

## INNOVATION CORNER

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### INVOLVING PATIENTS IN ACADEMIC CLINICAL RESEARCH: IT'S TIME TO WALK THE TALK

Author: **Cordula Landgraf**

Affiliations: Swiss Clinical Trial Organisation (SCTO) and European Patients' Academy on Therapeutic Innovation Switzerland (EUPATI CH), executive board member

Involving patients in academic clinical research ensures that research questions and clinical research outcomes are addressed and implemented in a manner relevant to patients. As one of our key strategic goals in the new 2021–2024 performance period, the Swiss Clinical Trial Organisation (SCTO) and its Clinical Trial Unit (CTU) Network are placing greater emphasis on the implementation of patient and public involvement (PPI) in academic clinical research. In pursuit of this strategic goal, the SCTO sent out a survey to relevant stakeholders in order to identify and characterise all PPI initiatives and projects in Switzerland and thereby establish the status quo. As a next step, the SCTO envisions establishing a central coordination and contact point that is pathology-independent and spans organisations. We aim for a sustainable, inclusive PPI approach in academic clinical research that is established in close collaboration with our partners and stakeholders.

The [Swiss Clinical Trial Organisation](#) (SCTO) and its [Clinical Trial Unit](#) (CTU) Network are strongly committed to clinical research being patient relevant. This patient relevance is anchored in the SCTO's [vision and mission statements](#), and many of our past activities reflect this

commitment. The SCTO is one of the founding members of Switzerland's European Patients' Academy on Therapeutic Innovation ([EUPATI CH](#)) and has run the association's secretariat on an in-kind basis since its inception.

## PATIENT AND PUBLIC INVOLVEMENT AS A STRATEGIC GOAL FOR THE NEXT FOUR YEARS

In the SCTO's new 2021–2024 performance period, even greater emphasis will be placed on implementing patient and public involvement (PPI) in academic clinical research as one of our key strategic goals. There is no denying the fact that patients can offer a unique perspective on clinical research.<sup>1,2</sup> Through their experience with a disease or condition, patients know best which aspects are most relevant to them. By sharing this specific knowledge, they contribute to the quality, feasibility, relevance, and

credibility of clinical research. Along with other important benefits, this can improve a clinical trial's recruitment rate and potentially patient retention and thus enhance the success of a trial. From an ethical point of view, one can argue that patients should have an influence on research that affects them, in line with the motto "nothing about us without us" (see the SCTO's [PPI Factsheet](#) and [PPI Guide for Researchers](#) for more PPI information).

## CURRENT PPI SITUATION IN SWITZERLAND

In reality, the practical application of PPI in academic clinical research is lagging behind in Switzerland when compared to other European countries such as the UK or the Netherlands.

Some initiatives exist that have been put in place by single organisations, but they more or less stand alone and are not connected. Yet they face similar problems and need to address comparable challenges. And above all, they rely on the same "resource": patient and public representatives who are willing to contribute and actively engage in PPI. Because the PPI approach is relatively new, trained and empowered patients who are able to make a more informed contribution are still a scarce resource in Switzerland. In addition, transparent compensation models for patients' contributions are often missing or insufficiently established due to a lack of funding. This does not support sustainable PPI implementation in the long run.

The SCTO is therefore advocating for a more holistic, adequately funded, and coordinated PPI approach that

includes different organisations and stakeholders and pursues the following objectives:

- build and leverage available resources
- use synergies where possible
- raise awareness of the concept of PPI
- implement the principles of PPI and realise its benefits in the most efficient and sustainable manner possible
- raise the visibility of clinical research and its significance for public health
- establish the trust and mutual confidence between patients/the public and the research community needed to lead to a true partner relationship.

In our endeavours to foster the implementation of PPI in academic clinical research, the SCTO is taking a stepwise approach and including all relevant and interested stakeholders as we go along.

<sup>1</sup> Gradinger F et al. (2015) Values associated with public involvement in health and social care research: A narrative review. *Health Expectations* 18(5):661–675. doi:<https://doi.org/10.1111/hex.12158>

<sup>2</sup> Crocker JC (2018) Impact of patient and public involvement on enrolment and retention in clinical trials: Systematic review and meta-analysis. *BMJ* 363:k4738. doi:<https://doi.org/10.1136/bmj.k4738>

### FIRST STEP: A MAPPING EXERCISE

As the first step, a multistakeholder working group was established in December 2020. This group developed and sent out a [survey](#) to identify and characterise all PPI initiatives and projects in Switzerland with the aim of

defining the status quo. The initial results of the survey are currently being analysed and will be summarised and published on the SCTO's website at the beginning of next year.

### SECOND STEP: ESTABLISH A SWISS PPI HUB

As a second step, the SCTO envisions establishing a central coordination and contact point that is pathology-independent and spans organisations (working title: Swiss PPI Hub). The conceptional framework for this Swiss PPI Hub will be built upon the results of the mapping exercise performed in the first step with the objective of bringing all relevant and interested stakeholders on board. Preliminary reflections on how the potential Swiss PPI Hub could be set up are depicted in **Figure 1** below. A central element would be a Patient Advisory Panel (PAP) consisting of a limited but diverse number of patient representatives whose main task would be to

advise the hubs' members and function as a think tank. Membership in the hub would be inclusive and open to all Swiss academic research organisations/institutions, funding bodies, and authorities with a mandate in clinical research. Specific tasks and activities, such as drafting best practice guidance or establishing a network pool of PPI contributors, could be performed in work packages and thereby co-developed by both patients (from the PAP) and hub members. The whole hub would be embedded in an appropriate governance structure, and its activities would be coordinated by an administrative secretariat or liaison body.

### STILL A WAY TO GO ...

The SCTO and its CTU Network have started the process of making PPI a sustainable reality in academic clinical research in Switzerland. However, sustainable PPI cannot be achieved overnight – but rather in the long run and only

in close collaboration with our partners and stakeholders. So join us as we walk the talk and run towards our goal of embedding PPI in Swiss academic clinical research!

**Figure 1: Potential set-up of the Swiss PPI Hub with its Patient Advisory Panel**

