

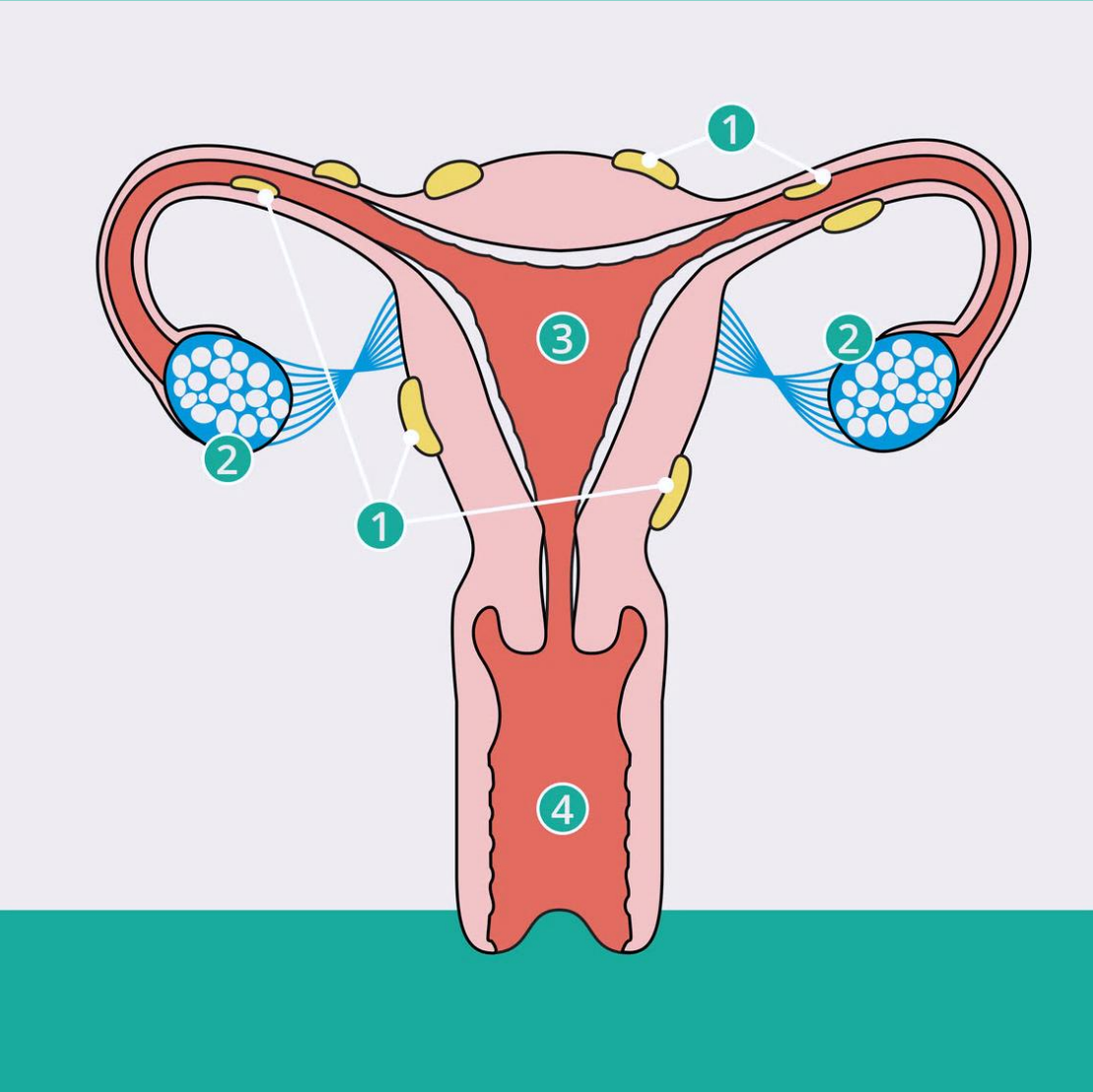
Co-Producing a Digital Symptom Reporting Tool for Suspected Endometriosis: Development and Pilot Study

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BACKGROUND



- Endometriosis affects 1 in 10 women and people assigned female at birth¹
- Significant impact on daily functioning and quality of life²
- Diagnosis takes 8 to 10 years on average in the UK³⁻⁴
- Welsh Government³ has stipulated that tools and resources are needed to reduce diagnostic delays.

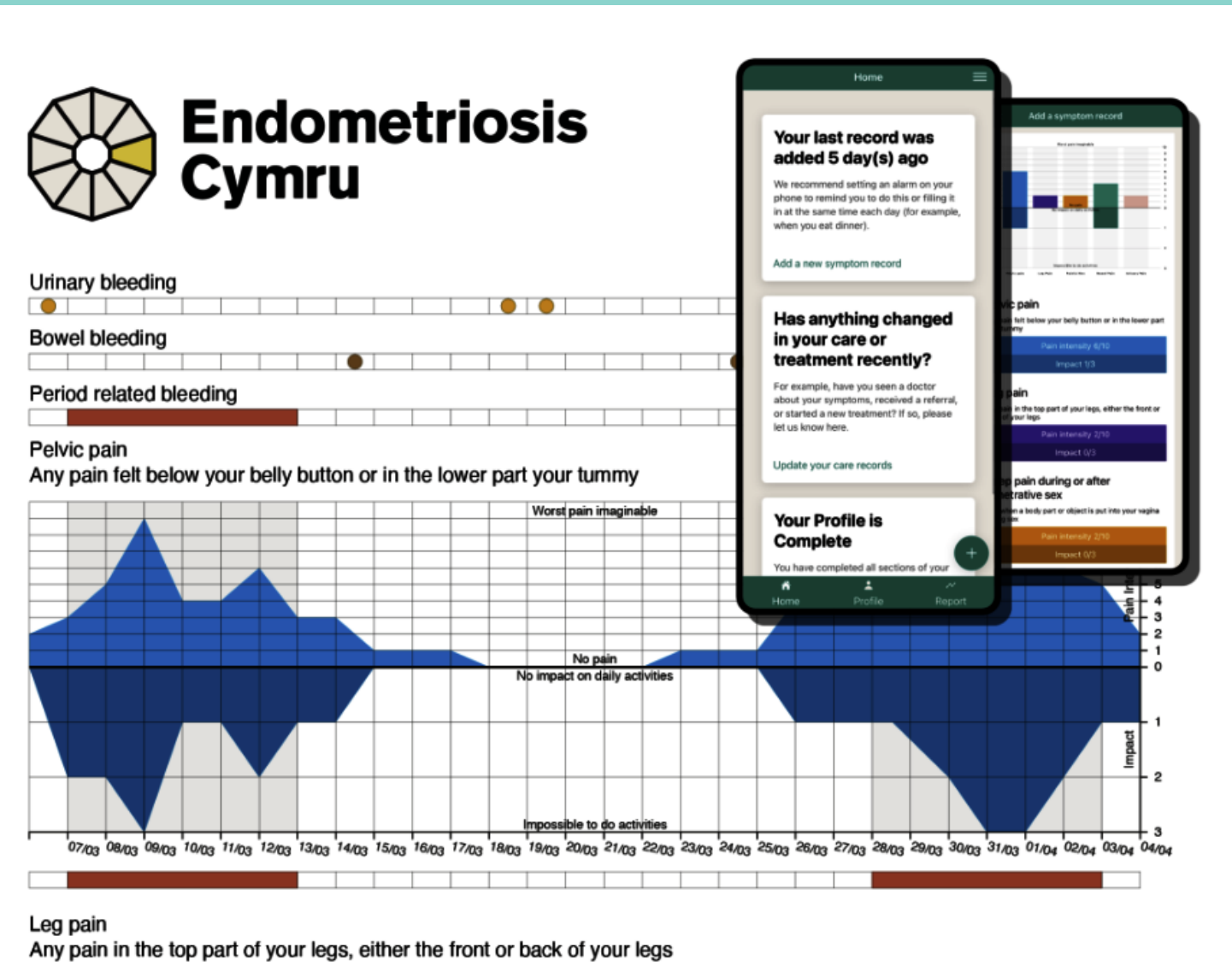
Aim: To co-produce and assess the acceptability of the Endometriosis Cymru Symptom Tracking and Reporting Tool (ESTR)

Co-Development

ESTR was co-produced, from conception to delivery, with FTWW and local digital designers. It was developed based on the NICE guidelines for endometriosis¹, and consultations with pan-Wales stakeholders: endometriosis nurses, GPs, gynaecologists, pelvic wellbeing coordinators, patients, third sector organisations.

What is ESTR?

- A free, digital, user-friendly, bilingual tool for people experiencing risk factors and/or symptoms that could raise suspicion of endometriosis.
- The tool helps users to track their symptoms and treatment history, which are summarised in a short report, so that they are ready to communicate key information to their doctor.



METHODS

Pilot participants: 64 undergraduate psychology students, aged 18 or older, at least one menstrual period in the past 3 months. Participants were randomised to 1 of 3 groups:

(1) Use the ESTR daily for one month

(ESTR; N = 22)

(2) Use an alternative version of the tool to track non-endometriosis specific period symptoms daily for one month

(ALT; N = 20)

(3) Complete a 30-minute writing task about menstrual symptoms

(Not Tracking; N = 22)

Measures: Baseline and 1-month follow-up survey about their menstrual health, health beliefs regarding period and pelvic pain, and feedback on the tool.

RESULTS

Demographics: Average age 19.8 years (SD = 2.85), 76.6% white British, 14.1% reported being part of a minoritised group

Baseline symptoms: 26.6% (N = 17) reported severe menstrual pain symptoms (PIPPA⁵), however, only 6.4% (N = 4) stated that it was very or extremely likely that their symptoms were due to an underlying condition.

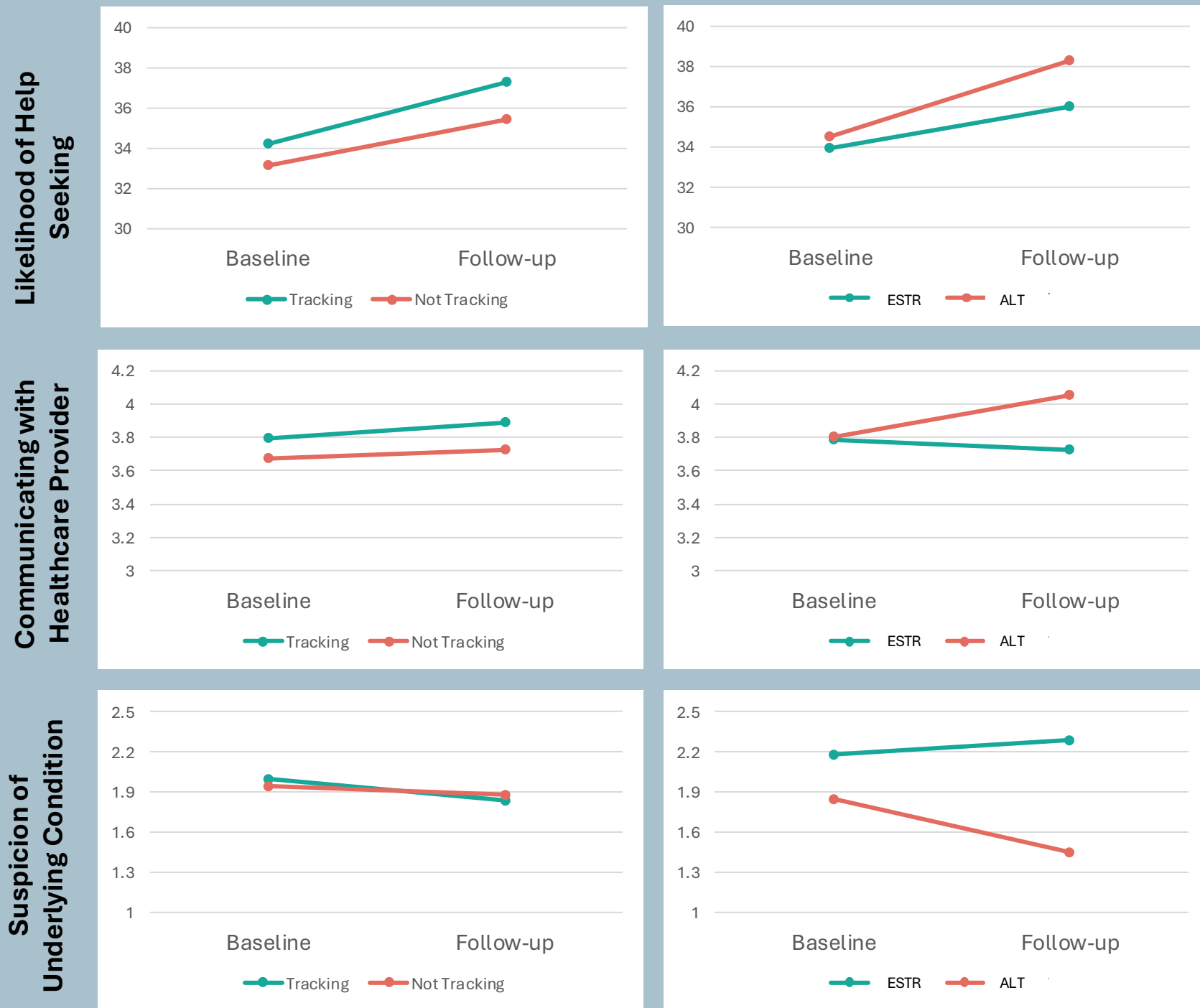
Acceptability of ESTR:

	ESTR M (SD)	ALT M (SD)
Bad (1) to Good (5)	4.1 (.78)	4.5 (.69)
Harmful (1) to Beneficial (5)	4.4 (.85)	4.4 (.75)
Unpleasant (1) to Pleasant (5)	3.8 (.84)*	4.3 (.80)*
Worthless (1) to Valuable (5)	4.2 (.94)	4.3 (.91)
Difficult (1) to Easy (5)	4.3 (.97)	4.6 (.89)
Average number of daily symptom-records completed	17.7 (9.5), Median: 21, Range: 0-29	20.2 (6.7), Median: 21.5; Range: 7-30

"Easy and quickly became part of my daily routine"

"Made me realise that perhaps the level of pain and difficulty I feel is not normal"

All estimated effect sizes small, except:
(1) Moderate estimated effect of time on likelihood of help seeking for all groups (tracking vs. not tracking; ESTR vs. ALT)
(2) Moderate estimated effect of tracker type (ESTR vs. ALT) on suspicion that menstrual symptoms are due to an underlying condition, specifically ESTR increased suspicion, while ALT decreased suspicion.



CONCLUSIONS

Participants unaware they should seek help: More participants experience menstrual pain symptoms that would warrant healthcare attention than consider the possibility of an underlying condition.

Tracking increases likelihood of help-seeking and type of tracker is important: Tracking associated with increased likelihood of help seeking for all groups. Tracking endo-specific symptoms may increase perception that menstrual symptoms are due to an underlying condition.

ESTR is acceptable to users: Attitude favourable and low attrition, but larger scale research with intended users and diverse population needed.

Future research for inclusivity: Ongoing realist evaluation of the ESTR (R Joseph, PhD) and proposals to increase accessibility; need for mobile app version.

IMPLEMENTATION & NEXT STEPS

Implemented into national patient and provider resources; Signposted on national third sector organisation websites; Features in the 10-year women's health plan for Wales; BBC news coverage.

Available to the public with 451 users to date. 26.9% of users who completed at least one symptom record reported a change in their healthcare (e.g., new diagnosis, investigation, referral, treatment) since using ESTR. ESTR rated as moderately helpful (M = 2.6/5) in accessing these healthcare changes by users.

Funding applications submitted to develop mobile app, inform larger efficacy and economic evaluation.

Visit endometriosis.cymru/srt/ for the free tool!

Community HealthPathways

NHS 111 Wales



BBC

References

¹NICE Guidelines, Endometriosis. <https://www.nice.org.uk/guidance/ng73>

²Rush & Misajon, 2018. <https://doi.org/10.1080/07399332.2017.1397671>

³Welsh Government, Endometriosis Task and Finish Group Report <https://www.gov.wales/endometriosis-care-review>

⁴Endometriosis UK. <https://www.endometriosis-uk.org/diagnosis-report>

⁵Parker et al., 2022. <https://doi.org/10.1016/j.jpag.2021.06.003>

