

## How to involve patients and the public in cancer research – in practice?

### 1<sup>st</sup> International Workshop on Patient and Public Involvement in Cancer Research

In November 2022, the first international workshop on patient and public involvement in cancer research was held in Lausanne. The experiences of cancer patients and their relatives are increasingly recognized as a valuable resource in research. At the workshop, various models and projects were presented on how these experiences can be successfully integrated to enrich and inform research.

Scientific knowledge in the field of cancer research has rapidly expanded in recent years. Without the participation of patients and their families, clinical cancer research would however not be possible. The notion that patients can contribute more to research than just in the role of passive study participants is increasingly acknowledged. Their experiences and knowledge are a valuable resource to motivate researchers and inspire projects.

But how can patient and public involvement (PPI) in cancer research be practically realized? Which are the current obstacles? And how does the situation in Switzerland compare internationally? These and other questions were discussed at the workshop by and with Swiss and international experts from both research and the public.

#### **PPI: Switzerland is only at the beginning**

Internationally, the number of publications on research projects with active patient involvement is continuously increasing. While the concept of PPI has been known and widely used for several decades in countries like the United Kingdom, the United States, or Australia, PPI in Switzerland remains in its infancy. Nevertheless, several initiatives have emerged in recent years:

- The Swiss Clinical Trial Organization (SCTO) provides detailed information about PPI on its website and maintains a PPI mapping of Switzerland, in which PPI initiatives and projects are catalogued.
- The Swiss Association for Clinical Cancer Research (SAKK) has a Patient Board that brings the direct patient perspective to SAKK projects.
- The platform "Patients Partenaires | PP + 3P" (Proches, Professionnels, Public) and the PartnerRec network ("partenariat patient dans la recherche") at the Geneva University Hospitals (HUG) provide information about PPI and promote collaboration between patients and researchers.
- Swiss Cancer Patient Experiences (SCAPE) is a long-term study conducted among the largest Swiss hospitals to collect individual experiences of cancer patients during their disease. The project aims to use the results to improve the quality of patient care.

#### **PPI in Denmark and the USA**

Prof. Helle Pappot from Copenhagen University Hospital (Denmark) presented the "Kræftværket" project, which she and her team are developing together with adolescents and young adults (AYA) affected by cancer. In this project, affected AYA have access to a dedicated room at the University Hospital where they can meet and discuss. In close contact with researchers, they have there initiated three research projects to date. One of them is the development of a smartphone app that facilitates mutual exchange and symptom control, and aids to improve quality of life. Important to note: Implementation of the app into clinical practice has been covered by the Danish public health system.

Mary E. Cooley, nurse scientist, and Rich Boyajian, patient representative from the Dana-Farber Cancer Institute in Boston (USA), informed about a project in which researchers and patients worked together to develop a decision support tool for people affected by cancer. The tool helps patients make clinical decisions, such as symptom management at home, or whether or not to seek medical attention.

### **Faster implementation into practice thanks to PPI**

The way until the results of a research project are implemented into clinical practice is often long. It is indeed estimated that around 85% of all research results never arrive in practice. "Involving patients and their relatives can help reduce this loss," said Prof. Sabina De Geest, head of the Institute of Nursing Science at the University of Basel. "Through PPI, research results can be improved and processes of practical application accelerated." She presented the SMILE project, which was developed with the active participation of patients. SMILE is an eHealth tool that improves the care of individuals following allogeneic stem cell transplantation.

Alison Reeve, head of the Patient Involvement Program, and Patrick McGuire, patient relative and volunteer partner at Cancer Research UK, reported on lived PPI practice in the United Kingdom. Their presentation was complemented by Anne-Fleur Guillemin of the Institut national du cancer (Paris), who presented newly created initiatives to promote PPI in cancer research in France.

### **Promoting and funding PPI**

In small breakout discussion groups, researchers, patients, members of research organizations, and public representatives discussed how to promote and fund PPI, how to find patients or relatives who want to participate in cancer research, and how research institutions can collaborate on PPI.

It was emphasized by all parties that patient involvement in research requires great respect in dealing with each other and that it is critical to appoint the right task to the right person in a mixed research team. Importantly, patient panels should be diverse. Participants also underlined that researchers and institutions wishing to implement PPI in their work require solid support - for example, good practice checklists - and financial resources. On the question of whether patients should be compensated for their participation in research, the majority opinion was that financial compensation was fair and appropriate. Institutional recommendations on this topic are currently in preparation.

At the end of the workshop, researchers and patient representatives agreed that the key to successful collaboration lies in close exchange and getting to know each other personally. For the future, a large number of participants expressed their interest for more similar events enabling exchange - also on the international level.

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