



Patient and Community Engagement Research (PaCER)

Stroke PaCER internship research presentation
April 4, 2016



History

- CIHR grant to create a curriculum for Seniors (Kerby Centre) and CHSRF grant to train patients in Health research (ABJN/SCN)
- PaCER, as a program, formed in 2013 at the Obrien Institute for Public Health, Cumming School of Medicine
- It is a partnership with *Strategic Clinical Networks*, Research teams, Health Care Providers and Patients.
- 40 trained patient researchers (PaCERs) to date, 13 completed internship research projects, and over 20 contracted research projects with health research and quality improvement teams



Structure

- Advisory Board: Dr. John Lacey Chair: with co chairs (one a patient) of teams: Science: Education: Enterprise, Grants and Innovation:Partnerships;
- Infrastructure: Director (in kind U of C), part time admin and research coordination, communications (mix of volunteers and paid staff from business)
- PaCER teams: Research lead, internship mentors, researchers and interns paid by contracts and sponsorships.



Research Support Services

- Social Enterprise Model within the O'Brien Institute in partnership
- profits are reinvested towards social good – improving the interface between patients and health system) Small business-like structure to encourage and foster experimentation
- Benefits include:
 - Low Risk
 - Hi Impact
 - Low cost
 - Commitment to experimenting with new methods
 - Payoff of results

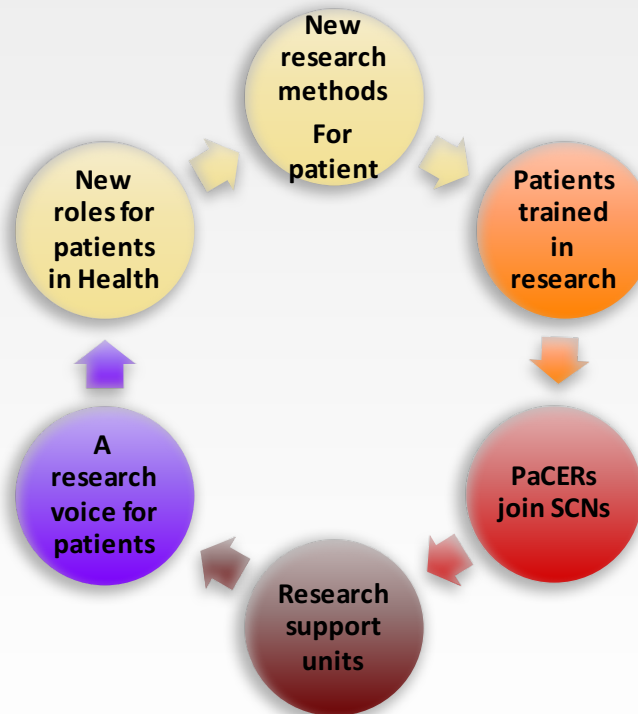


What is innovative?

- In international first for Alberta and Canada
- A twin innovation with the Strategic Clinical Networks (political synergy)
- University internship for patients and families
- Participants in PaCER research are engaged throughout the research cycle
- Sustainability: self funding payment to PaCER researchers and internship
- New Roles for patients, new careers
-



PaCER Evolution





PaCER Services

- Consultation, support and resources about Patient Engagement and Engagement Research options
- Year long internship for patients in Engagement research done by patients, with patients
- pacerinnovates, a service unit providing contracted supports patient led research as part of existing grants and projects
- Publication and Implementation support



PaCER GOALS and EARLY STROKE

- Bring patient insight to the search for sustainable and effective health care
- Reframe the role of “patient” as a key stake holder, partner, colleague
- Promote engagement in personal health and health care
- Improve the interface between patients and the health care system through research
- Patients see themselves in research and literature and can envision a new future



Who are PaCERs?

- Patients and Family members who:
 - Self identify significant, life impacting experience with their health or health care
 - Are committed to health transformation
 - Are curious and interested in research
 - Can make the commitment to learning advanced research skills
- PaCERs bring diverse perspectives, business, health, academics, cultural expertise. All learn together and from each other.
- People interested in new career directions or volunteer opportunities.



Research Internship:

- Three term internship, non credit or credit at undergraduate or graduate level
- Opportunity for patients to develop competence by designing, conducting and sharing their own research
- Theory and Methods units are integrated into internship
-



2015 Internship partners

6 Sponsored internship teams

- Libin: Young women with Chest Pain
- IBD Clinic: patient involvement in developing a comprehensive clinic
- Early symptoms of Mental Illness
- Stroke (PE CIHR grant): First Days of Stroke
- South Health Campus: Investing in patients
- St. Elizabeth's Health Care: Couples managing chronic health concerns at home.



Sept 2016 Internships: paired with research teams and sponsors

4-5 Teams with internship and research contracts, long range impact

- ERAS training patients to co design a provincial patient engagement strategy: Calgary Edmonton (3 year plan)
- Pediatric TBI: Training adolescents as part of Canadian network to do citizen based research with Dept. of Psychology and national roll out
- Syncope as part of CANnet, patient self management and patient resource network to prepare for National patient resource and coaching.
- Target SCN/AHS

PaCER Research Method: the foundation

A Participatory grounded theory method for Engaging
Patients in Research



Set
Co-design
scope and
methods

Collect
Data
collection
methods

Reflect
Collaborative
analysis and
translation

Marlett, N. & Emes, C. (2010). *Grey Matters. A Guide to Collaborative Research with Seniors*. University of Calgary Press,
<http://uofcpress.com/books/9781552382516>



Research Support Units

