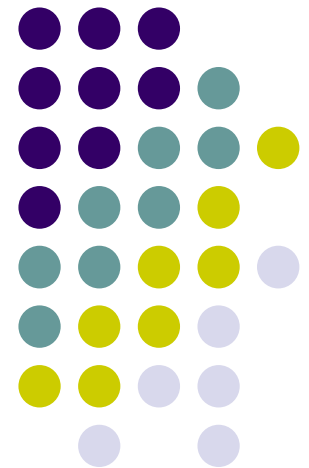


Patient and Community Engagement Research (PaCER): A Social Innovation Investing in the Science of Engagement

**Presented by: Deborah A. Marshall, PhD
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University of Calgary**

CAPT Panel Session 6
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UNIVERSITY OF CALGARY
O'Brien Institute for Public Health



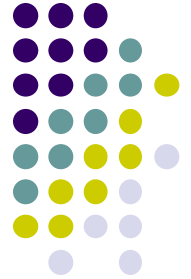
Canada Research Chair Program





Overview

1. Description and Evolution of PaCER
2. Example of PaCER project
3. Preliminary Assessment of Impact
4. Successes, Challenges and Myths



PaCER:
PATIENT AND COMMUNITY
ENGAGEMENT RESEARCH
PACERINNOVATES.CA

A Bit of History: How it all began?

Pilot project, 2011 – 2013

Patients Matter: Engaging Patients as Collaborators to Improve Osteoarthritis (OA) Care in Alberta

- ✓ Funded by *the Canadian Foundation for Healthcare Improvement (CFHI) [formerly CHSRF]*
- ✓ *Research Team Members: Nancy Marlett, Deborah Marshall, Tracy Wasylak, Tom Noseworthy, Svetlana Shklarov*
- ✓ Partnership with ***Alberta Health Services Strategic Clinical Networks***, Research teams, Health Care Providers, patient and community health organizations and patients.



Facilitating Factors

Contributing to PaCER Success

- Alberta Strategic Clinical Networks™, a Health system resource responsible for transformation of healthcare for a single health authority, willing to invest in patients.
- Canadian Strategies for Patient Oriented Research (SPOR) to increase research options and patient engagement
- Three ongoing partners: Health Care; Health Research and Patient Capacity Building
- Research curriculum and inquiry method of engagement that created an engaged team

Patient and Community Engagement Research (PaCER)

Patient and community engagement researchers (PaCERs) are people with various health conditions, trained to design and conduct health research, using specific adapted methods of qualitative inquiry.

PaCER graduates work in collaboration with health professionals and researchers to:



PaCER Objectives

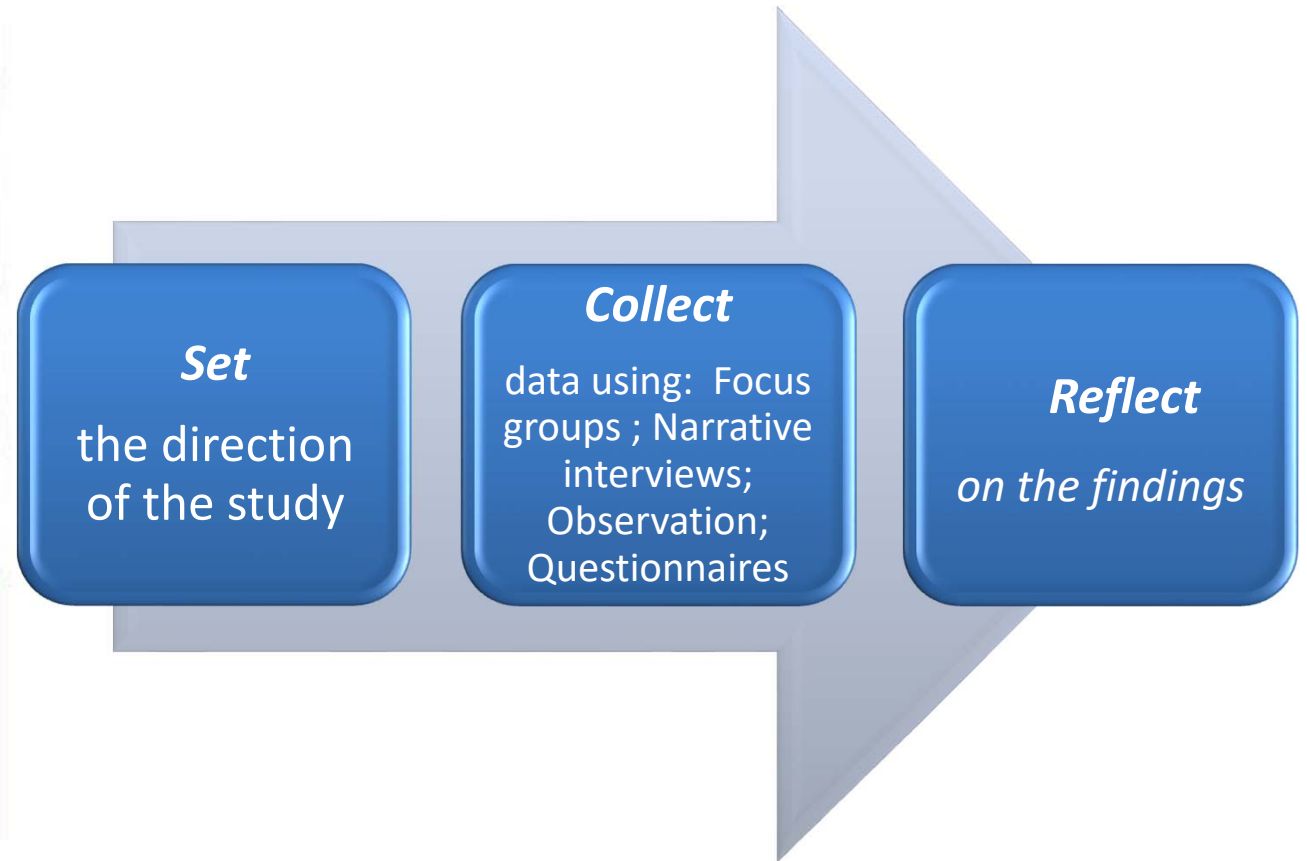
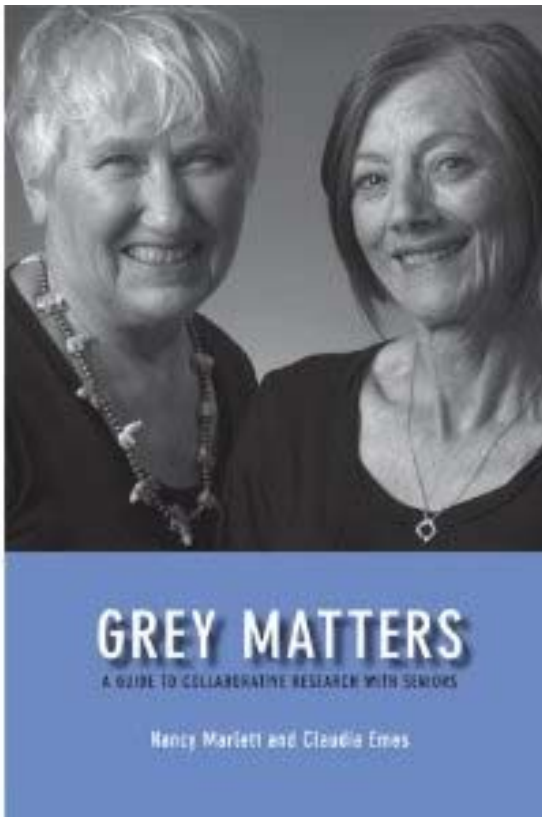
- Bring patient perspectives to the search for sustainable and effective health care
- Reframe the role of “patient” as a key stake holder in health care and research colleague
- Promote engagement in personal health and health care
- Improve the interface between patients and the health care system 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 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.

The PACER Research Method

A Collaborative Framework for Engaging Patients in Research



- N Marlett and C Emes. *Grey Matters. A Guide to Collaborative Research with Seniors.* University of Calgary Press, 2010.

How does Patient Engagement Research differ from more traditional methods?

Patients are ***fully engaged in:***

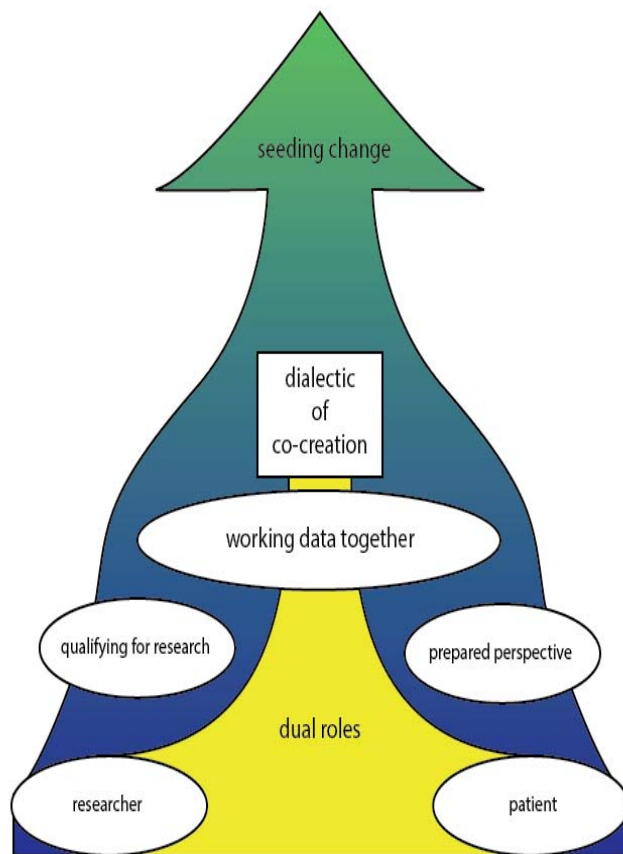
- Choosing research questions important to patients and their families and communities.
- Making decisions about how to collect and analyze information.
- Making decisions on how to communicate findings to other patients, professionals and the public.

Rigorous training involves mastering specific adapted methods of qualitative research: focus groups, field observation, questionnaires, and narrative interviewing.

A year-long training program =

120 hours in-class instruction plus an internship.

“Part of the Team”: Building New Patient Roles and Relationships in Health Research and Planning



Model: Co-creation of PACER role as a ‘Twin Innovation’

Results: 3 major areas of impact:

- 1) increased capacity of patients to engage in healthcare research and planning,
- 2) New roles for patients in health care planning – impacting attitudes and practices
- 3) New, collaborative roles for patients in research.

Interpretation: Fundamental cultural change, and a way to embed and measure patient value.

- Marlett N, Shklarov S, Marshall DA, et al. Building New Relationships in Research: A Model of Patient Engagement Research. *Qual Life Res* 2015;24(5):1057-67.
- Shklarov S, Marshall DA, Wasylak T, Marlett NJ. “Part of the Team”: Mapping the outcomes of training patients for new roles in health research and planning. *Health Expectations*, 2017;00:1-9

PaCER Project Example: Arthritis Models of Care

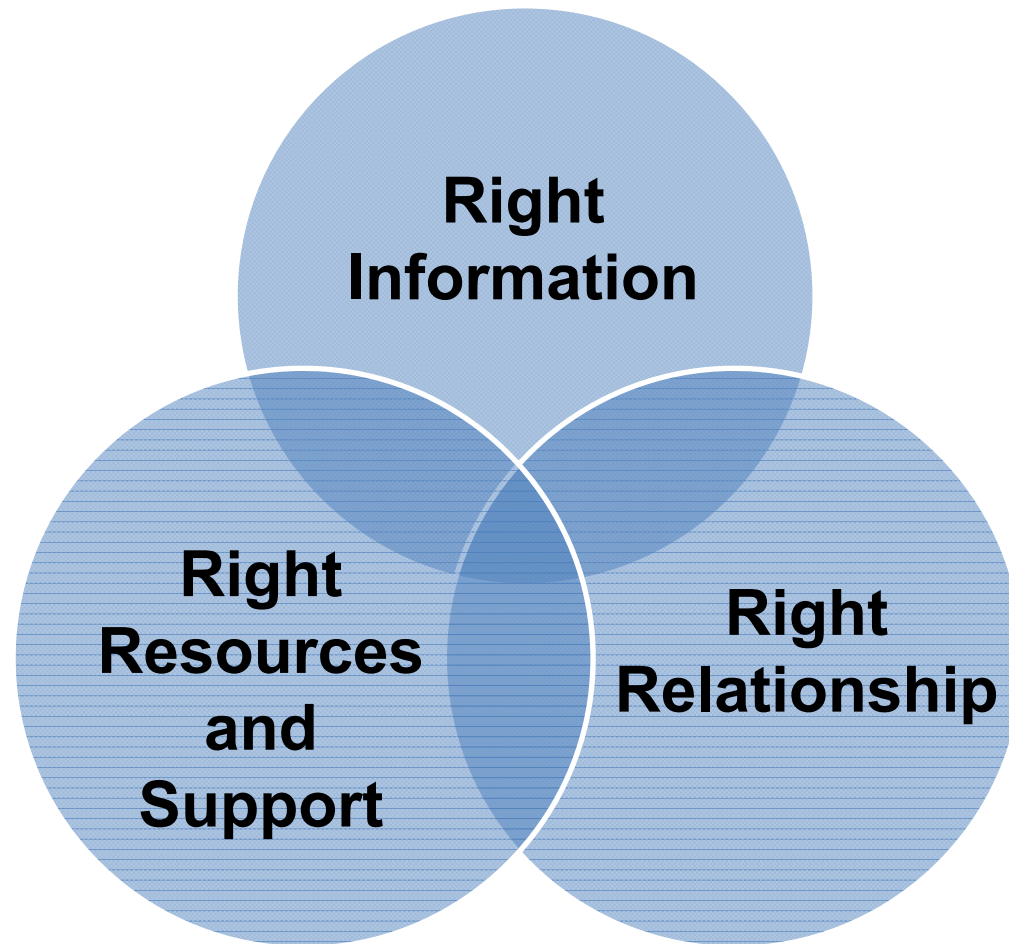


Purpose :

- Gather patients' perspectives on what quality-of-care means and
- Identify services and supports patients need and find most useful

- Partnership for Research and Innovation in the Health System (PRIHS) grant: Optimizing Centralized Intake to Improve Arthritis Care for Albertans (Funded by: Alberta Innovates Health Solutions and Arthritis Society Models of Care)

Three Components of Quality Care for People with Osteoarthritis

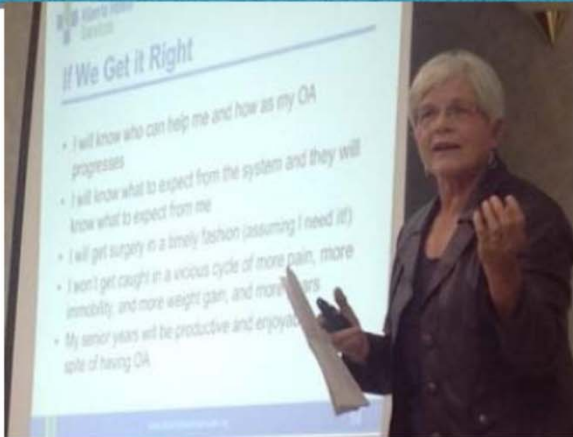


- Miller JL, Teare SR, Marlett N, Shklarov S, Marshall DA. Support for living a meaningful life with osteoarthritis: A patient-to-patient research study. *The Patient* Oct 2016; 9(5): 457-64.

Quality Care for Patients with OA Means...

- access to comprehensive, detailed and 'no-nonsense' information
- a personalized and evolving self-management plan
- access to evidence based information and OA expertise
- a collaborative ongoing relationship with health professionals
- greater access to system funded supports
- a system that recognizes the contributions of non-traditional supports

Are you interested in health research?



Are you a patient, caregiver or family?

Do you want physicians to understand
the experiences and expectations of patients and families?

Become a Patient Engagement Researcher.

Join the Patient and Community Engagement Research (PaCER) Program,
a free training program for patients
who want to be engaged in health research.

- Learn the methods of peer-to-peer research to bring forward patient experiences
- Acquire skills to design and conduct research about patient experience
- Gain career-based opportunities in health research
- Share the knowledge gained from research with patients and researchers



PaCER: PRELIMINARY ASSESSMENT OF IMPACT

- Canadian Academy of Health Sciences. *Making an Impact: A Preferred Framework and Indicators to Measure Returns on Investment in Health Research*. Ottawa, ON 2009

Early Impact of PaCER: Canadian Academy of Health Sciences Assessment Framework (1)



Advancing Knowledge

- Credit options for graduate and undergraduate students who meet the requirements: 2 faculties have used internship for credit.
- Over 150 presentations locally, provincially, nationally & internationally
- 12 peer-reviewed scientific publications, and 6 in preparation for submission
- 150 curriculum units in 17 topics of instruction related to patient engagement and engagement research
- Theoretical advancement of Patient Oriented Research Methods, Quality of Life, Salutogenesis, Grounded theory, Qualitative Health research, Engagement theory

- Wasylak T, Marshall DA, Shklarov S, McCarron T, Marlett NJ. Catalyst for change: A case study of two innovations in health transformation. Under review.

Early Impact of PaCER (2)



Building Capacity

- 42 Patients trained to work in research, advising, new patient leadership roles
- Internship base of sponsored teams, distance education pilot complete.
- Growing in number of PaCER research contracts, e.g. 18 research contracts
- Individual short term contracts are leading to ongoing research partnerships with research and quality improvement.
- New patient roles in health care based on engagement and research expertise, e.g patient navigators and coordinators
- Active social media
- Developing Patient Engagement Training programs with CIHR SPOR

Informing Decision Making

- 19 PaCERs embedded across 13 SCNs
- 15 employed by PaCER as research leads or assistants
- PaCERs on provincial and national committees e.g.CIHR SPOR

Health Impacts

- Implementation plans with 4 major health initiatives.

Socioeconomic impacts

- Anticipated, but too early to assess these impacts.

Sample of Patient Experience Research Projects



- Bone and Joint research (6 research studies)
- Surgery (ERAS, Safe surgery checklist, wait times)
- 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
- Aboriginal Rheumatoid arthritis care

Selected PaCER Publications



- Biondo PD, Kalia R, Khan RA, Boulton D, Marlett N, Shklarov S, Simon JE. Understanding advance care planning within South Asian communities. Health Expectations. 2016 (In press)
- Gill M, Bagshaw SM, McKenzie E, Oxland P, Oswell D, Boulton D, Niven DJ, Potestio M, Shklarov S, Marlett N, Stelfox HT. Patient researchers: An innovative approach to engage patients and families to identify priorities for improving critical care. BMJ. 2016 (In press)
- Miller JL, Teare SR, Marlett N, Shklarov S, Marshall DA. Support for living a meaningful life with osteoarthritis: A patient-to-patient research study. The Patient Oct 2016; 9(5): 457-64
- Haywood K, Brett J, Salek S, Marlett N, Penman C, Shklarov S, Norris C, Santana MJ, Staniszezwska S. Patient and public engagement in health-related quality of life and patient-reported outcomes research: What's important and why should we care? Quality of Life Research 2015 May. 24(5):1069-76
- Stelfox H, Gill M, McKenzie E, Oxland P, Boulton D, Oswell D, Shklarov S, Bagshaw S. Patient and family member researchers in the ICU. Critical Care Medicine 2015 December. 43(12):141
- Marlett N, Shklarov S, Marshall DA, Santana MJ, Wasylak T. Building New Relationships in Research: A Model of Patient Engagement Research. Qual Life Res 2015 May. 24(5): 1057-67
- Marlett NJ, Shklarov S. Interdisciplinary relationships and approaches in community mental health. International Journal of Disability, Community and Rehabilitation 2007. 6(2):2-7

Successes, Challenges and Myths

Successes	Challenges	Myths
<ol style="list-style-type: none">1. It is possible to engage patients as true part of the team2. Preliminary indications that we can transform the health system so it is more patient centered	<ol style="list-style-type: none">1. Overcoming traditional perspectives2. Doing things differently3. Payment for patients4. Capacity and Skills to Train5. Funding and Sustainability	<ol style="list-style-type: none">1. Engaging patients is easy2. All patients want to be engaged3. Everyone else on your team will support this idea

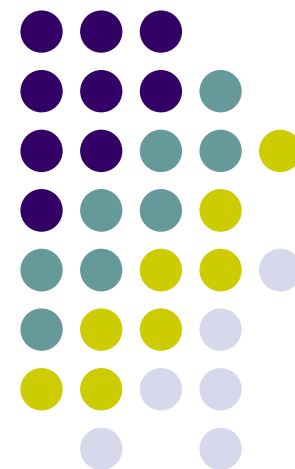
Acknowledgements

Thank You!

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SPOR IMAGINE Team



Questions?



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