

Patient Engagement in Research Community of Practice

April 2023: Engagement in Heart Research

This document provides a presentation summary about the diverse forms of engagement opportunities, lessons learnt, and significance of engaging patient partners in heart failure (HF) research.

Key Presentation Points

- Patient partners are engaged in governance, peer review of research funding competitions, as members of research project teams, and in developing health education materials.
- Patient partners identified the need for a patient engagement framework and health information priorities that led to the co-creation, design, and launch of The Heart Hub and the Heart Failure Medications Guide for Patients and Caregivers.
- It is important to ensure engagement opportunities have a purpose and allow for the contributions, ideas, and feedback of patient partners to shape the research and impact those living with heart failure.

What did we discuss?

- **Challenges include:** Recruiting diverse groups; offering orientation and ongoing support; continuous learning; addressing power imbalances; managing conflict; tokenistic attitudes, assumptions, and biases; necessary time for meaningful engagement of patients; and compensation and budget allocations.
- **Facilitators include:** Having a clearly defined patient engagement plan; leadership from principal investigators and patient engagement lead within the team; meaningful patient influence on research; adequate orientation and ongoing training; sharing and promoting research learnings; and enabling patient partners to contribute beyond story telling.
- It is important to understand the organizational mechanisms in place to compensate patient partners and have upfront conversations about their financial circumstances.
- Be deliberate with self-disclosure and the multiple perspectives that people bring to research projects and enable others to share.
- An 'ah-ha' moment or a moment of recognition of the values of patient engagement in research can be sparked when a patient partner challenges the assumptions and shifts the conversation.
- To address equity and diversity in engagement, meet people where they are at. Consider the voices that are not being heard and how to engage diverse groups with humility. Be reflective in the research question, methods, recruitment strategies, and ways the share knowledge. Identify different methods to connect and translate materials to diverse languages. Leave room for changes in response to the engagement, show active listening and inclusion of the input and contributions.
- Patient partners can play a critical role in supporting, mentoring, and creating a sense of belonging for other patient partners and people with lived experience.

Relevant Resources on Patient Engagement in Research

- [Patient framework](#): A framework for patient engagement created by the Ted Rogers Centre for Heart Research.
- [Patient Appreciation Policy](#): A policy to recognize, appreciate and compensate people with lived experience for their support and expertise.
- [Workshop](#): An introductory workshop on engaging people with lived experience for the TRANSFORM HF community.