



Press release

EURORDIS and partners launch major project to empower patient involvement in Health Technology Assessments

7 March, Paris – EURORDIS-Rare Diseases Europe has launched the European Capacity Building for Patients (EUCAPA) project as part of the EU4HEALTH initiative.

EUCAPA is designed to train patients and their representatives in Health Technology Assessment (HTA) – the multidisciplinary and systematic process that evaluates the added value of a health technology in comparison to other existing or new ones.

Through EUCAPA, patients and their representatives will gain knowledge and skills to participate in HTA decision-making processes and advocate for equitable access to innovative treatments for rare diseases.

The European Commission selected a consortium composed of EURORDIS, the European Patients Forum (EPF) and UMIT TIROL to build the capacities and knowledge for patient advocates to participate in HTAs at the national or European level.

EUCAPA will ensure that patients and patient organisations have the necessary knowledge of the HTA process to be meaningfully involved in HTA (both in scientific consultations and assessments), as foreseen by the new Regulation on HTA (EU) 2021/2282, which will start assessing health technologies in January 2025.

After undergoing the training programmes, patient experts will acquire the necessary skills, knowledge, and understanding of HTA, allowing them to constructively participate and present their lived experience in assessing health technologies.

“We are excited about the launch of EUCAPA. Through trainings and clear information, EUCAPA will contribute to the preparedness of the European patient community. We expect EUCAPA to make a concrete and long-lasting impact on the implementation of the HTA Regulation.”

- **Valentina Strammiello, Director of Programmes at EPF**

Focusing mostly – but not exclusively – on people living with cancer and people who need advanced therapy medicinal products (ATMPs), EUCAPA is set to last two years and will offer three types of trainings:

- **Online introductory training** for the larger patient community and patient organisations who need to know more about HTA to participate in joint clinical assessments (JCAs) and scientific consultations (JSCs).
- **Online fast-track training** enabling patients to gain the essential skills needed to participate as patient experts, which will be aimed at those who will participate in JCAs and JSCs at short notice.

- **In-person extended training** that will further develop concepts, skills and knowledge from the two previous trainings.

The EUCAPA training comes at a crucial time with the current implementation of the new Regulation on HTAs (EU) 2021/2282. The HTA Regulation's framework has significantly increased the role of patient experts, so the need to further and better train patients in HTA has become vital. Responding to this need, EUCAPA will become the largest coordinated HTA training for advocates provided to date.

"The HTA Cooperation is firstly about transparency of HTA procedures and reports, and high quality of the assessment. With appropriate training, patients can take part in EU HTA, understand how assessments are made, contribute, and improve their quality."

- **François Houyez, Information & Access to Therapies Director & Health Policy Advisor at EURORDIS**

The training is based on the consortium's joint experience in patient advocacy, international HTA research, and more than two decades of education in HTA (htads.org).

"We are extremely excited to participate in this high-quality joint EU4HEALTH project with our colleagues from EURORDIS and EPF. Most of all, we are looking forward to mutual learning with and from the participating patient advocates."

- **Uwe Siebert, Department Chair and Professor of Public Health, Medical Decision Making and HTA at UMIT TIROL**

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About EURORDIS-Rare Diseases Europe

[EURORDIS-Rare Diseases Europe](#) is a unique, non-profit alliance of over 1,000 rare disease patient organisations from 74 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe. By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and patient services.

About the European Patients' Forum

The [European Patients' Forum \(EPF\)](#) is an independent non-profit, non-governmental umbrella organisation of patient organisations across Europe and across disease-areas. EPF's 78 members include disease-specific patient groups active at EU level and national coalitions of patients.

About UMIT TIROL - Private University for Health Sciences and Health Technology

[UMIT TIROL](#) has specialised in new vocational areas in health sciences and health technology and provides guidance to health policy decision makers and the public. The Institute of Public Health, Medical

Decision Making and HTA has long-standing practice in developing HTA method, performing HTAs, and generating HTA publications, as well as in teaching HTA on a national and international level to multiple stakeholders in its HTADS Continuing Education Program (www.htads.org).

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