) and European Endometriosis League (EEL).

Objectives

To leverage AI research centered on patients’ priorities to improve endometriosis care.

Patient-led co-design methods

An online survey with patients and 4 iterative workshops, June 2025 to April 2026 (Fig. 1).

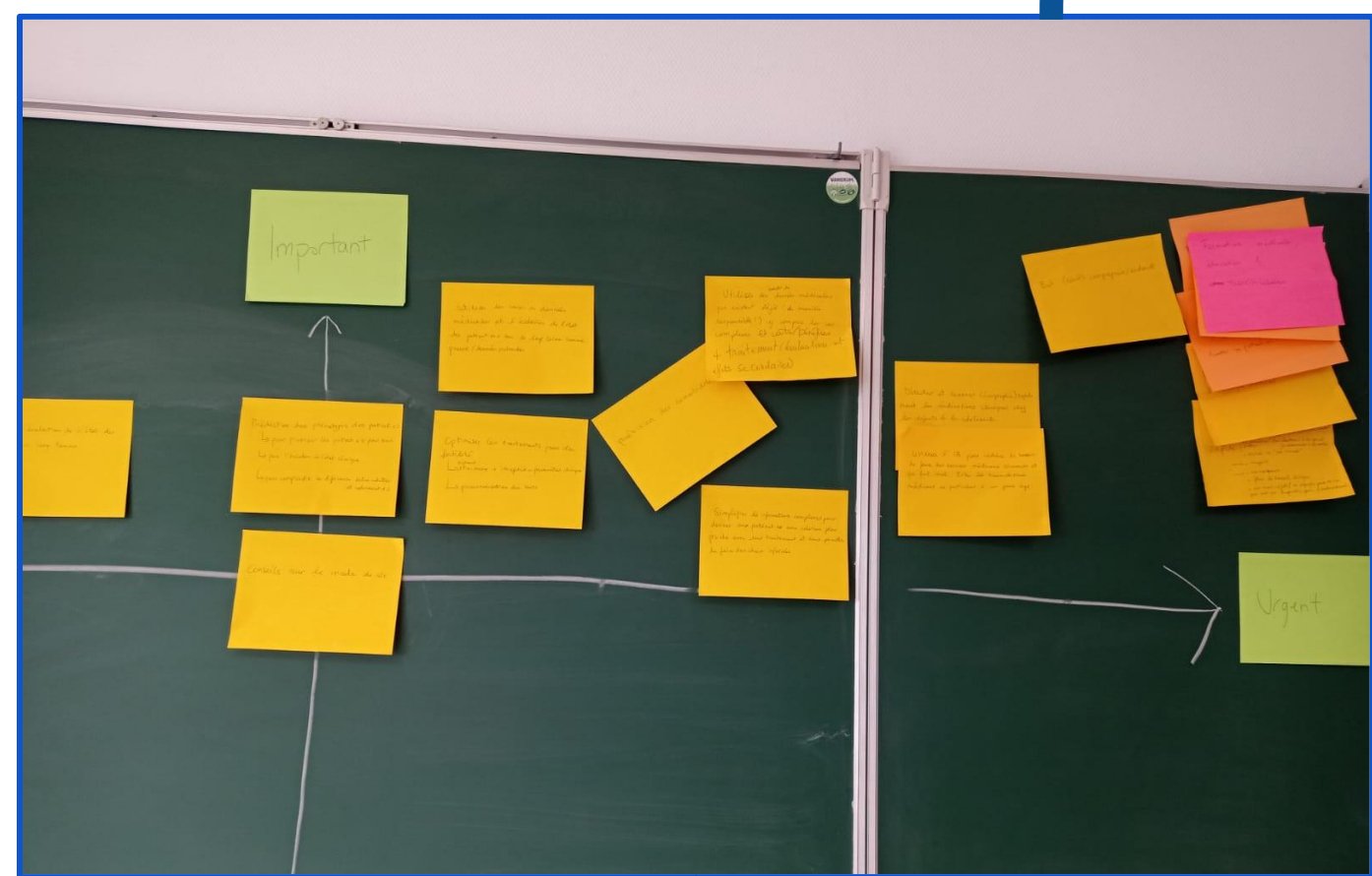


Figure 1. Co-design workshops with patients, clinicians, and AI researchers across the EU.

Results

We identified 21 research themes, including 7 priorities (Table 1). We show that:

1. Many themes are underexplored
2. Clinicians and patients have different research priorities for AI & endometriosis
3. Patients ask to be involved early in AI research.

Conclusion

Patient-led research priorities for AI & endometriosis are underexplored but key to:

- i) inform innovation, funding, AI medical training & public policies.
- ii) build AI tools that align with what matters the most: patients’ needs.

1. Faster diagnosis
2. Medical training, education, raising awareness, and reducing patient gaslighting among physicians
3. Holistic treatment / therapy
4. Predictive models based on medical records, e.g. for diagnosis, estimation of personalised treatment effect
5. Help patients prepare for visits
6. Tailored treatment based on (pain) symptoms
7. Detect and scan clinical signs of endometriosis in children and adolescents

Table 1. Top 7 patient-led AI research priorities for endometriosis in Europe.

The Alan Turing Institute

Amsterdam UMC
Universitair Medisch Centrum

CRASSH



More info:

Dr Bianca Schor

b.g.s.schor@amsterdmaumc.nl