

# EMPOWERING ENDOMETRIOSIS PATIENTS THROUGH CO-CREATION OF RESOURCES

INFORMENDO

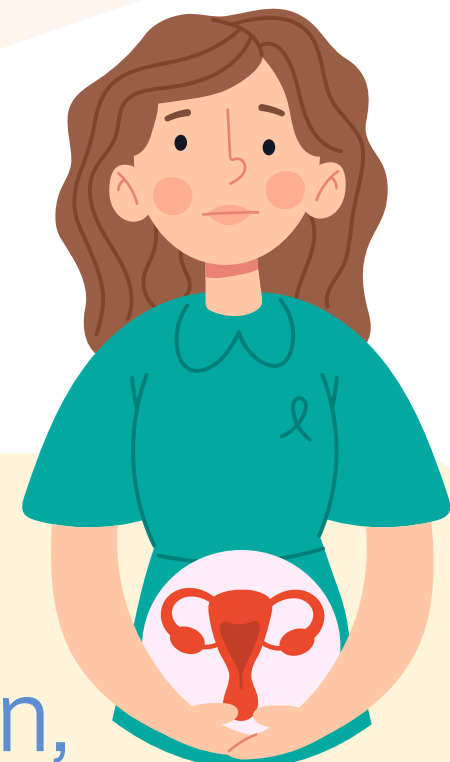
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FUNDED BY:  
LUDWIG BOLTZMANN GESELLSCHAFT  
Open Innovation in Science Center

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## ENDOMETRIOSIS



affects 10% of women, causing significant pain, reduced quality of life, infertility, and delayed diagnosis due to diverse symptoms and low awareness among patients and healthcare providers.



## PROJECT AIM

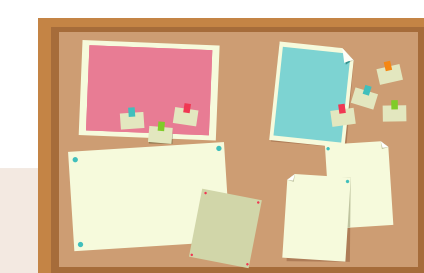
- evaluate **information needs** of patients, their social contexts and medical personnel
- evaluate **existing information** and co-creating improvements

## RESULTS

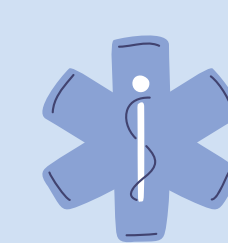


- **Urgent Needs:** Endometriosis patients require empowerment through accessible, high-quality information.
- **Impact of Delayed Diagnosis:** Extended time until diagnosis, along with challenging symptoms and treatment options, contribute to traumatic experiences.
- **Loss of Trust:** Many patients report losing trust in both their own judgment and the healthcare system.
- **Role of Self-Help:** Persistence and involvement in self-help groups are crucial for patients to navigate and overcome obstacles.
- **Lack of Accessible Information:** There is a significant gap in the availability of barrier-free information for patients.

## METHODS



**4 co-creational workshops**  
(2 online, 2 in-person),  
10-15 participants each  
**contents of discussions**



- information needs
- evaluation of existing brochures
- dissemination strategies
- required changes in the healthcare system

## CALL TO ACTION



- **Advocacy:** Enhanced advocacy at the policy level is necessary.
- **Education:** There is a need to raise awareness about endometriosis in both medical training and public health education.