AGORA
PÔLE DE RECHERCHE SUR LE CANCER

Patient lab

1st International Workshop on Patient and Public Involvement in Cancer Research

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Auditorium PATERNOT AGORA

Rue du Bugnon 25A, 1005 Lausanne

ABSTRACT BOOK

Registration fees – Registration deadline: October 23, 2022

Participant (researchers/others)	CHF 80.00
Participant (patients/relatives/public representatives)	free of charge

When registering, you will be asked to choose a breakout session in the morning and one in the afternoon.

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1 Promoting hands-on user-innovator exchanges for implementation of a relevant innovation in oncology

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The SILAB (Source Innovation LAB) is a department of the Institut et Haute Ecole de Santé La Source in Lausanne, member of the HES-SO. One of SILAB missions is to promote, facilitate and supervise Ra&D projects developing innovative solutions dedicated to the healthcare sectors. It relies on a multidisciplinary team that can handle projects encompassing most areas of healthcare, with a specific focus on user-centered issues, namely needs, expectations, fears and integration of innovation into current practices. These projects arise from multiple stakeholders, including start-ups, care institutions and innovators at large. SILAB can act as a research partner in Innosuisse-funded projects. SILAB also pursues the task of promoting the culture of innovation in healthcare institutions as a bottom-up approach. As such, SILAB promotes innovator-user interactions, having healthcare professionals express their needs and expectations and innovators proposing solutions, most of them still exempt from user feedbacks. SILAB can thus promote a relevant innovation that develops useful solutions with a clearly defined purpose.

Thanks to improved treatments, cancer is becoming a chronic state. Care pathway of patients is getting longer and more complex, involving a wide panel of stakeholders from various health sectors. It is therefore crucial that these professionals communicate and coordinate their efforts to improve the patient experience and comfort and the efficacy of its multiple, targeted treatments. SILAB mission and expertise is a perfect match to reach these goals by setting optimal conditions to foster exchanges, common identification of needs and implementation of projects to develop relevant innovative solutions.

2 Patient and public involvement at the Swiss Personalized Health Network (SPHN): A funder's perspective

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Introduction The Swiss Personalized Health Network (SPHN) was launched in 2017 to enable research in data-driven medicine in Switzerland. SPHN is an initiative of the Swiss government, and is led by the Swiss Academy of Medical Sciences and the SIB Swiss Institute of Bioinformatics. Driven by the notion that research in datadriven medicine can flourish only on a basis of trust with patients and the public, patient and public involvement (PPI) have been central in SPHN daily practice.

PPI Strategy SPHN has adopted and mandated PPI on multiple levels:

1) PPI experts have a seat in SPHN's main governing body, the National Steering Board **(executive level)**, and in the SPHN Ethical, Legal, and Social Implications advisory group (ELSIag) **(advisory level).**

2) For the call for National Data Streams (NDS), grantees have developed a PPI concept and were required to allocate a minimum amount of funding to PPI. In addition, the expert panel evaluating the NDS proposals included PPI experts **(executive level & PPI funding).**

3) SPHN is represented in the Swiss Clinical Trial Organization (SCTO) PPI Working Group, collaborating with PPI experts and other stakeholders on advancing PPI in Switzerland **(PPI funding)**. SPHN co-funded Swiss PPI mapping activities by SCTO, too.

Conclusions Since 2017, SPHN has initiated and funded PPI activities, recognizing the long way ahead to make PPI a standard in Swiss personalized health research.

3 Patient involvement in the Swiss Cancer Patient Experience (SCAPE) surveys

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Introduction Patient surveys represent unique opportunities for patients to evaluate whether current cancer care responds to their needs and expectations, ideally with a strong patient and public involvement (PPI). In 2018, we launched the first cross-sectional survey of patient experiences with cancer care (SCAPE-1) in the French-speaking region of Switzerland. In 2021, we repeated and expanded the survey (SCAPE-2) to hospitals in the German-speaking region.

Methods Over the course of SCAPE-1 and SCAPE-2, PPI was applied in all phases of the project. Patient Partners took part in the study steering committee. They participated in the translation, validation and pre-test of the questionnaire. They revised patient materials and answered patient email inquiries. They were included in the interpretation of the results. Finally, Patient Partners led the dissemination of the lay summary of results sent to participants.

Results We had a 44% and 49% response rate to the SCAPE-1 and SCAPE-2 studies. Results were transmitted to patients and hospitals, which implemented changes in areas of care less well rated. So far, for SCAPE-1, the Patient Partner also communicated the results on social media and co-authored a scientific paper. More dissemination activities under the lead of Patient Partners are planned for SCAPE-2.

Conclusions Patient involvement is highly valuable before, during, and after the study. We are now planning the next survey (SCAPE-CH) for 2023, including 20 hospitals in all regions of Switzerland, with a third Italian-speaking Patient Partner.

4 NCRI's consumer forum - patients promoting evidence-based medicine and evidence-based policy

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Methods Since its inception in 2000 the UK's National Cancer Research Institute ('NCRI') has committed to involve Consumers (patents and public) representatives in all aspects of its work.

Consumers are recruited in open competition, trained for specific NCRI roles, and supported to work beyond those roles. **The NCRI Consumer Forum** contains 140 members from all four UK nations, providing a pool of experienced advocates working in all areas of cancer research. 75% of Consumers also work beyond the NCRI Partners.

Results Consumers work with industry including Big Pharma and biotechs. They serve on Trial Management/Steering Groups, research funding committees and are Board members, Charity Trustees and NHS Commissioners. All have worked on patient information, websites, videos and audio.

During the Covid-19 pandemic in 2020-21 the Consumer Forum worked collaboratively with the UK Coronavirus Cancer Monitoring Project to create, distribute and analyse a survey asking cancer patients what was important to them for Covid-19 and cancer research. Results informed the direction of Covid-19 and cancer research in the UK. This collaboration further led to collaboration on peer-reviewed journal articles.

Consumers work with strategic bodies in the UK and beyond eg NICE, MHRA, HRA, BBMRI-ERIC, EORTC. Consumers have input into the strategy of the UK regulatory environment via the MHRA clinical trials regulation and shaped future strategy for cancer care and research via the national 10-year cancer plan.

Conclusions The NCRI Consumer Forum has motivated and educated consumers working extensively to promote evidence-based medicine and evidence-based Policy in the UK and beyond.

5 FORCES : Formation et implication des citoyen·ne·s et patient·e·s partenaires dans la coproduction et la recherche en santé

Magali Bilien, Samuel Abreha, Christine Bienvenu*, **Laure Bonnevie, Marie-Anne Durand, Océane Pittet, Kevin Selby, Christian von Plessen**
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Introduction Il y a une reconnaissance croissante en Suisse de l'importance d'impliquer les patient·e·s et citoyen·ne·.s comme partenaires dans la recherche en santé. Toutefois, le constat actuel est un manque de capacité autant du côté des chercheur·e·s (quand, comment, pourquoi), que des partenaires (reconnaître les possibilités, rôles, statuts).

Objectifs Créer une plateforme web, FORCES, avec quatre objectifs : 1) Offrir un programme de formation en ligne commun aux patient·e·s, citoyen·ne·s, professionnel·le·s de la santé et chercheur·e·s ; 2) Mettre en contact les chercheur·e·s et les patient·e·s, citoyen·ne·s ; 3) Proposer un service de conseil pour la recherche participative ; et 4) Former une communauté de partage de pratiques et de promotion de cette approche.

Résultats Grâce à un financement interne de 2 ans d'Unisanté, nous avons formé une équipe de quatre patient·e·s partenaires et quatre chercheur·e·s pour coproduire la plateforme. Nous avons fait une analyse des plateformes et formations existantes. Nous avons choisi de commencer par la création d'un module d'introduction, suivi par des modules complémentaires sur l'éthique en recherche, les méthodes de recherche, et l'inclusion de populations en situation de vulnérabilité. Le contenu du site web est en cours de rédaction.

Conclusions Une fois la plateforme en place, nous prévoyons une phase pilote où nous fournirons gratuitement le service de conseil pour 3 à 5 projets de recherche. A terme, l'objectif est que les groupes de recherche ayant un financement externe paient pour ces services. Nous maintiendrons la gratuité des formations pour tous les patient·e·s et citoyen·ne·s.

6 Supporting patient involvement in research – a funder's approach

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Background Rising Tide Foundation for Clinical Cancer Research (RTFCCR), a private philanthropy that funds academic research, has developed a novel approach for requiring and supporting patient involvement in designing and conducting research projects.

Methods RTFCCR partnered with Patvocates, a patient advocacy and engagement network, to create a set of guiding documents aimed at public and private health research funders within various national, international, and therapeutic settings. These documents guided the strategic measures described herein.

Results The measures to advance this effort were : 1) Full integration of patient involvement requirements in the foundation's funding guidelines ; patient input to prioritization of research focus areas and calls for proposals ; 2) direct involvement of patient experts in the grant review process ; and 3) a commitment to support high impact clinical research in Low- and Middle-Income Countries (LMIC). Moreover, the foundation has launched a collaboration with the International Cancer Research Partnership (ICRP), the global alliance of cancer research organizations to share its experience and support other funders in choosing their approach.

Conclusion This initiative led to several changes in the foundation's approach, such as the inclusion of patient partners in research teams and grant review committees, as well as having a patient research advocate on the RTFCCR advisory board. By using its grantmaking function and developing standardized approaches for implementation of patient involvement, RTFCCR is advancing the field of patient-centric cancer clinical research. This approach will continue to build and evolve as it is implemented, disseminated, and shared with partners throughout the world.

7 A citizen science approach to cancer survival stories

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[3] My Survival Story Foundation, Zurich, Switzerland

Background Cancer patients often search for information about their health condition online. Cancer patient narratives have established themselves as a way of providing information and education, but also as an effective approach to improve coping with the disease.

Objective We investigated how people affected by cancer perceive cancer patient narratives, and if such cancer survival stories potentially improve coping during their own cancer journeys. We reflect if our co-creative citizen science approach can contribute to gain knowledge about cancer survival stories.

Patient and public involvement We adopted a co-creative citizen science approach where citizens and researchers were equally involved throughout the whole project. We applied mixed methods with stakeholders.

Main outcome measures The understandability ; and perceived benefits of cancer survival stories ; coping ; emotional reactions to the stories ; helpful characteristics of the stories.

Results Cancer survival stories were considered as intelligible, beneficial, and potentially support positive emotions and coping in people affected by cancer. Together with the stakeholders, we identified four main characteristics that evoke positive emotions and were considered especially helpful : 1) positive attitudes toward Institut für komplementäre und integrative Medizin life, 2) encouraging cancer journeys, 3) individual coping strategies for everyday challenges, and 4) openly shared vulnerabilities. Please find here a short video of our results : Sharing personal experiences with cancer: My Survival Story

Conclusions Cancer survival stories potentially support positive emotions and coping in people affected by cancer. A Citizen Science approach is suitable to decide about relevant content of cancer survival stories towards becoming a helpful education resource for coping with cancer.

8 Experiences and roles of caregivers within a phase I clinical trial in oncology : An experience-based co-design study

Nina Canova [1]**, Nils Graber** [2]**, Sara Colomer-Lahiguera** [2]**, Laetitia Della Bianca** [1]**, Francesca Bosisio** [1]**, Denise Bryant-Lukosius** [3]**, Manuela Eicher** [2]**, Alain Kaufmann** [1]
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Although the scientific literature highlights the difficulties encountered by caregivers to cope with clinical trials in oncology, their experience and their role in the particular context of adoptive cell therapies remains understudied. To address this lack of knowledge, the aim of our study* is to inform and improve the support offered to caregivers by examining their experiences and perspectives across the treatment trajectory of a phase I clinical trial in adoptive cell therapies.

Mobilizing Experience-Based Co-Design methods (EBCD), this participatory research involves gathering experiences from caregivers through in-depth interviews, group discussions and consensus meetings. A major contribution from this research design, is to consider caregivers as active partners in the research process. Therefore, they will validate the qualitative results of the interview analysis, identify needs across the trajectory of care and work with patients and healthcare professionals to co-develop priorities and propose solutions for service improvement. This involvement throughout the research process will allow to prioritize and design more specific, relevant and comprehensive interventions.

The results of this innovative study will reflect for the first time the needs, concerns and experiences of patients' caregivers involved in research on adoptive cell therapies and will promote visibility and sensitivity to their significant role of accompaniment throughout the care trajectory.

* This study is part of a larger research entitled "Patient, caregiver, and healthcare professional experience in adoptive cell therapies: an experience-based co-design study" that is currently (2022-2024) taking place at the Lausanne University Hospital (Switzerland).

9 Improving hospitality in oncology, with and for cancer patients

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Rationale Patient centred care requires comprehensive cancer care that includes hospitality services along the care trajectory. We describe participation of and collaboration with cancer patients in the development of a programme aiming at improving hospitality in an oncology department in Switzerland.

Methods We followed a multi-methods approach to design hospitality interventions in cancer care, drawing on the expertise of the hotel industry and transferring it to the health sector, including patients in different phases. Design, data collection and analysis benefited from the collaboration of a patient representative (second author), to work on relevance and comprehensibility of the program. Her involvement was consultative, as an advisor and co-researcher, member of the advisory board. Furthermore, unmet hospitality needs were identified based on a large Cancer Patient Experience Survey. Additionally, seven patients participated in a focus group to identify priorities, validate and complete unsatisfied hospitality needs.

Results Patient involvement is integrated in the design, implementation, evaluation, and dissemination stages of the project. This involvement has enabled the identification of nine unmet hospitality needs, and the development and implementation of a program designed with and for cancer patients, dedicated to address these needs.

Conclusions Involvement of patients at different stages of the program development has helped to increase the relevance of the intervention, as well as ensure its appropriate targeting. The intervention and implementation process will be evaluated mainly measuring the experience of hospitality at the oncology department.

10 Patient, caregiver, and healthcare professional experience in adoptive cell therapies : An experience-based co-design study

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Adoptive cell therapy with tumor-infiltrating lymphocytes (ACT-TIL) is a rapidly growing strategy in the field of cancer therapies that relies on delivering specific autologous anti-tumor immune cells. While ACT-TIL entails a complex treatment procedure, the experience of care in this context remains understudied. Experience-Based Co-Design (EBCD) positions patients as active partners together with healthcare providers in services quality improvement.

EBCD relies on different stages articulating qualitative and co-design methods, from observation, interviews, and workshops. We herein present the approaches used to involve patients on a phase I clinical trial of ACT-TIL aiming to build consensus on priorities and solutions to improve care delivery.

Patient and Public Involvement (PPI) strategies is applied on three dimensions. As participatory research method, EBCD involves patients as participants whose personal engagement contributes to validate qualitative results and to develop priorities for service improvement. In addition, we involve two patients representatives with experiences in similar contexts. The first patient was consulted to give advice on the content of the information provided to participants including the informed consent, and provided feedback on the relevance and comprehensibility of the interview guides; a second patient representative is member of the Advisory Board constituted to guide the study progress. This positions the patient as co-researcher participating on the protocol design, analysis and dissemination of the results, and to elaborate recommendations for implementation.

By applying different involvement approaches (stages, levels and types) we aim to assure the relevance, comprehensibility and to increase the acceptability of the study and results.

11 **Implementation of digital technology in the establishment of an integrative healthcare management practice to meet patient and provider needs**

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Introduction Prostate cancer survivors travel great distances, at a financial cost for a 15-minute visit to check blood work and symptoms. A cancer survivor turned oncology nurse practitioner used his and his patients' experiences to create a virtual alternative to traveling to the cancer center for care.

Methods In 2015, We developed a digital platform based, APP-led, virtual prostate cancer clinic (VPCC) to take the place of routine in-person follow-ups. Monitoring consisted of PSA at a local lab and patient-submitted digital questionnaires. Interactions were direct by telephone, or video, or asynchronous via EHR portal, secure email, or SMS. Symptoms were managed virtually and patients with evidence of PSA recurrence were worked up per guidelines. We analyzed the clinical and treatment volume, financial data and surveyed patients on their satisfaction.

Results From March 15, 2016, to August 31, 2022, a total of 1837 patients have been enrolled in the VPCC. 94.3% of patients were comfortable with this form of monitoring, with 3.4% neutral and 2.3% uncomfortable. 92.4% saved time & 53.2% saved > 3 hours per visit. Compared to 2015, increased physician availability was associated with an ~ 162% increase in access and a 43.0% increase in patients treated through FY21. The increases in patients treated also led to a corresponding increase in gross patient services revenue as well.

Conclusions The VPCC patient centric model is an innovative approach to coordinating remote care that has high patient satisfaction, significant patient time-savings, substantial improvement in access to care, along with revenue growth.