

PATIENT-ORIENTED RESEARCH

Partnering with patients for better results

QUESTION

DESIGN

PATIENTS ARE KEY

OUTCOME

METHOD

ANALYSIS

SHARING

STUDIES WITH PATIENT PARTNERS



YOUTH CAN IMPACT TRIAL

- Provide rapid access to youth mental health and addiction services
- Youth selected primary outcomes and co-designed drop-in centres to be more youth-friendly
- Important to set clear expectations, monitor engagement, ensure diversity

“The research team’s initial thoughts were to focus on symptoms, but the youth expressed the importance of focusing on functioning in various spheres of life.”

OUTCOMES AFTER ED VISITS – PROM-ED STUDY

- Develop a patient-reported outcome measure after discharge home from emergency department to improve care
- Patient partners were critical in each phase, guided outcome measure selection
- Challenges: delays in adequate ethics training, giving patient partners access to confidential data



DIABETES IN FIRST NATIONS

- First Nations diabetes rates and complications over 20 years on- and off-reserve
- Co-developed by Chiefs of Ontario senior staff, an Elder, two First Nations patient navigators, and the academic research team
- Six-member patient advisory group and community involvement key, but is time-intensive

“A key impact of our patient-engaged approach has been to acknowledge the complexity of the causes and implications of diabetes in First Nations individuals.”

ESSENTIAL MEDICINES – CLEAN MEDS STUDY

- Measure effects of giving people free, convenient access to essential medicines
- Community members guided and co-designed study, including how to contact participants
- Novel recruitment: researchers canvassed downtown Toronto streets in T-shirts saying “Free medicines?” and gave out postcards



POLICY IMPLICATIONS

- Outcomes relevant to patients → more efficient health care system
- Funding for services patients need
- Better use of health care resources



GOAL

Improve quality of life by making research more responsive to patient needs

BENEFITS

- Patient input into research outcomes
- Better recruitment and data collection
- Diverse perspectives
- Translation of findings into plain language
- Partnerships with underserved populations

LESSONS

- Engage early
- Clarify role, expectations, time commitments
- Build in longer timelines
- Manage ethics board submission
- Flexible scheduling for patient participation
- Partner with multiple patients
- Value patient partners’ time

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Patients as passive participants
Clinical or system outcomes
Researcher-focused

SHIFT TO PATIENT PARTNERSHIP

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Patients as active partners
Patient experiences
Patient priorities → better outcomes

