



UNIVERSITY OF CALGARY  
CUMMING SCHOOL OF MEDICINE



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O'Brien Institute for Public Health



# Hidden Pathways Study: Enriching PROMs and PREMs?

*PaCER (Patient and Community Engagement Research) Program,  
Cumming School of Medicine, University of Calgary*

[www.pacerinnovates.ca](http://www.pacerinnovates.ca)

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*Measuring Patient Centered Care: PROMs and PREMs  
W21C Forum, U of C, November 28, 2014*

# Disclosure of Potential Conflicts of Interest

**The authors have no involvement with industry and cannot identify any potential conflict of interest.**

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# Definition: The Concept of 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:* patient-led, peer-to-peer research.



# Training – Internship in PaCER



- ✓ One-year training
- ✓ Weekly full-day sessions = 120 hours – *theory and method*
- ✓ Internship = 120 hours – *conducting research*
- ✓ Mastering skills: 1) *focus groups*, 2) *structured interviews & questionnaires*, 3) *narrative interview*, 4) *participant observation*



PACER class 2013,  
and a PACER graduate in Ottawa, 2014



# How do we conduct research?

*How does PaCER differ from more traditional methods?*

The simple answer is that patients are *fully engaged in all stages of research*:





## GREY MATTERS

A GUIDE TO COLLABORATIVE RESEARCH WITH SENIORS

Nancy Marietti and Claudia Ennes

### ***SET***

set the direction  
of the study  
together with  
participants

### ***COLLECT***

collect and  
analyse data:  
field work,  
focus groups,  
narratives, or  
questionnaires

### ***REFLECT***

reflect on  
findings  
together with  
participants

# Methodology

## Patient Engagement Research



# The Hidden Pathways of Chronic Illness

*(a PaCER internship research study, 2013)*

## PaCER Team:

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# The Hidden Pathways of Chronic Illness

## ✓ Research question:

*How do patients make sense of living through chronic illness?*

## ✓ Study objective:

*Conceptualize and share what patients learn through their experience with chronic illness, and expand the clinical understanding of patients' pathways with chronic illness.*



# Sample and Data Collection

**22 participants**

50 to 81 years old, with one or more chronic illnesses

*(Crohn's disease, diabetes, kidney disease, lung problems, COPD, rheumatoid arthritis, a thyroid condition, neuropathy, Parkinson's disease, scleroderma, chronic leukemia and other cancers, lupus, heart disease, allergies and asthma, and insomnia)*

**2 focus groups, in the beginning and at the end**

**7 narrative interviews**

**Using creative expression (“mind maps”)**



# Findings

**Six paths: hidden destinations that are not seen from the clinical pathway**

The paths are not consecutive stages. They are highly individual and can be retraced, interrupted and re-experienced:

1. Finding Yourself in an Alien Land
2. Searching for Answers as a Way Out
3. Finding You are on Your Own
4. Searching for Meaning
5. Presenting Your New Self
6. Understanding You are Your Own Boss



# Alien Land

The shock of losing the life that you want

## *What just Happened?*

*“Life proceeded as normal and then one day a huge, foreign landscape was before them. The future looks bleak and the situation impossible to understand.”*

*“[I feared] anger would grasp me and I could easily get stuck in my box.”*

*“I can hope that I will not die feeling this way.”*



# Searching For Answers

Searching for answers & solutions: exercise, diet,  
alternative treatments

## Where is the way out?

*"[We] were like shoppers in a market place ... searching for something that would be an answer to pain or anger or fear. For some ... the answers did help to ease the pain and anger and fear, but the disease did not go away."*

*"My long days in hospital were spent trying to understand this beast that was in front of us. I was convinced that if we educated ourselves about our opponent, we would outsmart him."*

*"Getting to know the disease ... – fears are dispelled by education."*



# On Your Own

This is now me, my responsibility

*Am I on my own, is it all up to me now?*

*“This illness is my journey, now that I am on my own. I will be my own counselor and take it into my own hands.”*

*“I needed to come up with my own plan ... and do a lot of research. .” “You have to decide how you're going to feel about stuff and walk down that path.”*



# Searching For Meaning

Developing new priorities, values, personal meaning

## *What do I want to do in my life now?*

*"Too often we are overly focused on us. Helping and working with others ... gets us out moving, thinking and contributing to a more dynamic self."*

*"When you do the things you love to do, there's a healing process ... [you can] and make the most of that day."*

*"In spite of my own issues and chronic illness, I can still be productive and worthy."*





# Presenting A New Self

Integrating illness with your new self for others

*Which hat do I need to wear for you?*

*"I started to see my new self through other people's eyes and adjusted my persona depending on the situation and the people in it. I took one approach with medical personnel and another with family, friends and employers."*

*"I go to counselling ... for advice on how to deal with other people. Because very often it's not how I deal with my disease, it's how other people deal with my disease."*

*"But it is a bit like learning to be a chameleon. You may have to learn not to speak about your illness with some and hide it from others."*



# Not the Boss of Me

Sharing leadership of your healthcare with your team

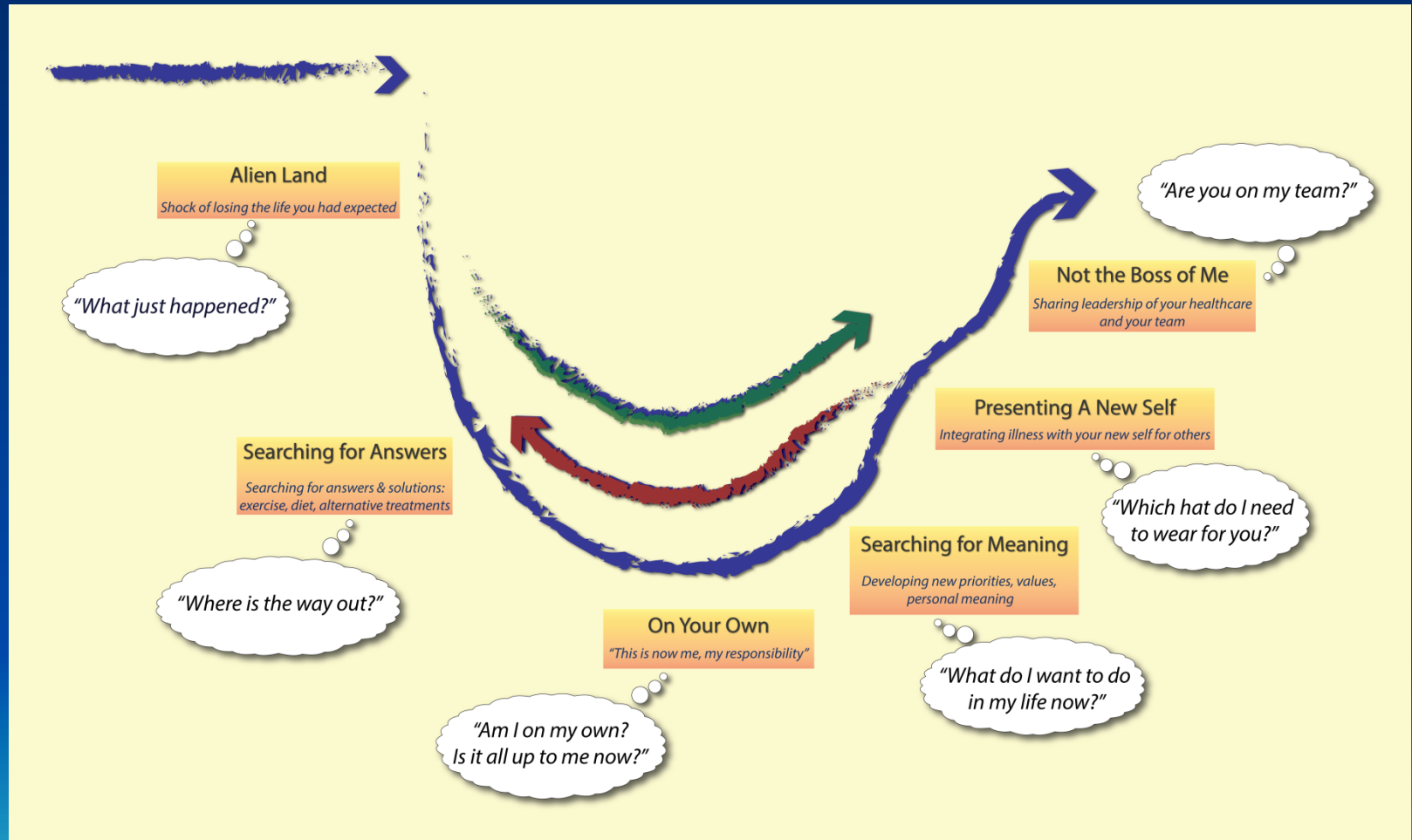
## Are you on my team?

*"I am the expert of me. [I told my doctor], You do not understand! You aren't dealing with the illness. We need to explain what we deal with on a daily basis."*

*"It is really important to take charge of your own treatment. They [health care providers] are not always right. ... We know our own bodies better than somebody sitting on the other side of the table. ... Learn to listen to your body."*



# The Hidden Pathways of Chronic Illness



## ***Conclusion:***

### **Will PaCER help enrich PROMs and PREMs?**

- ❑ This study ***uncovered specific pathways*** of patients' active engagement in seeking wellness and health.
- ❑ These experiences are represented effectively ***through valid patient-led, peer-to-peer research*** – conceptualizing patient collective voice.
- ❑ ***A simple and universal method*** that can be applied to any patient experiences and outcome analysis, in multiple health areas.

