

PRECISEU Best Practice Recognition

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ENGAGE-ATMP: Engaging Patients in the Institutional ATMP Model

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ENGAGE-ATMP is an innovative, patient-centric translational model for ATMP research and healthcare, to provide holistic, accessible care while empowering patients and caregivers to actively participate in the process.

Since 2014, Fundació Sant Joan de Déu (FSJD) and Hospital Sant Joan de Déu (HSJD) have advanced a patient-centered model in research and healthcare, engaging patients and caregivers from basic to clinical research and care delivery. Supported by the Patient Engagement in Research and Patient Experience departments, this model integrates patient perspectives from diagnosis to treatment and follow-up. In 2021, the UNICAS SJD project launched, providing integrated care, diagnosis, data management, and treatment access—including Advanced Therapy Medicinal Products (ATMPs)—for paediatric patients with rare diseases. The hospital's expertise in ATMPs, clinical trials, and its Advanced Therapies Platform reinforce this comprehensive model.

ENGAGE-ATMP positions patients and caregivers as active partners in ATMP research, care, and treatment. The goals include promoting early-stage patient involvement in ATMP research, facilitating access to ATMPs and clinical trials, educating patients on therapies and impact and enhancing the patient experience. The ultimate aim is to empower patients as co-creators in ATMP development and implementation.

FSJD/HSJD apply structured participation strategies such as:

- Voice of the Patient – collecting feedback via surveys (PREMs), complaints, acknowledgments, and social media.
- Permanent Participation – engaging patients and parents in councils (Youth Scientific, KIDS Parents, Family and Youth Councils).
- Patient Experience – applying qualitative methods to detect pain points and co-design solutions across the patient journey.

ENGAGE-ATMP delivers a patient-centric institutional model that strengthens ATMP research and care for paediatric patients. It unites clinical care, research, manufacturing, regulatory alignment, and patient co-creation under one strategy. Outcomes include improved trial design, humanized care environments, co-designed care models, and increased trust, participation, feasibility, adherence, and satisfaction.

ENGAGE-ATMP is a scalable, patient-centered model fostering empathetic, collaborative culture in ATMPs, offering a replicable framework to enhance patient involvement in ATMP development.

ENGAGE-ATMP is a scalable, patient-centric institutional model that redefines the patient experience in ATMP research and healthcare, setting a new EU-wide standard for trust, transparency, and meaningful patient engagement in the development and access of advanced therapies.