Patient and Community Engagement Research

An Alberta innovation

Alberta SPOR Summer Institute, 2016
What is PaCER

A new research combination of engagement strategies, grounded theory and adapted qualitative techniques ……participatory grounded theory

Patients supporting patients to build new knowledge about health and health care

Patient researchers skilled in engagement methods collaborating with researchers trained in other methods to solve complex and troubling challenges.

Patients using research to inform planning and research decisions
A Short History

- 2008 Canadian Institute for Health Research grant to create a research curriculum for Seniors
- 2011 Canadian Health Services Research Foundation grant to train patients in Health research for Strategic Clinical Networks
- 2012 Strategic Clinical Networks (SCN) launched.
- 2013 PaCER program within O’Brien Institute for Public
- 2013 Internship supported by SCN
- 2013 pacerinnovates, a social enterprise serving research and QI
- 2016 13 internship research projects and over 20 contracted research projects completed and over 40 graduates of PaCER internship
Facilitating factors

- SCN wanted patients with new competencies to bring fresh perspectives
- SPOR provided incentives for researchers to include patients in research
- Three partners from health care, health research and patient engagement committed to investing in patients
- An existing engagement method and curriculum ready to adapt to health research – Grey Matters
PaCER goals:

- Bring patient perspectives to the search for sustainable and effective health care
- Reframe the role of “patient” as a key stake holder in health care and research colleague
- Promote engagement in personal health and health care
- Improve the interface between patients and the health care system through research
- Patients will see themselves in PER research and literature and envision a new future in health care.
Who are PaCERs?

• Patients and Family members who:
  • Self identify as having significant experience with their health or health care
  • Are committed to health transformation
  • Are curious and interested about research

• PaCERs learn from each other’s skills and perspectives: business, cultures, health care providers, academics, cultural expertise..

• People interested in flexible new career directions or volunteer opportunities.
Lack of funding options prompted PaCER to become self funding though a small start up research incubator

**Social Good:** bring patient insight to health transformation and sustainability through innovative peer to peer research.

**Contract business** to train patients and provide research supports to researchers and health care about patient engagement

**Benefits:** Low Risk Hi Impact Low cost Commitment to experimenting with new methods

**Problems:** reliance on volunteers and good will, no infrastructure or communication stability, insecure academic continuity, burnout.
Collaboration with Research Teams

1. Build PaCER into grants
2. Negotiate contract for research services
3. Conduct research in partnership
4. Publish and implement findings

PaCER: Links for Community Research
Sample of patient experience research

- Bone and Joint research (6)
- Surgery (3)
- Intensive care: family and patient priorities (3)
- Intensive care: Cardiovascular (3)
- Advanced care planning South Asian communities
- Hidden pathways of Chronic Illness
- What works and how in community wellness centers
- Palliative and end of life care policy
PaCER Internship
Investing in Patient Capacity

- Prepare and support patient engagement researchers for careers in research, consultation and advising
- Year long specialized training for patients, family members, undergraduate and graduate students
- Competency based curriculum supports research project
- Internship teams have PaCER mentors and field mentors
- Interns and graduates are supported by SCNs and PaCER research teams

May 7, 2016 Orientation for PaCER interns
<table>
<thead>
<tr>
<th>Curriculum</th>
<th>Competence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Apply theory to learning and practice</td>
<td>Apply engagement, health promotion, and salutogenic theory lens to research literature and their practice</td>
</tr>
<tr>
<td>Supervised labs in research skills</td>
<td>• Participatory grounded theory methods: data, open and selective coding, memoing, theory development</td>
</tr>
<tr>
<td></td>
<td>• Participant observation: Observation, process recording, and reporting</td>
</tr>
<tr>
<td></td>
<td>• Developing interviews and demonstrating interviewing skills; taping and transcribing, coding and reporting</td>
</tr>
<tr>
<td></td>
<td>• Focus groups: recruiting, facilitating, process recording, flip charts as data, co-analysis, consensus building</td>
</tr>
<tr>
<td></td>
<td>• Narrative research: peer-to-peer interviewing, stories as units of analysis, interpretation and scripts for action, reporting collective narratives</td>
</tr>
<tr>
<td>Co-design of research proposal</td>
<td>• National ethics course and PaCER ethics of engagement</td>
</tr>
<tr>
<td></td>
<td>• Co-design of stages of engagement research protocol: agenda setting, methods, recruiting, data collection, analysis, dissemination and implementation.</td>
</tr>
<tr>
<td></td>
<td>• Write research proposal and protocol for approval by university ethics board and related SCNs</td>
</tr>
<tr>
<td>Conduct ethics approved research</td>
<td>• Timelines, budgets, project management of project team</td>
</tr>
<tr>
<td></td>
<td>• Preparing logistics of the research</td>
</tr>
<tr>
<td></td>
<td>• Recruitment, preparation, engagement strategies</td>
</tr>
<tr>
<td></td>
<td>• Iterative data collection, transcription, co-analysis</td>
</tr>
<tr>
<td></td>
<td>• Report writing, sharing and publication</td>
</tr>
<tr>
<td></td>
<td>• Implementation strategies</td>
</tr>
</tbody>
</table>
2015 Internship projects completed

- Young women with Chest Pain in ER
- Patient involvement in developing a comprehensive clinic
- Early symptoms of Mental Illness
- First Signs of Stroke
- Investing in patients
- Couples managing chronic health concerns at home.
PaCER Research Method: the foundation

A Participatory grounded theory method for Engaging Patients in Research

Workshop

Four to Five Tables tasting PaCER research

1. SET As a co design team, experience what it is like to test drives the method and advise on language, methods, scope

2. DATA Collection: Look at data collected using four basic data collection methods,

3. DATA analysis: Look at co analysis as part of iterative analysis used in grounded theory

4. REFLECT: experience the emergence of working theory by working with analyzed themes.

5. IMPLEMENTATION; explore how patient research impacts implementation.
Contact

Dr. Nancy Marlett
PaCER Director
www.pacerinnovates.com
pacergroup@ucalgary.ca
1 403 220 5657

Thank you, and looking forward to sharing ideas