What endometriosis apps may still be missing

What a new symptom-tracking study reveals about the gap between recording symptoms and understanding disease burden.

Endometriosis

1 in 10

women of reproductive age affected

170 million

women living with endometriosis worldwide

4 - 12 years

from symptom onset to diagnosis

What a new symptom-tracking study reveals about the gap between recording symptoms and understanding disease burden.

The bridge

Patients

- Struggle to present all symptoms
- Tracking feels overwhelming
- May feel misunderstood and dismissed

Clinicians

- Have limited appointment time
- May receive an incomplete picture of symptoms over time

Digital tracking could help connect the two.

But tracking has often relied on predefined or semi-customized categories.

The study

Instead of handing participants a checklist, researchers let them build their own using their custom app.

34

participants

up to 12 mo

daily tracking

Participants defined their symptom sets with guidance from the research team

The finding

24.5 median **unique symptoms** tracked per participant

228 distinct symptoms across just 34 people

10 median number of organ-system categories represented per participant

No two symptom profiles were the same.

One symptom isn't the story

One participant's data shows why this matters:

- Abdominal cramps: 12–33% of days per cycle
- Waist pain: 15–55% of days per cycle
- Her five gastrointestinal signs and symptoms grouped together: 75–100% of days

When looked at one at a time, her symptoms seem intermittent. But when grouped together, she was symptomatic on 75–100% of days in every cycle.

Tracking symptoms separately can hide their cumulative burden.

Design insight

Participants said that naming symptoms in their own language made tracking feel more relevant and gave them a greater sense of ownership.

They **drew distinctions** that a dropdown would erase, such as left vs. right pelvic pain and stabbing vs. dull.

They **recorded symptoms that standard endometriosis instruments may not** routinely capture, such as eye allergies, cold sensitivity, ear pain, and mouth ulcers.*

*Their inclusion does not establish that endometriosis caused them, but it makes them visible for further investigation.

Takeaway

This points toward tools that are:

- Flexible enough to **record many symptoms in a patient's own language**
- Structured enough to **reveal cumulative burden** over time
- Concise enough to become **useful during a clinical appointment**.

Source: Zelovich, T., Zelovich, A., Feiglin, S. et al. Patient-tailored symptom tracking in endometriosis: a framework to explore disease variability and burden. npj Digit. Med. (2026). (Article in press)

Competing interests: two authors are founders of SymptoLab, which is developing the app used in the study.

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