https://www.iprolepsis.eu

iPROLEPSIS

HorizonEurope-funded project developing a novel personalised digital care ecosystem for people with PsA

iPROLEPSIS project newsletter | Issue No. 2

September 2023

Welcome! This is the second edition of the Newsletter series of the iPROLEPSIS project. In this newsletter issue, we delve into the transformative power of user research and co-creation in the healthcare innovation research process.

Inside this issue

Exploring User Research and Co-Creation in Healthcare Innovation: Putting Psoriatic Arthritis (PsA) Patients and Healthcare Practitioners (HCPs) First

Funded by
the European Union

iPROLEPSIS received funding from the European Union under Grant Agreement No. 101095697.

Funded by the European Union. Views and opinions expressed are however those of the author9s) only and do not necessarily reflect those of the European union or European Health and Digital Executive Agency. Neither the European Union nor the European Health and Digital Executive Agency can be held responsible for them.

https://www.iprolepsis.eu

The iPROLEPSIS Digital Health Ecosystem

Within the **iPROLEPSIS**, we aim to develop a suite of **digital health tools (DHTs)** designed **to detect early transitions to PsA, predict flares** for timely intervention, and **provide personalised recommendations and interventions** for managing the disease.

The DHTs to be developed:

miPROLEPSIS patient app

biAURA biaural sounds app

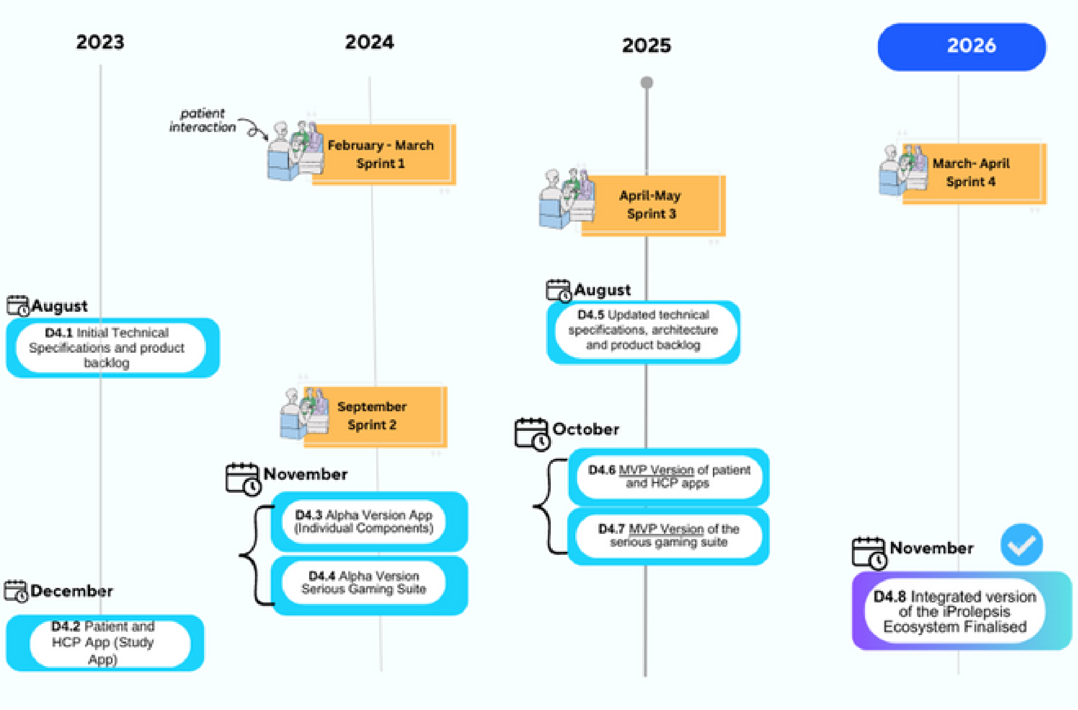
miPROLEPSIS HCPs dashboard

Personalised Gaming Suite (PGS)

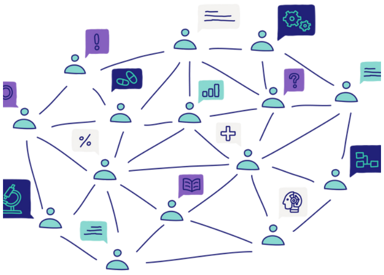
Personalised recommendation system

PROLEPSIS **DHTs development follows** an **iterative User Research & Co-Creation approach.** It started in August 2023 with initial technical specifications, architecture, and product backlog development, considering user research and co-creation session results for the first product version.

iPROLEPSIS Ecosystem Roadmap



User Research and Co-creation



Our **innovative approach blends Lean, Scrum, and Design Thinking methodologies**, placing social innovation and patient-centered perspectives at the core.

By engaging PsA patients, clinicians, and healthcare enablers in agile co-creation, we **aim to map user needs, guide research questions, develop empathy/journey maps**, and **identify core user stories**, laying the foundation for the iPROLEPSIS digital health ecosystem.

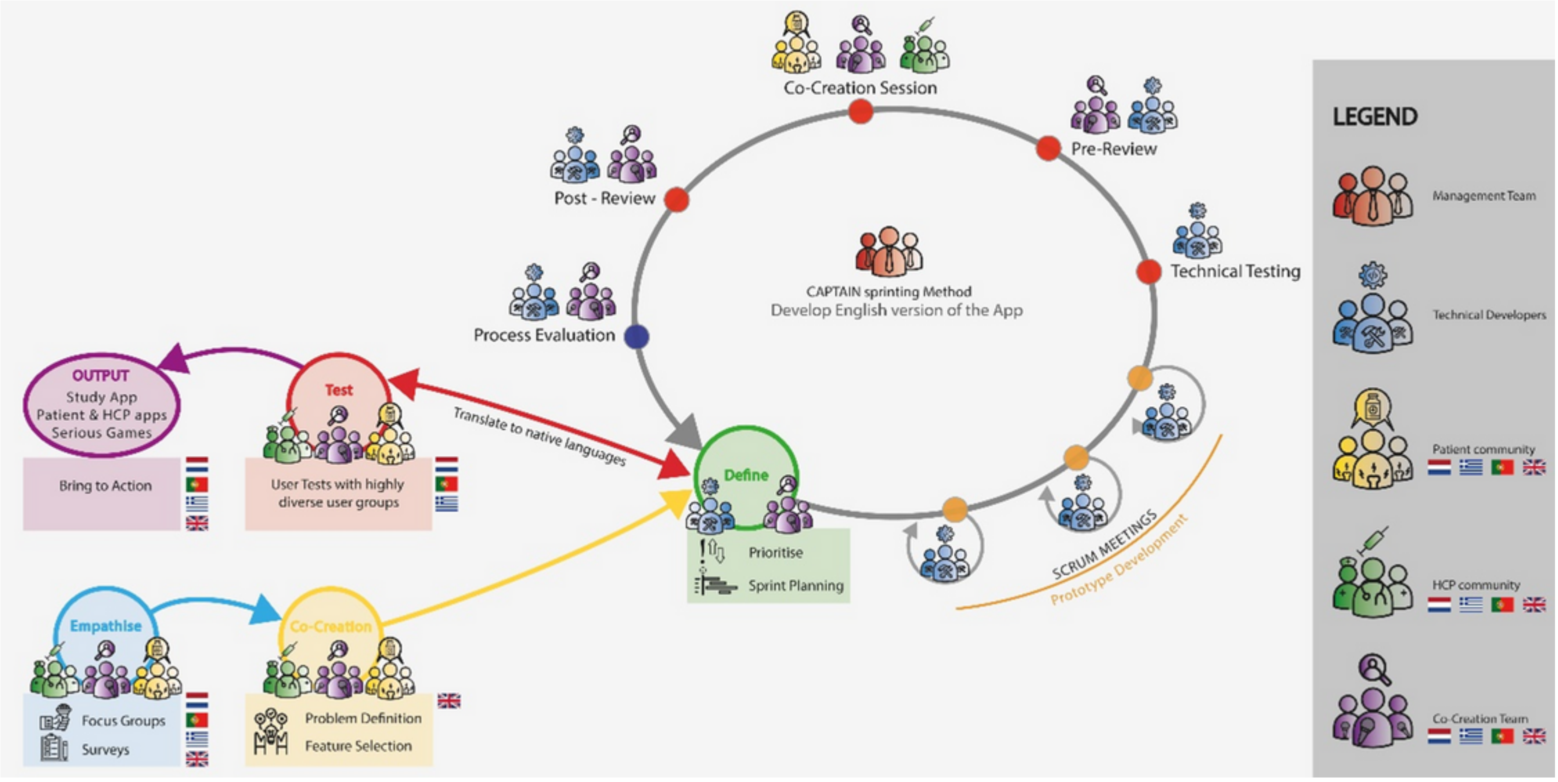
The End-users engagement strategy involves:

User research focus groups

Online surveys

Continuous co-creation workshops

iPROLEPSIS user researh procedure



Focus Groups and Survey

Focus groups

The **iPROLEPSIS focus groups**, an increasingly popular method in health research, **aimed to gather** patient **insights on disease activity, management, care needs, and their attitudes toward digital biomarkers** for future development directions.

The **iPROLEPSIS** team between January and May 2023:

Conducted	**Spoken with**	**From**
10 **Focus groups**	**39** **PsA patients**	🇳🇱 🇬🇧 🇵🇹 🇬🇷 **Countries**

4 Themes emerged from the focus group discussions:

- **Disease activity**
- **Coping**
- **Care Experience**
- **Digital Biomarkers**

Survey

A comprehensive **survey** was designed **to obtain more specific input** from a broader range of PsA patients. The **survey covered** various **aspects, dedicated to:**

- **Demographics & Technological experience**
- **miPROLEPSIS patient app - Content& Appearance**
- **BiAURA app – preferences**
- **Personalised SeriousGaming Suite – Content and Appearance**

The **aim was to collect responses from 100 patients per country.** Based on the provided data, **the demographics of technological literacy and device usage** across different countries were analysed.

https://www.iprolepsis.eu

Key Takeaways

Key takeaways from User research and Co-creation:

Complexity

The iPROLEPSIS aims to develop DHTs for a complex healthcare context. **The compatibility of these innovations with diverse care systems is crucial** for successful adoption.

Heterogeneity

PsA is highly diverse, presenting varying symptoms, severity, and onset ages. **Designing DHTs** for such diversity **is challenging.**

Trial and Error

PsA patients navigate uncertainty **through trial and error. iPROLEPSIS DHTs** aim to **support them in this process**.

Preference Differences

Survey and focus groups revealed diverse DHTs preferences. Clarity in explanations, visuals, colours, notifications, and daily questions are crucial.

Insights from patients with PsA:

“Digital health platforms have the potential to be very useful, but it is also important to ensure the quality of the information available. I have tried a few platforms related to my condition, and my experience has been mixed. Some have been very helpful, with features such as symptom tracking, disease education and a supportive community. However, others have been less reliable and have not provided relevant or accurate information.”

“I would like to see information about daily symptoms, such as pain, joint stiffness and fatigue. It would also be useful to have a record of daily activities, such as exercise and sleep quality.”

“It would also help a lot to understand the evolution of the disease, and what could also cause a crisis, because there are situations that sometimes trigger a crisis, and it would also help us, the patients, to understand what we could change, what we could do, to minimize the pain, and also the doctor to have a record of these situations.”

What’s next?

In the upcoming phase, we will **involve co-creation with patient partners,** focusing on design sprints to develop the miPROLEPSIS PDPID app. This version is set to launch in December 2023.