

# ENGAGING CANCER SURVIVORS IN HEALTH RESEARCH: INSIGHTS FROM PARTICIPANTS

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## Introduction

- Patient involvement and stakeholder engagement have been increasingly recognized as improving quality of health care and research.
- The involvement is aimed at helping to improve the relevance, quality and impact of health research.
- Researchers are moving with increasing frequency to incorporating stakeholders, but levels and timing of engagement vary widely.
- Levels of engagement have ranged from consulting on priorities for investigations beforehand, to serving on steering or advisory committees, to full membership on a research investigation team.
- The goal of this work was to share our experiences and insights as members of a Patient Advisory Committee (PAC) on a large multidisciplinary cancer research study that has spanned years.
- We anticipate the reflections on our successes, challenges, and lessons learned could help guide future health research initiatives.
- To the best of our knowledge, few publications describing patient engagement in health research have been written by patients, survivors or family member caregivers themselves.
- Our PAC was involved with CanIMPACT, a 5-year project to elucidate gaps in care and develop strategies to enhance the capacity of primary care for cancer patients. The activities occurred in two phases: foundational research using 4 sub-groups which informed a randomized trial to test an innovation.

## Methods

### Design

- We used a qualitative approach to capture our experiences and reflections as patient/caregivers on the Advisory Committee.

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- Members engaged in reflection and writing about the experiences with the Committee for publication.
- One member with qualitative expertise then circulated a list of open-ended questions to each member to guide personal reflection and description in writing.
- All members submitted written descriptions of their personal experiences and reflections or discussed these by telephone.
- All responses were collated, and themes were identified.
- Themes were shared and used as a focus for conversation (via Zoom) regarding shared and unique experiences.
- The group decided together what messages were most pertinent to share about patient involvement in health research based on our experiences.

## Results

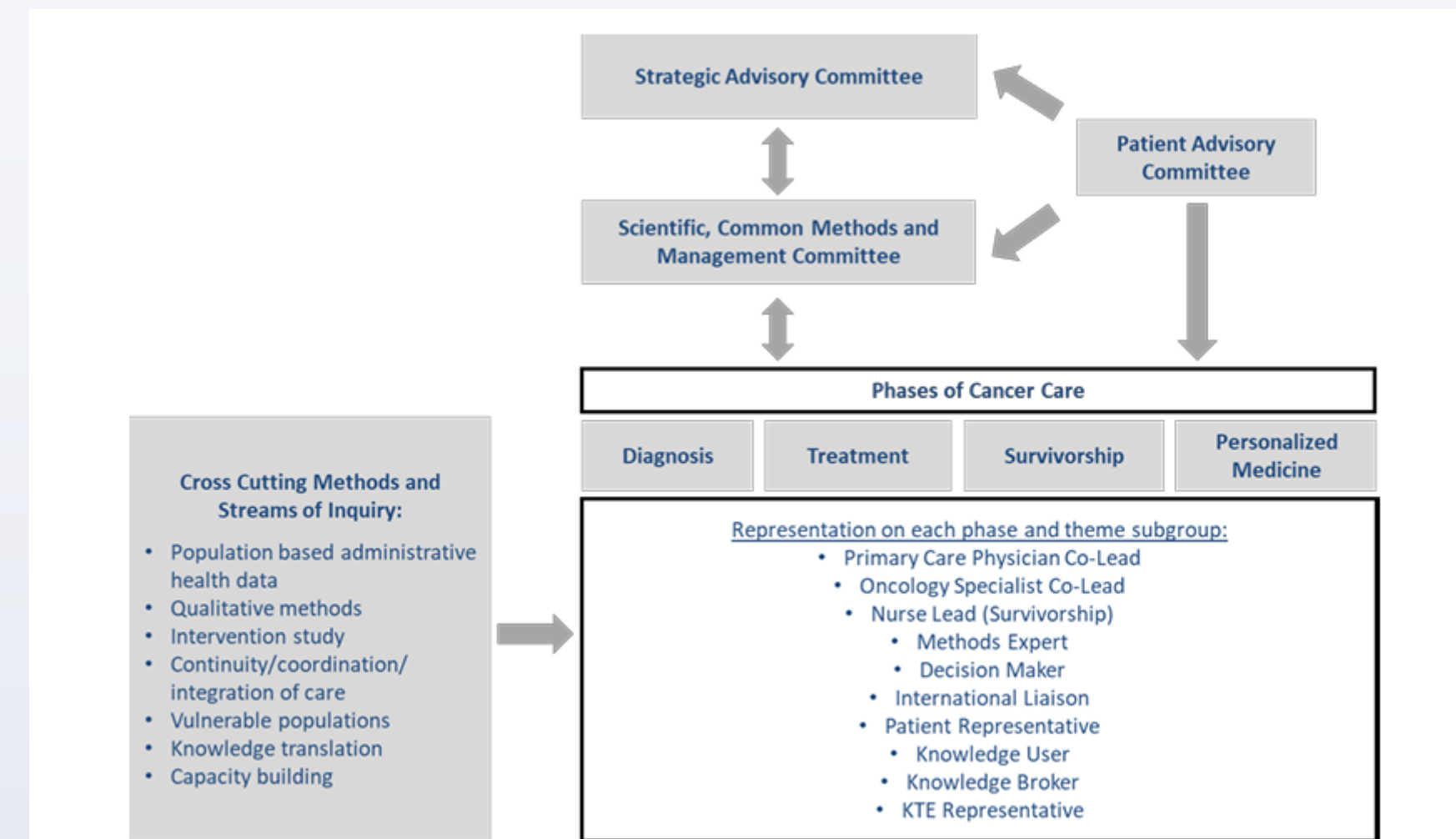


Figure 1. CanIMPACT Research Program Organizational Structure [25].

Figure 1

The Patient Advisory Committee served as an overarching committee as well as having patient representatives integrated into each of the research subgroups.

The Committee included both patients (a range of ages and disease sites) and caregivers from across Canada, including Atlantic provinces, Ontario, the Prairies, and the West Coast.

The Research Team The researcher team was comprised of primary care physicians, nurses, oncology specialist physicians, researchers, knowledge users, patients, and caregivers from across Canada.

Success – what worked well	
<b>Great working relationships and treated with respect</b>	Great working relationships and camaraderie among the members of the PAC and with the research team Functioned well as a group despite different cancer experiences and backgrounds Able to speak with a collective voice Research team members willing to listen to our input when presented
<b>Administrative Support and Co=Chair Roles for the Committee</b>	Administrative and structural factors contributed to our success as a committee. Administrative support was provided by a Research Project Co-ordinator – helped with organizing and coordinating our efforts and any travel required to attend meetings. The PAC was co-chaired by a patient representative and a research team member – this leadership helped to provide insight and answers to questions that arose; provided integration with the rest of the research team and provided consistency as project staff changed and corporate memory dissolved.
<b>Patient experience synthesis map</b>	Synthesis mapping is a unique knowledge translation tool and technique used for visual interpretation of research evidence. As a clinical Cancer Care Map was designed, the PAC was able to initiate an additional map which better represented the journey from their perspective. One member described: "We simply told them that we do not see ourselves in this health system map."

Challenges – areas for improvement	
<b>Timing of engagement</b>	The PAC was only established after grant funding was approved and research program was fully planned and already underway; engagement at the onset would have been beneficial. As one member stated: "It was like being asked to board a train that was already moving without having any say on the destination or route."
<b>Training/guidelines needed</b>	At the time of the onset, there were few resources or guidelines available on how to meaningfully engage patients. There was a learning curve for both the members of the PAC and research team members on how to best engage and work together. Roles and expectations needed to be clarified for all involved.
<b>Tokenism</b>	At beginning, several members experienced feelings of tokenism toward the patient advisory members. Some patient members felt sidelined in the beginning.
<b>More communication opportunities with research team</b>	Key accomplishments made during face-to-face meetings between the PAC and the research team members. Funding precluded frequent in person meetings and teleconferences had to be utilized
<b>Patient Advisory Committee recruitment and lack of diversity</b>	Recruitment of patient representatives and ensuring diversity was challenging. Committing for 5+ years ahead of time was a barrier.
<b>Need for midpoint evaluation</b>	It would have been beneficial to engage in a midpoint process evaluation to identify shared perspectives about areas for improvement.
<b>Reflections on our overall contribution and impact</b>	There were meaningful moments of engagement throughout the project where our voice was influential, however, there was variation among the subgroups in the extent to which our suggestions were incorporated. As one member stated: "We were informed and engaged as requested. We were approached respectfully and responded in kind. We met our obligation of affirming that the program had invited and engaged the patient population. But there were no crucial questions brought to our attention nor were we presented problems or questions that would have required real intellectual deliberation from a panel of cancer patients." Another PAC member noted, "Our level of engagement was good at the time for what was known about PE at the beginning of the project. But lots has changed and improved over the last six years, so things may be a lot different if we were starting out now."

## Lessons - recommendations

<b>Communication and connection</b>	Communication is key to the effectiveness of a Patient Advisory Committee – open dialogue, trust, respect, integrity, and transparency facilitate timely input of patients/survivors in a research project. Establishing connections and building relationships is essential.
<b>Early engagement and training</b>	Including patients early in the research process and providing appropriate training for both patient representatives and research team members is essential to fostering meaningful communication. Clarifying roles and responsibilities is vital.
<b>Evaluation throughout life of the research project</b>	On-going evaluation of the Patient Advisory Committee is essential. Ongoing process evaluation can ensure the engagement experience is meaningful and positive for all involved. The evaluation process helps to ensure patients and family caregivers remain active and informed and there is opportunity to adjust and adapt the engagement strategies.

## Discussion

Defining success and what constitutes meaningful contribution in Patient Engagement depends on the goals and expectations of both the Patient Advisory Committee and Research Team.

Allowing space in early stages of a research endeavour to discuss and define Patient Engagement goals and expectations together as a team is an essential step in building relationships, trust, and mutual respect, and fostering open dialogue.

## Reference

Easley, J.; Wassersug, R.; Matthias, S.; Tompson, M.; Schneider, N.D.; O'Brien, M.A.; Vick, B.; Fitch, M. Patient Engagement in Health Research: Perspectives from Patient Participants. *Curr. Oncol.* 2023, 30, 2770–2780. <https://doi.org/10.3390/currenconcol30030210>