

Exploring the Development, Evaluation, and Impact of Researcher-Led Patient and Family Advisory Councils in Cancer Research

Christie Farrer Rogers^{1,2}, Madison Leia², Winson Cheung¹, Colleen Cuthbert^{1,2}
 1 Department of Oncology, Cumming School of Medicine, 2 Faculty of Nursing



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CALGARY

BACKGROUND

- Patient engagement is essential to establishing patient-centered care, which in turn, positively impacts the patient experience, builds trust between patients and providers, and creates more empowered patients.
- Patient and Family Advisory Councils (PFACs) are one mechanism to engage with patients and their families.
- Our team established a 12-member PFAC to garner input on research and quality improvement initiatives. After the first year, we evaluated the initiative.

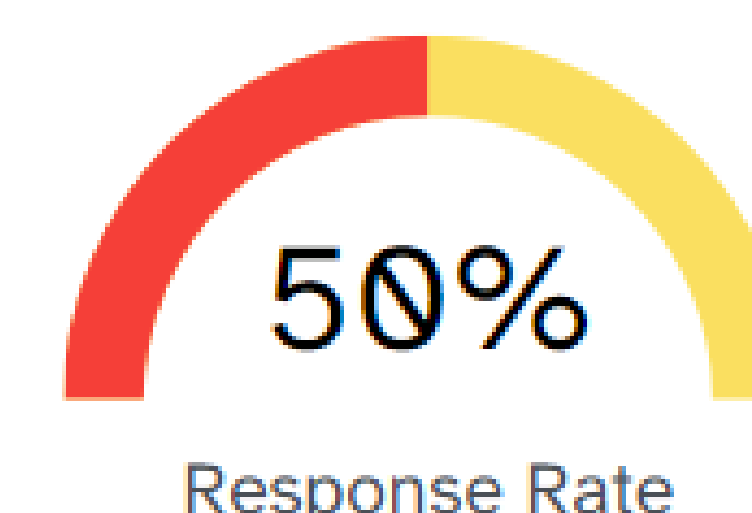
METHODS

- The council was developed in consultation with the Alberta Strategy for Patient-Oriented Research team.
- Recruitment focused on balanced representation of:
 - cancer tumor sites
 - age
 - race
 - sex and gender
 - geographic location
- Evaluation included an online survey based on The Public and Patient Engagement Evaluation Tool, focusing on:
 - communication and support for participation
 - sharing views and perspectives
 - overall satisfaction



RESULTS

- The response rate for the survey was 50% with all respondents agreeing or strongly agreeing that:
 - the PFAC achieved its objectives
 - they are satisfied with the initiative
 - a broad range of perspectives are represented
 - they are confident their input will be used to inform research and be clinically impactful
- Strengths include:
 - member input being highly valued
 - the two-way exchange of knowledge
- Increased communication between meetings was an area for improvement.



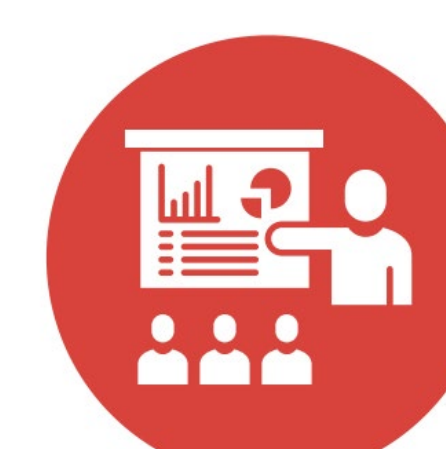
THE VISION:
Improving outcomes and experiences in the cancer care system...



...through patient and family input on research and quality improvement initiatives

DISCUSSION

- Recognizing the lack of evidence for the adoption and implementation of guidelines and evaluations of PFACs, we plan to host a one-day symposium.
- This will include representation from individuals across Canada who have experience in forming, leading, or participating in PFACs to share their perspectives, including:
 - health researchers
 - healthcare professionals
 - patients
 - caregivers



✉ christie.farrer@ucalgary.ca
 🔗 rb.gy/9fsnt
 🌐 oncoutcomes.com
 🌐 cuthbertlab.com

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