

# New model of care for endometriosis patient through citizen science

**Short name**

EndoHealth

**Formal name**

New model of care for endometriosis patient through citizen science

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*Actively involving patients is key to improve people-centered care*

**Summary**

The Patient Experience Observatory at Hospital Clínic Barcelona in collaboration with the Gynaecology Department is embarking on a citizen science initiative aimed at developing an innovative care model for women receiving treatment for endometriosis at the hospital. Globally, approximately 10% of women of reproductive age are affected by endometriosis. However, due to factors such as limited awareness and understanding of the condition, patients encounter numerous challenges, including prolonged wait times for diagnosis (averaging 8 years), difficulties in effectively communicating their symptoms, ineffective treatments, and insufficient support.

To address these challenges, the project aims to adapt a digital patient monitoring platform that collects real-time patient-reported indicators of experience and health outcomes throughout their entire healthcare journey. By incorporating individual and aggregated analysis of quality-of-care data, this platform will identify unmet needs and facilitate the design of appropriate interventions.