

# Empowering Patients as Partners: Patient Engagement in Healthcare and Research

20 of March of 2024

Saló de les Cròniques - Barcelona City Hall

## Meeting objectives

There is strong evidence that patient involvement, engagement and empowerment have the potential to improve not only patient satisfaction with care, but also the quality of care provided and patient outcomes. Patient engagement recognises that patients have unique insights into their conditions, treatment outcomes and quality of life. By actively involving patients in research, drug development, clinical trials, regulatory decisions and post-marketing surveillance, healthcare stakeholders can use this wealth of knowledge to improve patient outcomes. In clinical trials, for example, patient involvement helps to ensure that trials are designed in a way that is relevant and meaningful to patients. Patients can also contribute to the development of patient-reported outcome measures, which are used to assess the impact of treatments on their quality of life.

In such activities, patients and healthcare professionals work in equal partnership to promote and support patients' active involvement in improving their health and healthcare, as well as in research and innovation.

This hybrid public meeting, which is part of the initiatives of the **CLOSER** project (Overcoming distance between South America and Europe Regions), is being organised to discuss approaches and opportunities for engaging patients, patient groups, leukemia experts, and experts on studies and clinical trials. The meeting will focus on how to best understand patients' experiences and how to incorporate those experiences and priorities throughout their health care and their treatments, clinical trials, research and innovation.

Designed as an interactive roundtable to give patients, researchers and institutions a voice, the meeting will consist of several moments. The first will focus on patient engagement in treatments, and the second will see speakers discuss on the role of the patient in innovation and research.

**Maximum capacity: 50 persons.**

**A Zoom link will be provided for people attending remotely.**

**Interpretation will be provided in English and Spanish.**

**Fill the survey to register  
for the workshop**



This project has received funding from the European Union's H2020 research and innovation program under Grant Agreement number 825749

Co-organized by



**SJD**  
Sant Joan de Déu  
Barcelona - Hospital

**cliclab**  
transformative agent

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## Sessions

### Session 1: Effective engagement of patients in their health care and treatment

Patients and their families play a crucial role in the healthcare system and drive changes in health culture. Patient engagement focuses on making sure that patients and providers work together to improve the patient's health. In order to create patient engagement strategies that allow patients to become actively engaged in gathering information and making decisions about their symptoms, illnesses, and treatment options, providers need to empower the patient to have a voice in their healthcare experience. In this session, panelists will discuss the current situation in Europe and Latin America.

### Session 2: Engaging patients in research and innovation

Patients can also be key drivers of Research and Innovation in Health. There are plenty of examples on how, if listened to carefully, patients, families and carers can be at the centre of change. In this session, we will look at how the R&I actors (from the funders to the developers) are starting to take patients more into account from the very beginning of the innovation processes. Clinical trial developers are ensuring patients voice along the whole procedure, companies take patient onboard during its R&I and the initiatives from patients are supported by the funding authorities. Both EU and LATAM cases will be discussed.

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## Agenda

### 15:30-15:40h. Welcome to Barcelona

**Marta Villanueva.** Health Councilor of Barcelona City Council.

### 15:40-15:50h. Welcome and Overview of CLOSER project

**Marta De Santis.** Istituto Superiore di Sanità, Rome.

**Mireia Camós.** CLOSER Project coordinator. Hospital Sant Joan De Déu, Barcelona.

### 15:50-16:50h. Session 1: Effective engagement of patients in their health care and treatment

**Moderator: Mireia Camós.** CLOSER Project coordinator. Hospital Sant Joan De Déu, Barcelona.

- **Anna Faura.** Oncology Department, Hospital Sant Joan de Déu, Pediatric Cancer Center, Barcelona.
- **María Sara Felice.** Oncology Department, Hospital de Pediatría Juan P. Garrahan, Buenos Aires.
- **Joan Vinyets.** Patient Experience Area, Hospital Sant Joan de Déu, Barcelona.
- **M<sup>a</sup> Cruz Hernández.** Radio Nacional de España, Radio Televisión Española, Barcelona.
- **Agustín Farías.** KIDS Fundación Maria Cecilia, Buenos Aires.
- **Daniel Marín.** KIDS Barcelona.

### 16:50-17:50h. Session 2: Engaging patients in research and innovation

**Moderator: Anaïs LeCorvec.** Director at Council of European BioRegions (CEBR), Co-Founder at CLICLAB Transformative Agent, Barcelona.

- **Migdalia Denis.** Patient advocacy and President of Pulmonary Hypertension Latin Society, Caracas.
- **Edith Grynszpanholc.** Fundación Natalí Dafne Flexer, Buenos Aires.
- **Anita Kienesberger.** Chair of CCI Europe Committee, ePAG of ERN PaedCan and member of SIOPE, Vienna.
- **David Sánchez.** Asociación Pulseras Candela, Barcelona.
- **Begonya Nafria.** Patient Engagement in Research Department, Fundació Sant Joan de Déu, Barcelona.
- **Representative of the European Commission.**

### 17:50-18:00h. Closing Remarks

**Paola Torreri.** Istituto Superiore di Sanità, Rome.

**Mireia Camós.** CLOSER Project coordinator. Hospital Sant Joan De Déu, Barcelona.

### 18:30h. Closing Cocktail at CLICLAB: Patient-driven innovations



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