



Participatory research on endometriosis results in six recommendations to inform public policies in Catalonia

Endometriosis affects 10% of girls, women (and sex-gender diversities) of reproductive age worldwide. Its diagnosis takes between 8 and 10 years from the onset of symptoms, a time during which these people suffer serious physical, psychological, social and professional consequences. Participatory research on endometriosis has resulted in the co-creation of 6 general and 28 specific recommendations, written in the first person by patients, with the aim of informing public health policies and contributing to improving the clinical approach and care services to patients.

Through citizen science, Science for Change has led this pilot project in collaboration with the [Gynecology Area of the Hospital de la Santa Creu i Sant Pau](#), the [Agency for Health Quality and Assessment of Catalonia \(AQuAS\)](#), the Economic Strategy Area of the Generalitat de Catalunya and the [OpenSystems research group of the University of Barcelona](#).

"Endometriosis in the first person: participatory research on experiences and recommendations of women with endometriosis for the improvement of health services" is an innovative pilot that applies citizen science in women's health within the framework of the [European Project H2020 TRANSFORM](#). This pilot has involved women with endometriosis to deepen their experiences of the disease and their experiences regarding health services. In the research, 20 women diagnosed with endometriosis participated as co-investigators, having an active role in the data collection phases, in the formulation of recommendations and in the dissemination of the results.

Marta Fonseca has been suffering of endometriosis for 18 years. She has undergone four surgeries and has participated in the pilot.

"The fact of being in this group does not cure, but it helps a lot to share this experience and contribute to these recommendations. Yes, it is a complex disease, but if there are so many women who suffer from it, more attention must be paid to the various areas that





endometriosis involves. Endometriosis exists and we must have better ways to deal with it with more informed professionals and resources dedicated to research."

With the results of the research, a [policy brief](#) has been written for policymakers and health personnel, presenting the recommendations co-created by women for the improvement of health services. The policy brief was presented on the 19th October at an event at the Hospital de la Santa Creu i Sant Pau that was attended by the women participating in the research and Gynecology professionals from the Hospital.

"The pilot and the policy brief aim to give voice and raise awareness about how endometriosis is experienced and its effects on people's global health, as well as present recommendations to improve diagnostic and health care services." Diana Reinoso, Project Manager at Science for Change

The six general recommendations contained in the policy brief are:

- Increase awareness of endometriosis at the healthcare level
- Develop strategies for an early diagnosis of endometriosis
- Improve the process of conveying information to patients to increase self-awareness and contribute to shared decision-making
- Define and implement a comprehensive endometriosis management model
- Improve care for people with endometriosis in healthcare services
- Develop more personalised and patient-informed treatment models

The ultimate goal of the policy brief is to influence public health policies at regional and local level, and specifically, to influence [the Endometriosis Care Model of Catalonia](#), in addition to the new model of innovative approach to the disease in the Hospital of Santa Creu i Sant Pau.

Dr. Ramon Rovira, surgical coordinator of the Gynecology and Obstetrics Service of the Hospital de la Santa Creu i Sant Pau – IIB Sant Pau, in Barcelona, comments that *"with the*



TRANSFORM project we have really put the patient at the center. It has been an opportunity, as a professional, to know first-hand what patients need and a possibility of radical improvement to face changes in the therapeutic approach to this pathology at all levels”.

In addition, he adds that the results of this initiative are “a clear example for new projects in different areas of health that allow a paradigmatic change in what patient care entails, in general. Knowing what the patient needs is one of the obligations of the medical care of the future”.

According to Nora Salas Seoane, Head of the Health Area of Science for Change, this pilot project is a clear example of how we can use citizen science, participatory strategies and co-creation in health to incorporate the patient's experience and transform together with them certain health practices and their healthcare services. *“We are helping to understand women's health from their perspective and their feelings, taking into account gender barriers in health. This pilot demonstrates that the patient experience is key and necessary to improve care services and influence the planning of health policies”* says Nora Salas Seoane.

