

VIEWS AND OPINIONS



POWER TO THE PATIENT: HOW EUPATI (CH) IS CHANGING THE FACE OF PATIENT EDUCATION

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The European Patients' Academy on Therapeutic Innovation (EUPATI) is an independent, non-profit foundation committed to changing the face of patient engagement through education. It provides training for patients and patient representatives on medicines research and development (R&D). EUPATI Switzerland (EUPATI CH) is the official Swiss EUPATI National Platform and acts as a central point for inquiries and cooperation for patient empowerment and involvement in medicines R&D in Switzerland. After successfully launching the increasingly popular annual Swiss Patient Forum (SPF) in 2017, EUPATI CH is currently developing a Swiss training module for Swiss patients and patient representatives who wish to be involved in patient engagement activities and who are interested in learning about the Swiss legal and ethical framework for clinical R&D in one of Switzerland's national languages.

Involving patients in research can provide a significant benefit to the medicines development process. Patients can contribute to developing better treatments for themselves and others by sharing their priorities and

perspectives. Experience has shown that greater patient involvement in R&D increases the efficacy and safety of new treatments and increases public support for medical research.

EUPATI: EMPOWERING PATIENTS THROUGH EDUCATION

[EUPATI](#) was launched as a flagship project of the Innovative Medicines Initiative (IMI) in early 2012. The project aims to trigger a major rethink in the way patients and the public understand medicines development and their own involvement in the medicines development process. Equipped with a deeper understanding of this process, patient experts are empowered to work effectively with relevant authorities, healthcare professionals, and industry partners to influence medicines development for the benefit of patients and the public.¹ The main goal of the EUPATI project is to develop and disseminate accessible, well-structured, comprehensive, scientifically reliable, and user-friendly educational material to patients.

The EUPATI project provides [educational resources](#) in key areas of medicines research and development that have been translated into several languages under Creative Commons licenses.

The educational resources are aimed at two main audiences:

- The EUPATI [Toolbox](#) is intended for education-level patients with little or no prior knowledge of the topic.
- The EUPATI [Open Classroom](#) (a newly designed version of its [Patient Expert Training Programme](#)) is intended for expert-level patients who are already experienced, knowledgeable advocates.

Following the huge impact of the pioneering and well-recognised EUPATI Patient Expert Training Programme, which has been conducted in four cohorts since its start in 2015, EUPATI recently launched a new format called Open Classroom. This new format enables participants to take courses online or on-demand at their own pace and in their preferred sequence.

EUPATI CH: PROMOTING PATIENT INVOLVEMENT IN SWITZERLAND

In parallel with its international activities, EUPATI has established [National Platforms](#) in more than twenty countries, including Switzerland, with the aim of bringing patient, academic, and industry partners together to foster patient education and involvement in medicines R&D at a national level.

The Swiss National Platform [EUPATI CH](#) was formed as an association in November 2016. As stated in its statutes, the association is fully committed to acting as a central point for inquiries and as a cooperation platform for patient empowerment and involvement in medicines R&D in Switzerland. The EUPATI CH association consists

of a steadily growing number of members who form the General Assembly, an Executive Committee that oversees strategic operations, and an Advisory Board that is currently in the planning phase.

Since its inception, EUPATI CH has promoted awareness of EUPATI and its educational resources by actively participating in various public events and conferences throughout Switzerland. In 2017, EUPATI CH successfully launched the [Swiss Patient Forum](#), an increasingly popular annual event whose programme is co-developed by EUPATI CH members and external experts; the event is sponsored by industry.

¹ See the EUPATI project's [2017 Executive Summary](#), which can be downloaded from its website.

SWISS TRAINING MODULE: TRAINING PATIENTS TO BECOME CLINICAL RESEARCH PARTNERS

More recently, EUPATI CH decided to create a Swiss training module, its own national training programme to empower Swiss patients and patient representatives to contribute as partners in the design, planning, and conduct of clinical research through patient engagement. In contrast to the EUPATI Open Classroom, the Swiss training module can be done by patients and patient representatives with little or no prior knowledge of the topic. It will offer an introduction to clinical research and patient engagement for Swiss patients in a national language (German) and will be adapted to the Swiss legal framework and regulatory environment for research involving human beings.

Thanks to its flexible structure (similar to that of the Open Classroom), the Swiss training module will accommodate the special needs and often challenging schedules of prospective participants. To do this, it will offer a blended learning format and modular structure, thereby allowing for greater flexibility as to when and where content can be completed. The course will consist of three basic mandatory modules that will introduce the topic of research, including ethical and legal aspects,

and will consider why the latter aspects are important for improving healthcare. In addition, four voluntary advanced modules will be offered that focus on specific aspects of clinical trials and how patients can become involved in them. Generally, each module will last 12–15 hours and will be available online; each module will also include virtual Q&A sessions and face-to-face training sessions. At the end of each module, participants can either take a short test or complete written assignments in order to obtain a certificate of completion.

The Swiss training module is currently being developed in close collaboration with the Department of Clinical Research (DKF) of the University Hospital Basel. EUPATI CH plans to launch the programme in early 2022; the exact date will be confirmed once sufficient funding has been secured. The Swiss training module will allow EUPATI CH to train patients for the ever-increasing number of opportunities for patient involvement in Switzerland. Looking ahead, EUPATI CH continually seeks interesting initiatives related to patient education and remains grateful for input from the public.