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**FIRST-PERSON EXPERIENCES OF  
ENDOMETRIOSIS IN CATALONIA:  
RECOMMENDATIONS OF WOMEN WITH  
ENDOMETRIOSIS FOR IMPROVING HEALTHCARE  
SERVICES AND PUBLIC POLICIES**

*TRANSFORM Policy Brief 2022*

Research coordinated by the Catalan Cluster of the TRANSFORM project:



**Science  
for Change**



**Generalitat  
de Catalunya**



**UNIVERSITAT DE  
BARCELONA**

Collaborating  
entities:

**Salut/**



**HOSPITAL DE LA  
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UNIVERSITAT AUTÒNOMA DE BARCELONA

**Agència de Qualitat i Avaluació  
Sanitàries de Catalunya**

**EXECUTIVE SUMMARY**

This Policy Brief is the result of a participatory research using citizen science methodologies where women act as co-investigators speaking in first-person about endometriosis in Catalonia. The research aims to explain and raise awareness about how endometriosis is experienced and its effects on people's overall health, as well as to generate recommendations made by the participants to improve early diagnosis and healthcare services.



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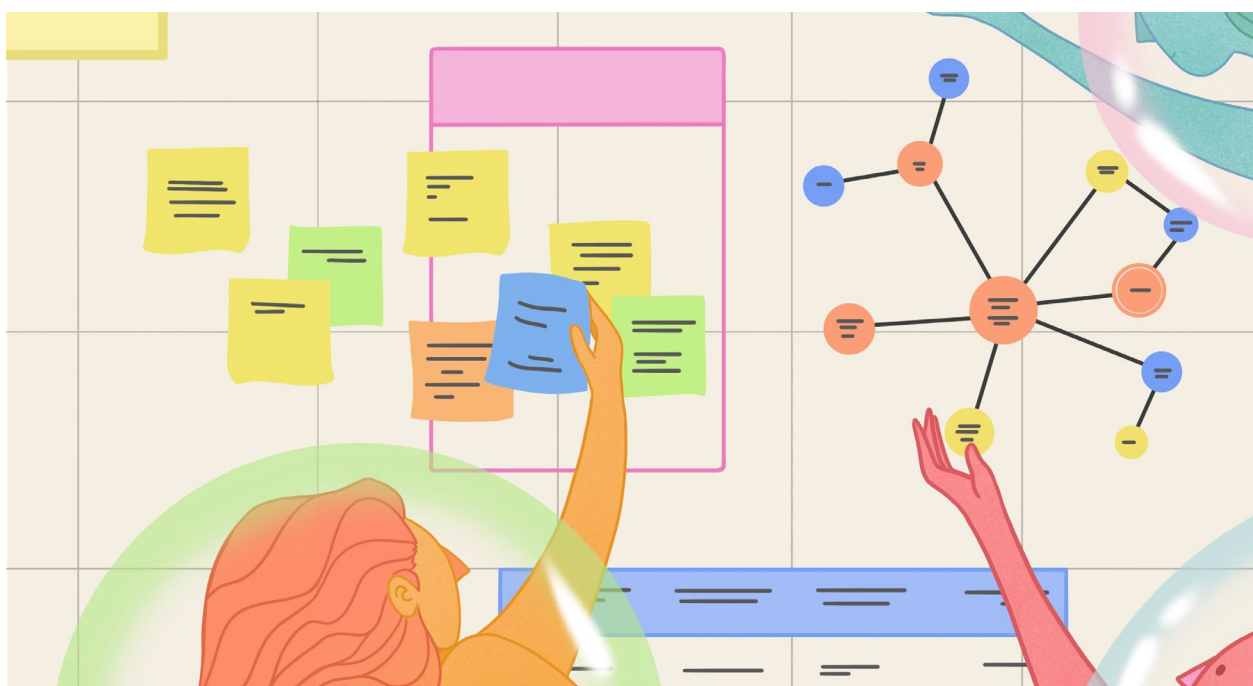
## ENDOMETRIOSIS, AN INVISIBILIZED WOMEN'S DISEASE

- Endometriosis is an **underdiagnosed disease** affecting women's (female and other sex-gender identities) health, in which the **endometrium grows outside the uterine cavity**.
- It can cause severe **menstrual pain, painful sexual intercourse, chronic pain, fertility problems and psychological disorders**, such as depression and anxiety<sup>1</sup>.
- The drama comes with the statistics: endometriosis affects **10-20% of women of reproductive age** globally<sup>2</sup> and its **diagnosis takes 8-10 years** from the onset of symptoms<sup>3</sup> - a time during which women suffer serious physical, psychological, social and professional consequences.
- Endometriosis is **surrounded by gender issues and social norms** that have led to the creation of myths, erroneous beliefs and misconceptions - such as that menstrual pain is normal - affecting the professional practice within healthcare services and the necessary political support.
- The **lack of knowledge of the disease** at both social and healthcare levels and the **underestimation of the pain expressed by women** have contributed to a long delay in the diagnosis of endometriosis, poor research and inadequate health care.

### THE WOMEN'S HEALTH PILOT ON ENDOMETRIOSIS

*"First-person experiences of endometriosis: participatory research on experiences, assessments and needs of women with endometriosis"* is an innovative pilot project in women's health in the framework of the European H2020 Project TRANSFORM<sup>4</sup>. It aims to **integrate the dimensions of Responsible Research and Innovation** (specifically citizen participation) within the Smart Specialization Strategy of three European regions, in order to make innovation policies more responsible and aligned with society.

In Catalonia, the methodology used has been Citizen Science. The Gynaecology Area of Sant Pau's Hospital in Barcelona posed the challenge of **improving the infra diagnosis and healthcare services for endometriosis by integrating the voice of the patients in an innovative way**. Together with the Catalan cluster of the project (the company *Science for Change*, the Area of Economic Strategy of Generalitat de Catalunya and the *OpenSystems* research group of *Universitat de Barcelona*) and the *Catalan Agency for Health Quality and Evaluation of Catalonia* (AQuAS), this pilot has been developed to contribute to the challenge of improving public health policies and the approach to endometriosis.





## THE PHASES OF THE PILOT

### 1. The challenge

The Gynaecology Area of Sant Pau's Hospital in Barcelona proposes the challenge of **introducing the perspective of patients with endometriosis to improve healthcare services and the under-diagnosis of the disease** thanks to their participation in the webinars organised by TRANSFORM to include Citizen Science in the Research and Innovation Strategy for the Smart Specialization of Catalonia (June-December 2020).

### 2. First-person stories of endometriosis

**Groups of women with endometriosis** are set up to act as co-researchers, **sharing their first-person stories and experiences** of living with the disease and its effects. They **map their journey** through healthcare services as patients and their needs in relation to them (April-July 2021).

### 3. Co-creation of recommendations for the improvement of healthcare services

**Women co-create their recommendations** for the improvement of healthcare services and diagnosis. The recommendations are addressed to policy makers and health care personnel (July 2021-April 2022).

### 4. Impact in public policies

The **results will be taken into account by Sant Pau's Hospital**, which is committed to making **improvements in healthcare services**. The research also aims to **influence regional health policies** in the Catalan Health System (April 2022-December 2022).

## THE PILOT METHODOLOGY: CITIZEN HEALTH SCIENCE IN ACTION!

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Citizen science is a way of doing science in which citizens are involved in the scientific process. In this case, 20 women diagnosed with endometriosis participated as co-researchers in the pilot in the phases of data collection (generating data themselves); formulation of recommendations (co-creating the recommendations with the other participants); and dissemination of the results (through round tables, activism events and social networks). The research consisted of an iterative process of collaborative research, responding to the needs and contributions of the different actors involved throughout its development and also responding to the standards of scientific research. The methodologies employed have been a combination of qualitative research methods and participatory and co-creation methodologies, with the aim of generating data on:

- **First-person stories of Endometriosis**
- **Journeys through healthcare services** up to the diagnosis of endometriosis, treatment and surgical interventions (*Patient Journey*)
- **Needs assessment** in relation to healthcare services
- **In-depth study of key endometriosis issues** to understand the biopsychosocial dimensions of the disease
- **Co-creation of recommendations** for the improvement of healthcare services

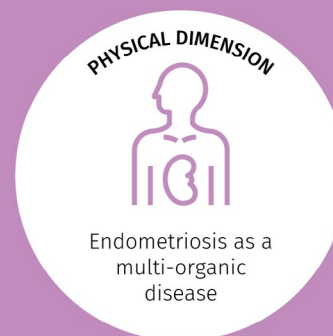


## QUALITATIVE FINDINGS: EXPERIENCES AND NEEDS OF WOMEN WITH ENDOMETRIOSIS

The research analysis has been developed taking as a reference the biopsychosocial and gender model of health, which understands health and illness as processes influenced by biology, the socio-cultural context, subjective psychic lived experience and gender in a continuous interaction throughout life<sup>5</sup>. In this way, the following key dimensions are drawn from the accounts of women living with endometriosis (developed at length in the report of the research findings):



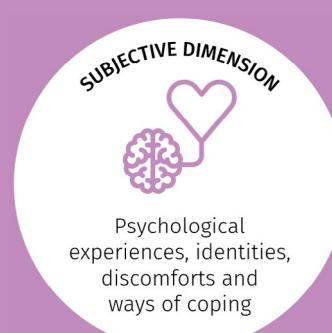
difficulties in reaching a diagnosis, recognition of menstrual pain by professionals and satisfactory treatments



Need to recognise endometriosis as a disease with multi-organic, not just gynaecological involvement



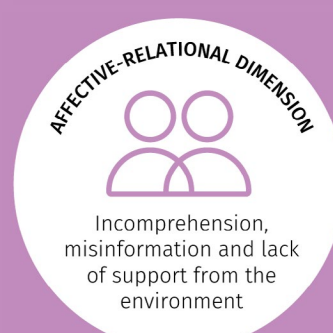
Effects on motherhood projects. Enduring and bearing pain as a differential gender trait in women



Depression, anxiety and stress, as well as fears and guilt. Crucial need for psychological support



Difficulties at work due to incapacitating pain. Incomprehension



Support and understanding from social environments is key

## RECOMMENDATIONS **IN FIRST PERSON** FOR THE IMPROVEMENT OF HEALTHCARE SERVICES IN RELATION TO ENDOMETRIOSIS

### 1 Increase awareness of endometriosis at the healthcare level

To **break the myth** that menstrual pain is normal

To **increase the number of professionals** who are knowledgeable about endometriosis at all levels of healthcare

To **study the cases** where endometriosis has taken too long to be diagnosed in order to find out the causes

### 2 Develop strategies for an early diagnosis of endometriosis

To **prioritise and reduce waiting time** if an appointment is requested because of menstrual cramps

To **prioritise and reduce waiting time between visits** to specialists and time to receive results of diagnostic tests

To encourage **screening for endometriosis** during routine primary care visits

To facilitate the **performance of necessary tests** on the same day and/or at the same healthcare facility

### 3 Improve the process of conveying information to patients to increase self-awareness and contribute to shared decision-making

At the time of diagnosis, to **inform the patient appropriately** so that she has a thorough understanding of endometriosis and possible treatment options

At the time of diagnosis, to **give the patient more time to ask questions and process information**

To **provide informative material** to enable further comprehension beyond the doctor's office



## 4 Define and implement a comprehensive endometriosis management model

To understand and recognise endometriosis as a **global and holistic condition that greatly affects the patient's life**

To offer **consultations with other specialists** within the framework of a multidisciplinary endometriosis team

To **offer psychological support** throughout the entire disease process

To **create therapeutic support groups** and patient councils to share experiences and to act as a support network

To encourage **good coordination between health professionals** visiting the same patient with endometriosis

To facilitate **easy communication between patients and specialists** beyond the consultation room

To develop a **network of centres or groups specialising in endometriosis** throughout Catalonia (not only in Barcelona)

To **create an App** where symptoms can be recorded and which is connected to the patient's clinical history

## 5 Improve care for people with endometriosis in healthcare services

To encourage an **empathetic attitude** towards the patient

**Pain** should be treated as a **key symptom of endometriosis**, not just as a collateral symptom

To develop a **pain scale that is more appropriate** and more sensitive to patients' feelings (not 1-10)

To provide **tools to manage pain**, from medicalisation to alternative therapies according to the patient's principles.

To **prioritise and reduce the patient's waiting time** in the emergency room (ER)

To create an **adapted physical environment** to the patient in pain

To perform **comprehensive follow-up of the patient** to ensure adherence to treatment and improvement of symptoms, among others

## 6 Develop more personalised and patient-informed treatment models

To allocate more resources to research into **personalisation of treatments**

To encourage **active listening** to the patient

To take the **patient's opinion into account** when making a decision about possible treatments or interventions



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## Illustration and graphic design

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*This research has been possible thanks to the active participation, motivation and enthusiasm of 20 women co-investigators who have been involved in the different phases of the scientific process. We greatly appreciate their support, dedication and effort throughout the research, and we hope to achieve, as they wish, an impact on public health policies that result in an improvement in the approach to endometriosis at the health level and that allows improving the quality of lives of present and future patients.*

*This report reflects the views of the authors only, and neither the European Commission nor the Research Executive Agency can be held responsible for any use that may be made of the information it contains.*



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