CCS/CIHR Cancer Survivorship Team Grants

Guidance for engaging survivors/caregivers in research

Successful teams will employ a research model that embodies the values of community-based participatory research (CBPR), in which survivors and/or their family/friend caregivers are engaged throughout the entire research process from the development of the initial research questions to the dissemination and application of research findings.

Regular networking events/activities will be facilitated by CCS that are designed to support and augment individual teams' capacities to catalyze survivor/caregiver engagement and knowledge mobilization.

Substantial and varying resources exist to support patient engagement in research. Teams are encouraged to utilize the methodologies that resonate most appropriately with the type of project being proposed, as well as the needs of individual members, particularly the survivor/caregiver team members. The following is provided as additional guidance for this competition.

Principles for engaging survivors/caregivers in the research process:

- Develop mutually beneficial and respectful relationships – where researchers learn from survivors/caregivers and survivors/caregivers learn from researchers
- Provide a safe environment for survivors/caregivers to share their input
- Encourage survivors/caregivers to suggest additional ways in which they may assist in the process – consider their 'other hats', as professionals with expertise in complementary fields, for example
- Establish expectations regarding frequency and type of communication, as well as expectations around the amount of time to be devoted to the research process
- Ideally, survivors/caregivers will bring a collective perspective to the process, reflective of not only their own personal experience, but also insights and experiences shared by others

How to effectively involve survivors/caregivers in the research process:

- Engage early, and often, throughout development of the research question

- Provide an opportunity to consider and comment on the methodologies proposed and identify potential concerns or ways that the participant experience (for research involving human participants) could be improved
- Ensure ongoing engagement throughout implementation of the project, seeking input where applicable, particularly where unexpected issues arise
- Consult survivors/caregivers on the anticipated end-products or impacts of the proposed research – are the outcomes desired by and important to them?
- Include a plan for evaluation of engagement (see https://ceppp.ca/en/our-projects/evaluation-toolkit/ for support)
- Cover out-of-pocket expenses, and provide compensation that is reflective of the effort involved, but that also takes into consideration the potential impact on any constraints due to benefits the survivors/caregiver may be receiving, such as employment insurance, disability support, etc.

Resources

Emerging Guidelines for Patient Engagement in Research.
https://www.sciencedirect.com/science/article/pii/S1098301516340505

Patient Engagement. CIHR. http://www.cihr-irsc.gc.ca/e/45851.html

Patient Engagement: Tools & Resources. St. Michael's Hospital.
http://stmichaelshospitalresearch.ca/patient-engagement-resource/

Patient engagement in Canada: a scoping review of the 'how' and 'what' of patient engagement in health research.
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5804082/

Strategy for Patient-Oriented Research – Patient Engagement Framework. CIHR.
http://cihr-irsc.gc.ca/e/48413.html

The First Nations Principles of OCAP. https://fnigc.ca/ocapr.html

The Value of Engagement. PCORI. https://www.pcori.org/about-us/our-programs/engagement/value-engagement