Advancing on equitable and inclusive health for women and LGBTQIA+ people

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1- Universidade do Algarve, Portugal; 2- ISGlobal, Spain, 3- La Mandarina de Newton, Spain; 4-Foundation for the Promotion of Health and Biomedical Research in the Valencian Region (FISABIO), Spain; 5- Science for Change, Spain

IMPETUS Project

IMPETUS will be setting a **citizen science innovation programme for exploring innovative funding schemes and boosting recognition in the EU**, reinforcing networks and contributing to the fulfilment of the SDGs.

It will set **3 Open Calls for an accelerator program on 6M,** selecting the initiatives based on expected impacts, volunteer engagement, EDI, openness and quality data - **20k to kick-start 100 CSIs and 10k to sustain 25 CSIs** addressing the pressing needs of European society

It will launch the **EU Prize for Citizen Science, awarded to CSIs for outstanding achievements**, with 3 prize categories for 3 years: outstanding achievements, diversity and innovative grassroots projects

IMPETUS Project

IMPETUS ACCELERATOR

Accelerator program offers

- **6 months** projects
- Funding of **20,000€** for new (kickstarting), or **10,000€** for established projects (sustaining)
- A **mentor** to guide projects through the entire process
- Extensive **training and support** suitable to project needs
- Regular meetings across projects to enable **peer learning**

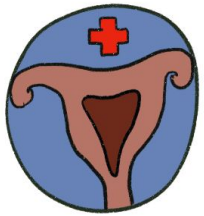
IMPETUS Project

IMPETUS ACCELERATOR

Total of 34 CSIs, 6 under Health Topic

MENtal Health and wellbeing Improvement during pregNAncy

Patricia Martínez Galisteo



New model of care for endometriosis patient through citizen science

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Healthcare space UX

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Every walk you Take

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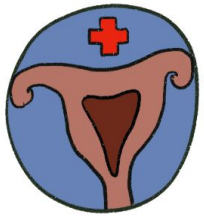

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CS4HEALTH + Gender perspective

Despite the progress made in recent years, **women's health research and/or care** is still far from being **equitable and inclusive**.

The **reasons are varied and intersectional**, with evidence showing that certain social groups are **discriminated** against, and specific diseases remain **underdiagnosed**, conditioning access to health care, with consequences for **morbidity and even mortality**.

People don't seek out or don't speak openly to health professionals for fear of being mistreated, and in turn, health professionals still lack specific knowledge and training or might experience communication difficulties.

Citizen science offers an opportunity to **reduce the gap between health professionals and women and LGBTQIA+ people** encouraging the participation of the latter in the research process in multiple stages, whilst pushing decision-making and the implementation of strategies that promote communication, mutual trust and further empowerment.

CS4HEALTH + Gender perspective

1. “MENINA”, evaluating mental health and wellbeing improvement during pregnancy;
2. “Equity in health for LGBTQIA+ people”, evaluating the knowledge and perception of discrimination of general practitioners about sexual and gender minority people's health.
3. “Obstetric co-evolution”, analyzing the relationship between obstetric practices and mothers’ mental health;
4. “Endo-Health”, working towards the co-creation of experience and health outcomes questionnaires to implement a new model of care for endometriosis;

IMPETUS

Today's session: to explore common barriers and solutions to embed and mainstream gender perspective and intersectionality within health care and research from the patient perspective

14:07-14:27 MENINA project (20 min)

14:27-14:47 LGBTQIA+ project (20 min)

14:47-15:20 Endo-Health + Obstetric Co-evolution (30min)

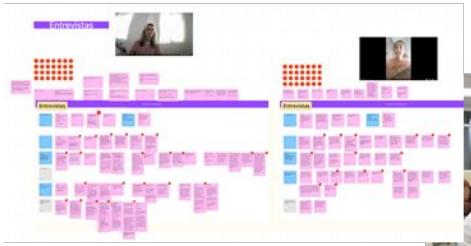
15:20-15:30 Main conclusions and wrap up (10 min)

MENINA: MENtal Health and wellbeing Improvement during pregNAncy

The objective of the MENINA project is to carry out a **citizen science initiative to further investigate mental health status and wellbeing of pregnant women by including them as part of the research** to understand in depth what women feel, care about, and need during pregnancy and the role that have the healthcare services.

ACTIVITIES

PROFOUND INTERVIEWS AND FOCUS GROUPS
October



DATA ANALYSIS RESULTS PRESENTATION
November

COCREATION SESSIONS
23rd November

MENINA FINAL WORKSHOP
14th December

RECRUITMENT PROCESS

- **12 citizen scientists** estimated (pregnant women)
- Week 12 of pregnancy. **1st trimester visit control** (Obstetrician consultation).
- Initial **inclusion criteria:**
  - From different age stages (18 a 29// 30 a 39// more than 40)
  - First pregnancy
  - Low risk pregnancy
- Support of **healthcare professionals**.
- **Ethics Committee approval** (Informed consent and Information Sheet)

RECRUITMENT: BEST PRACTICES

- **Low sample → 18 participants recruited but only 9 involved in the project**

  considering withdrawal (health issues, personnel issues, disappearing…), loss of diversity (exploring other realities like fertility problems, mums with previous children)

- **Limited timing to recruit → pilot project with obligations to start and finishing on time**

  considering reinforcing recruitment campaign (opening more visits per day); establishing margin period for recruitment.

- **Proper moment to recruit → crucial in these kind of projects**

  involve participants after obtaining the results of the obstetric visit, NOT BEFORE (very sensitive moment)

ENGAGEMENT: BEST PRACTICES

- **Recruiting and agile involvement →** women recruited at the beginning of July waiting too much until first activity (loss of interest).
- **Importance of creating community →** Kick off meeting with the citizen scientists (solving doubts, meet each other, creating trust in the process and in the project team).
- **Managing expectations →** balance between the final objective (adoption of new solutions to improve current situation) and the stage that the project will reach. Citizens need to know that their involvement has a meaningful purpose.

JOIN THE CONVERSATION

How could we improve the engagement strategy to manage expectations and avoid the loss of interest of our participants?

MENINA

Fundació Fisabio

THANK YOU!

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Equity in Health for LGBTQIA+ People

Finding the gaps and training
primary healthcare setting

1. Inequity in health, leading to higher mortality and morbidity [1-5];
2. Non-inclusive clinical environment [6-10];
3. Lack of healthcare professionals training [11-5; 15,16];
4. Language and behaviours not very inclusive, if not discriminatory [14].

But Why?

You don't look lesbian!

That's not how a lady should behave!

Have you talked with your husband about this?

It's just a phase...

Microaggression Minority Stress

*(11-17)

Objective 1 Access the LGBTQIA+ health-related level of knowledge shared by primary care workers and medical students.

Objective 2 Engage with the LGBTQIA+ citizens to prioritize their feelings about this topic and create an action plan.

OBJECTIVE 3 TRAINING & AWARENESS PROGRAMS TO PRIMARY HEALTHCARE PROFESSIONALS AND MEDICAL STUDENTS.

Objective 1 Access knowledge.

Cross Section Study | Survey

Measures [17-19] : specific health topics knowledge / beliefs / communication / willingness to treat / encouraging disclosure / perceived importance of training.

432 ANSWERS: 195 (45%) Medical Students | 122 (28%) Med Doctors | 43 (10%) Nurses | 72 (17%) Other Health Workers.

Objective 1 Access knowledge.

Specific LGBTQIA+ Health Topics Knowledge

45% with less than 6 correct answers out of 12.

+ Medical Doctors.
+ Non-Heterosexual.
+ No. of LGBTQIA+ friends/relatives.

No relation:

- Religion.
- Age.
- Profession Years.
- Gender Identity.

Objective 1 Access knowledge.

Beliefs & Confort Regarding LGBTQIA+ in Healthcare

27% assumed that had sufficient training.

- 50% of the non-heterosexuals assumed sufficient training.
- 24% of the heterosexuals assumed sufficient training.
- No difference beside sexual orientation.

Objective 1 Access knowledge

Mortality from breast cancer is higher among lesbian women (true)	4%
Lesbian women have a higher risk of obesity compared to heterosexual women (true)	4%
Smoking is higher among LGBTQIA+ people (true)	12%
Women who only have sex with women have a lower risk of HIV infection than heterosexual women (true)	14%
LGBTQIA+ people avoid health services because they don't feel comfortable (true)	48%
Transgender men should be screened for breast cancer (true)	49%
Young transgender people have a much higher risk of suicide than young homosexual people (true)	58%
A homosexual person's gender identity does not coincide with their biological sex (false)	61%
Homosexual people have an increased incidence of anxiety and depression (true)	61%
Most homosexual women and men would like to be heterosexual (false)	72%
Lesbian women need to be screened for cervical cancer less often than heterosexual women(false)	86%

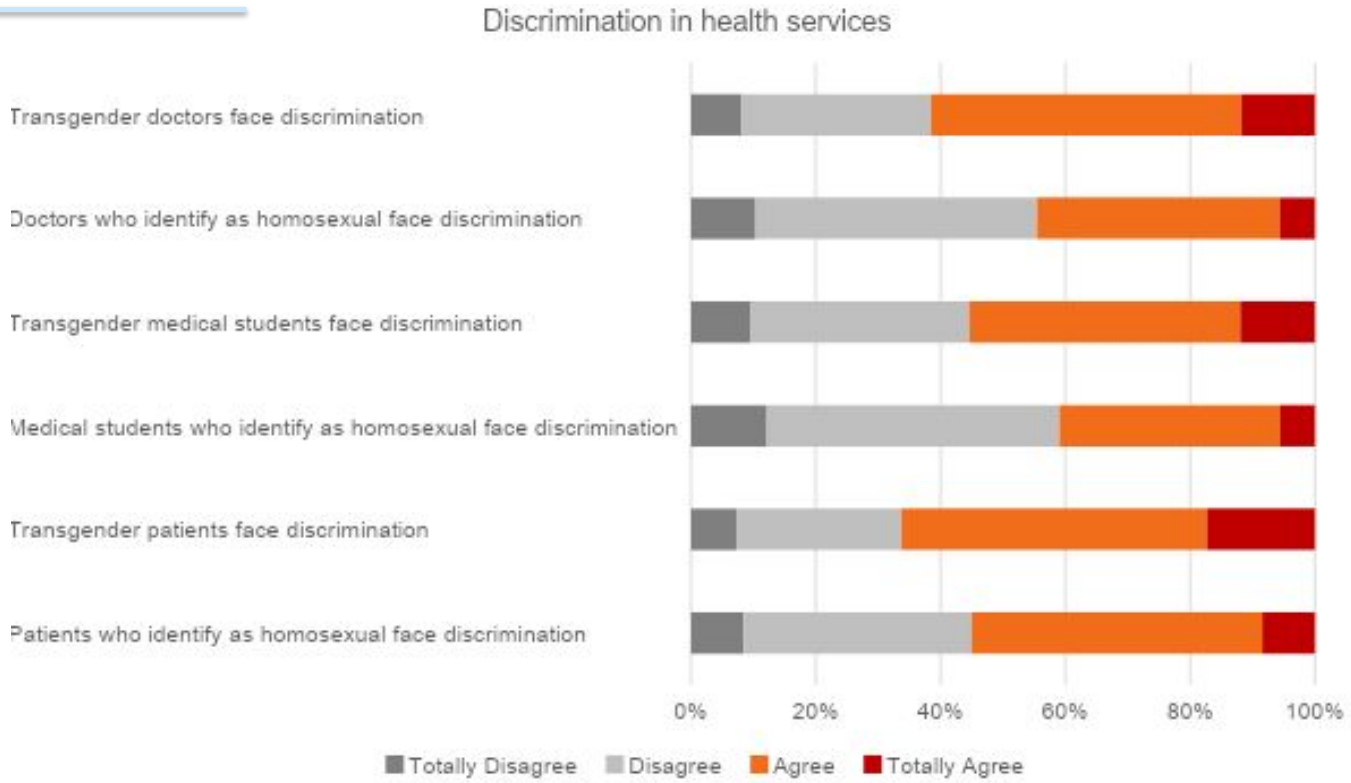
>> % of Correct Answers.

Objective 1 Access knowledge.

Perception of LGBTQIA+ Discrimination in Healthcare

+ Transgender
- Homosexual

+ Transgender Patients



Objective 1 Access knowledge.

→ First Results In...

Objective 2 Engage with th community.

→ Focus Groups (?)

Objective 3 Training.

→ Training by citizen scientists to healthcare providers & students (?)

Objective 1
Access knowledge.

Join the discussion...

Objective 2
Engage with the community.

Objective 3
Training Strategies.

For bibliography , suggestions or questions:

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Would you like to participate in this project? Send us an e-mail!

obstetric coevolution

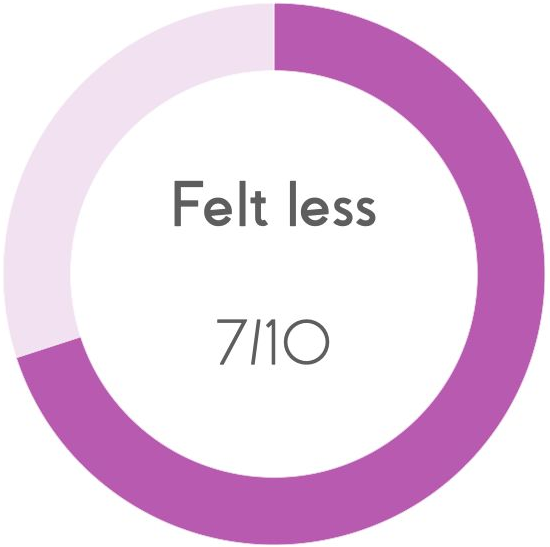
Un projecte de:

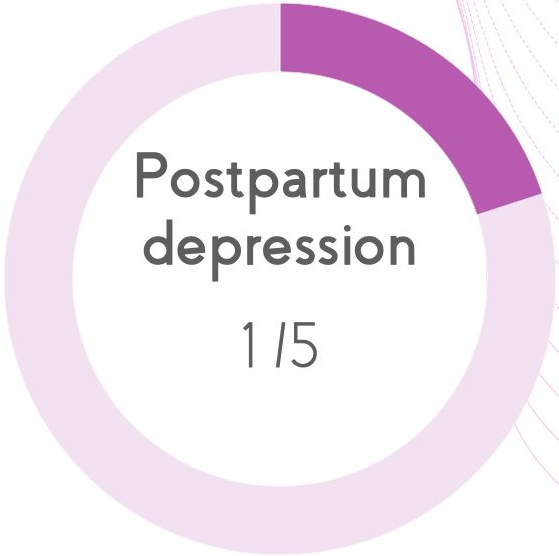
mandarina newton

Finançat per Impetus i la UE:

IMPETUS

Origins





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We go from...

We've gone from birth at home without other options to birth at hospitals without other options.

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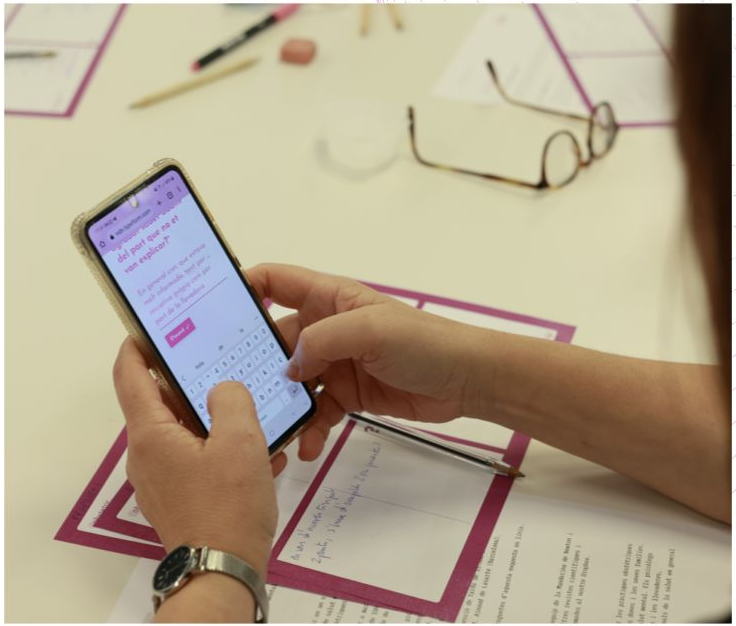
Research question

Not listening to women's needs and wishes may contribute to postpartum depression.

The project



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Cocreation workshops

We run two empathy workshops with mothers and interviews.

We had a sample of 20 mothers.

Preliminary results

Mother's workshop- Key words and concepts

- Pain management
- Information management
- Programmed induction (Recommended for 90% of the attendees)
- Epidural
- Episiotomy
- Recommendations vs. insistence
- Separation of baby at birth
- Environment
- Difficulty with breastfeeding
- Right to decide
- Listening

- **Fear**
- **Fragility**
- **Guilt**
- **Deception**
- **Mistrust**
- **Anger**
- **Disappointment**
- **Frustration**

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Preliminary results

Mother's workshop- Medical interventions

- **3.5 interventions** on average per woman
- Women who start with **induction accumulate more medicalisation and instrumentation** (up to 7 or more impacts).
- Women who have to accept induction, without agreeing to it, are also forced to accept epidurals. **Up to 50% will end up with a caesarean section**.
- Women who can **wait at home until active dilatation**, and therefore live through labour and early dilatation as they choose, are **happy and motivated**.

Professional workshops

We run one empathy workshop with professionals.

We had a sample of 8 professionals.

They are now our advisors.

Preliminary results

Professionals' workshop - Key factors

- The Catalan Department of Health protocol has a classification of risk factors for pregnancy, but not for childbirth.
- Obstetricians are used to seeing many risks.

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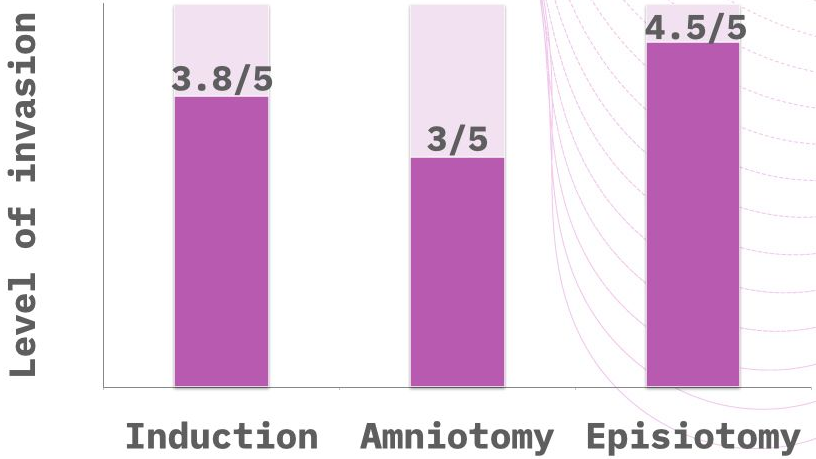
Preliminary results

Professionals' workshop - Key factors

WHO recommends 10%



Preliminary results

Professionals' workshop - Reflections

- Not allowing labour to start **spontaneously** is a **risk**.
- All medicalisation and instrumentalisation, and the way women are treated, **affect women's mental health**. The mother needs to understand what has happened and why.
- How many inductions do you have to do to avoid stillbirth? **Many**!

Identified challenges

- **FEAR:** How do we get mothers to go into labour without fear?
- **MEDICALISATION:** How can we reduce the level of medicalisation in births following WHO recommendations?
- **POSTPARTUM:** How can we improve the experience of families and professionals during the postpartum period?
- **COMMUNICATION:** How can we improve communication (bi-directionality) between practitioners and mothers/families?
- **MENTAL HEALTH:** How can we reduce the mental health effects on women during the postpartum period?

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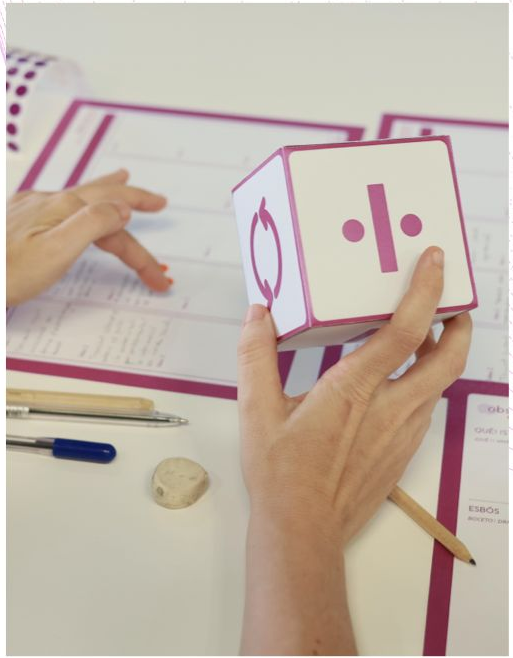
Proposed solutions

- **Women's Circle** (transversal). Spaces outside health centres where to give value to experience and co-learning women and professionals
- **Feedback sessions** with professionals. (Including women's voices in their clinical report)
- Pregnancy as part of the **educational curriculum**.
- Normalizing **needs during postpartum**, such as the need to be around other mothers sharing concerns.



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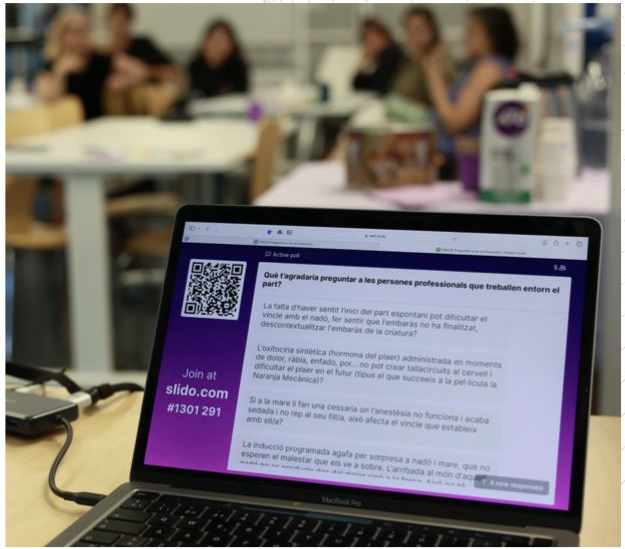
Cocreated survey

We co-created a 70-question survey and we tested with a sample of 12 people (mothers and professionals).

It’s currently open in Catalan, but we will also translate it into Spanish and English.

We are looking to get quantitive information related to the qualitative data already gathered.



To...

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- Scientific impact
- Social impact
- Political impact

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Thanks!

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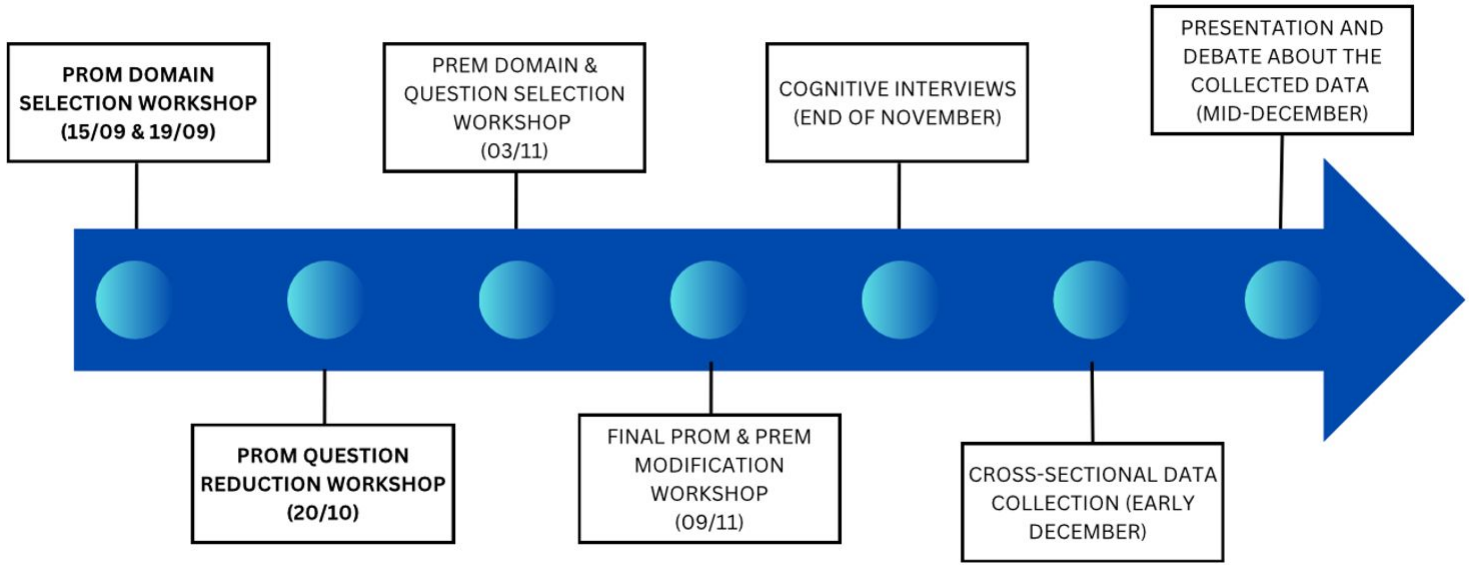
Endo-Health

About the project

A citizen science project aimed to co-create a new set of PREM and PROM endometriosis-specific questionnaires, applicable at various stages of the patient journey, to identify unmet needs for appropriate interventions to be undertaken.

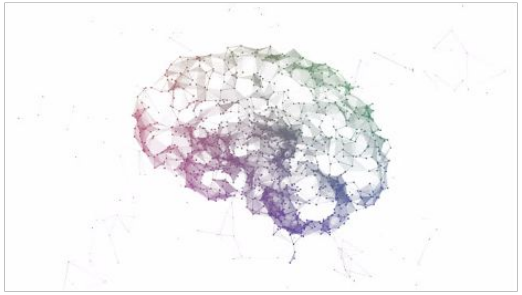
Endo-Health

Co-creation process with patients



Endo-Health

Impact - **Scientific, Social** & Political



- New PREM and PROM questionnaires
- New dataset on endometriosis
- New co-creation methodology

- Community building and empowerment
- Social inclusion
- Growth within clinical and research communities
- Change in perspectives

BEYOND IMPETUS

To understand how experiences and outcomes of individuals with endometriosis changed as a result of the legislation in Colombia, the UK, France, and Spain

Endo-Health

Limitations

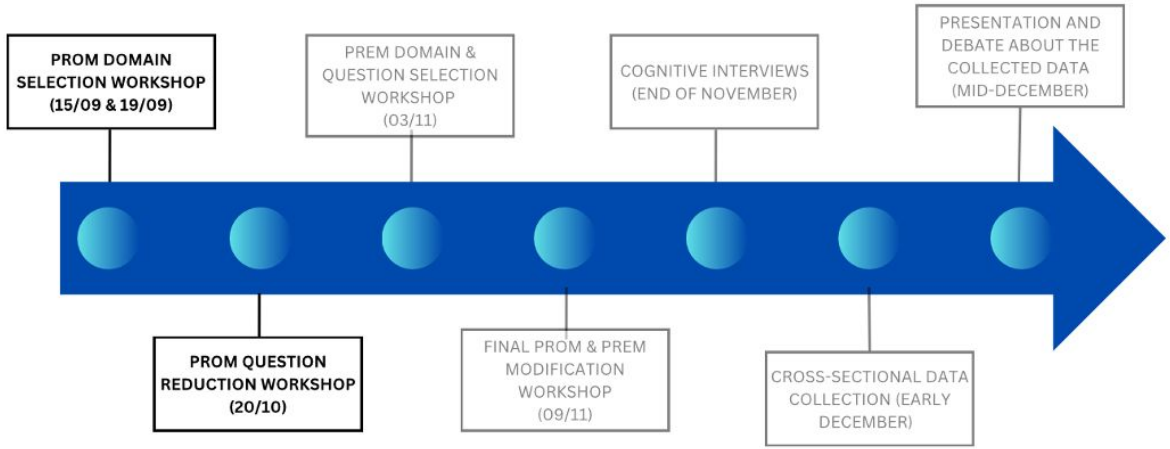
- Attendance at our co-creation activities is not as high as desired due to potential participants having other work obligations, among other factors. To address this limitation, we have been providing medical certificates to our participants.

- We work with citizen scientists/patients attended to at the Hospital Clinic, making it challenging to achieve representation of different profiles of women.

- The Hospital Clinic only serves adults (ages 18 and older). However, endometriosis is not limited to adults, which may result in some limitations in the domains covered by the co-created PROM and, consequently, a limited dataset. To mitigate this limitation, we have identified potential domains from the existing literature and suggest them to patients, aiming to reduce bias.

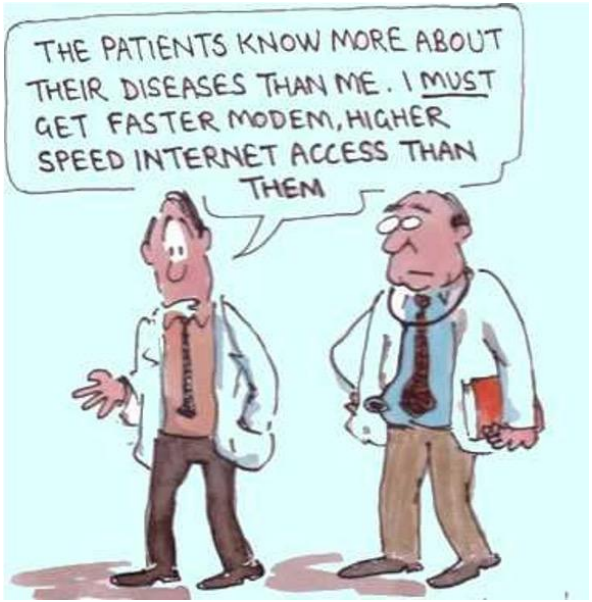
Endo-Health

Project Progress



Endo-Health

Contact Us



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Receive more information about our activities:
http://eepurl.com/hPAPHL

Final Conclusions

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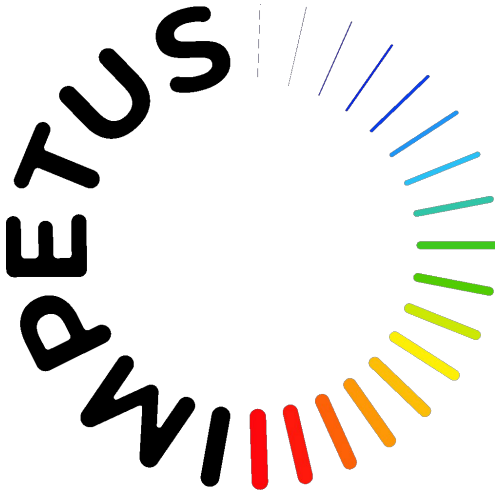

For more information

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