Patient Engagement Workshops

for cancer research funding organizations

Virtual Meetings 1&2
10 September & 11 November 2021

Co-hosted by:
RISING TIDE. Foundation for Clinical Cancer Research
ICRP International Cancer Research Partnership

ICRP
International Cancer Research Partnership

Workshop Summary
December 2021

Background: why did we set up the workshops?

Patient (or advocate/consumer) engagement is vital in ensuring that cancer research focuses on addressing patients' priorities. We organized two introductory virtual meetings for cancer research funders in September and November 2021 to explore what best practice looks like for patient engagement across the spectrum of cancer research, from basic to clinical research. During the session participants:

- Heard from a patient advocate and scientist involved in developing guidance for funders
- Explored how funders can promote best practice and identify gap areas in patient engagement in an interactive forum, by discussing the following questions:
    - HOW AND WHERE do you integrate patient advocates in RFA/CFP planning, review of applications, and how do you encourage patient involvement in the projects you fund?
    - Are you COLLABORATING with other organizations, e.g. on patient expert training, scientist training, identification of patient organizations, patient engagement methodologies?
    - GAPS AND CHALLENGES - what would help you to make patient engagement in CFP/RFA, applications review and funded projects more of a reality? Would a workgroup help?

Chair and Presenters

Chairs

Our partners at the Rising Tide Foundation for Clinical Cancer Research chaired both workshops (Dr Alex Alencar and Dr Valerie Behan)

Presenters

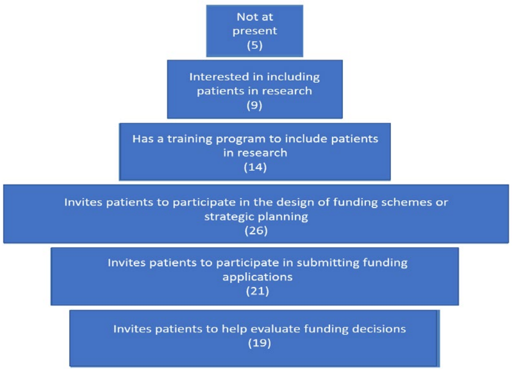
Jan Geissler - a patient advocate and social entrepreneur. Jan is a founder and CEO of Patvocates - a think thank, consultancy and social enterprise in the area of patient advocacy and patient engagement. Jan is also Chair of the EU Patients' Academy (EUPATI) and Co-Founder of the CML Advocates Network

Cordula Landgraf is responsible for communications and stakeholder engagement at the Swiss Clinical Trial Organization (SCTO). She seeks ways to enhance strategic collaboration with stakeholders – with a special emphasis on patient involvement

Participants' current inclusion of patients in research

During the two workshops, 37 representatives from 24 funding organizations in 10 countries participated, and many other organizations who were unable to attend expressed interest in joining the network. From a pre-meeting survey, it was encouraging to see that the majority of organizations already included patients in aspects of the research funding process (see box, right), from inviting patients to participate in designing funding schemes or strategies, submitting funding applications and evaluating funding decisions, to running training programs to enable patients to participate in the research funding process and having national infrastructure to support patient engagement.

Organizations' inclusion of patients in research:



Knowledge exchange and sharing best practice

During the breakout sessions, participants shared experiences and expressed strong support for patient engagement. There was a sense that momentum was building to enhance patient participation in research and the following areas of good practice were highlighted:

- **Involvement** of patients from the early stages of the grant application process: this could be required by funding organizations to ensure a strong patient focus for research.
- **Access** to a pool of patient advocates for researchers: this could be done through hospital pools of advocates (for clinical research), funding organizations own contacts or regional/national cancer networks (for all types of research).
- **Integration** of patient advocates or lay representatives (e.g. for prevention programs) in funding organizations' strategic planning for research funding schemes, grant assessment and evaluation.
- **Training** programs for patients interested in cancer research, with ongoing development and opportunities to join a community of practice. This could include partnering patients and researchers, for example during conferences, to further patients' understanding of current research questions and results.
- **Training for researchers** in best practice in patient engagement.
- **Grant support** for researchers exploring new ways to engage patient advocates.
- **Funding** to enable patient advocates to be involved (to compensate for time and expenses).
- **Diversity**: ensuring that patient advocate pools are diverse and representative of all types of patient, and that include people with lived experience of specific cancer types.
- **Collaboration**: cross-funder collaborations are helpful to share best practice, share resources and develop patient networks. Collaboration was also important between countries, e.g. between high, middle and low income countries.

Gaps and challenges for cancer research funders

The workshop participants identified a number of gaps and challenges, both for patient advocates and funding organizations:

Challenges for patients:

- **Volunteer time and resource**: dedicated budget is needed to cover expenses and widen the pool of patients to avoid over-reliance on a small number of patients.
- **Access to training:** additional training would be welcomed.
- **Acknowledgement:** patients should be acknowledged in publications arising from research that they had helped to shape.

Funder challenges:

- **Changing organizational culture:** it was difficult for organizations with no current involvement to know where to start, especially when the organization funds basic, non-clinical, research. Training was needed for researchers and grant review panels in best practice in patient engagement.
- **Evaluation and evidence:** evaluating and measuring the success of patient involvement could be challenging.
- **Access to patients:** a wider pool of patients with lived experience of specific cancer types is needed.

What next?

- We are sharing resources (e.g. guidelines, training documents) via our ICRP partner library to assist funding organizations in developing and expanding patient engagement using established models from other funders. In addition, we are looking into the possibility of a shared pool of patient advocates or matchmaking services for researchers and patients.
- We will continue to expand the patient engagement network, working with funders and patient representatives to identify areas where collaboration would be valuable. **Our next meeting will be in early 2022.**

Want to join us or find out more? Contact us at operations@icrpartnership.org

www.icrpartnership.org

@icrpartners1 #ICRP2021