

Building Partnerships to Improve Care of Early Knee Osteoarthritis Patients: Co-developing a Risk Management Tool

# A funny thing happened on the way to an app

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# PROJECT TEAM

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## Research Team

- **University of Calgary:** Deborah Marshall, Benham Sharif, Brittany Shewchuk
- **Patient and Community Engagement Research Program (PaCER):** Sylvia Teare, Jo Miller, Nancy Marlett
- **Enhancing Alberta Primary Care Research Networks (EnACT):** Lee Green, Tanya Barber



## Collaborators

- **Arthritis Research Canada:** Jolanda Cibere, Linda Li, Jacek Kopec
- **Alberta Bone and Joint Health Institute:** Chris Smith
- **University of Alberta:** Dr. Denise Campbell-Scherer
- **Alberta Health Services:** Tracy Wasylak, Kelly Mrklas, Peter Faris
- **Tactica Interactive:** Kevin Glasier, Michael Coutts, Bryce McEwan, Robin Hillman, Chris Lacey



# Presenter Disclosure

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## **Presenters:**

- Jean Miller
- Sylvia Teare
- Lee Green

## **Conflicts of interest:**

*We have no relationships to declare that may introduce potential bias and/or conflict of interest*

# Acknowledgements

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Sincere thanks to the 4 patients and 5 family physicians who were involved in all stages of this project including the three co-design sessions

Thanks to Toward Optimized Practice (TOP)

# A Knowledge Translation Study

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## **The Issue:**

There is a gap between what health professionals know about the risk for and management of knee osteoarthritis

**and**

the use of that knowledge with patients

## **Study Objective**

To develop a quantitative measure of clear expected outcomes of OA and promote self-management strategies to slow OA progression

# Objectives of this Session

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- 1) Understand the value of co-design in developing an eHealth tool (app) for patients with knee OA
- 2) Understand how the voices of patients and family physicians changed the study from a risk prediction tool to one that supports patient/family physician communication and patient self-management
- 3) See the juxtaposition between family physician mental models of knee OA and patients' identified needs

# Presentation Overview

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- Overview of research that informed the direction of this co-design study
- Description of the co-design process used to develop the e-health tool
- Discussion of the juxtaposition between family physicians' and patients' views of knee OA

## It all began with.....

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- Behnam Sharif's risk prediction research that was based on Jolanda Cibere's data from the University of British Columbia
- Patients from Patient and Community Engagement Research (PaCER) and family physicians from EnACT invited to an early proposal development meeting

Findings from related studies were discussed:

- Risk prediction for severity of knee OA
- Family physician Cognitive Task Analysis
- Patient-to-patient research on self-managing OA



# Quantitative Prediction Research

## ***Objective of the Quantitative Research***

**The goal:** develop a risk calculator to predict the severity of knee osteoarthritis (OA) in 7 years using patient's symptoms.

**With a plan:** to develop a web-based risk calculator for physicians

## ***Methods and Results***

Used the Vancouver Longitudinal Study of Early Knee OA (VASEKO), a 7-year dataset on 122 knee OA (KOA) subjects (*Cibere et al. Arthritis Care Res (Hoboken). 2010;62(12):1691–1698*)

Identified predictors for the progression of KOA:

- Age
- Sex
- Body Mass Index
- Stiffness severity and Pain location

Sharif, B., Marshall, D., Faris, P., Kopec, J., Guermazi, A., Sayre, E., Cibere, J. Development of Predictive Models for 7-year Whole-joint Multi-feature MRI score among a Population-based Early Knee Osteoarthritis Cohort: Results from the Valesko Study. *Osteoarthritis and Cartilage*, April 2017 (25-81): S294-95.

# EnACt Research



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## Part 1: Critical Decision Method CTA with 3 FPs

- *Mental model* of knee pain: KOA vs other
- Patient expectations
- Risk calculator: “meh”

## Part 2: CDM with 4 FPs

- Intentional sampling
  - “early majority” FPs – not keepers or OA experts
  - Gender, age, and urban-rural distribution
- Mental model of KOA specifically, in depth
  - Wear and tear
  - Not “serious disease”
  - Lifestyle factors

# PaCER

## PaCER researchers:

- are citizens with health conditions trained to design and conduct health research, using specific adapted methods of qualitative inquiry
- complete a one year program that includes theory and a student internship
- work under the guidance of the Program Director, Faculty of Medicine, University of Calgary
- work in collaboration with health professionals and researchers

## The PaCER method:

- uses a tested co-design process based on participatory grounded theory involving interactive data/analysis cycle
- is designed to create a robust collective patient voice

# PaCER Research Process

**SET** the direction for the study

**COLLECT** data using focus groups, narrative interviews, observation, & questionnaires

**REFLECT** on findings  
Patients from set and collect come together to review the findings, & make recommendations

**IMPLEMENT** with SCNs & sponsors  
Recommendations move forward to stakeholders to bring about system transformation

# PaCER Research

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**Part 1:** Two studies: experience of waiting for help with OA; what quality care means to people with OA

- 45 participants: 13 men & 32 women; age range 30s to 80s
- Method: PaCER research method
- Participants: people who self-identified as having OA

**Part 2:** To understand OA patients' experiences with their family physicians and their perspectives on a self-management tool

- Method: Semi-structured face-to-face interviews
- Participants: patients with knee pain on most days of the month in the past and any pain in the last 23 month
- 7 patients: 2 men & 3 women between age 57 and 72

# PaCER Research Findings

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As patients with OA we need our family physicians to:

- Take our OA more seriously
- Listen to what we are doing to manage our OA
- Help us find solutions that work

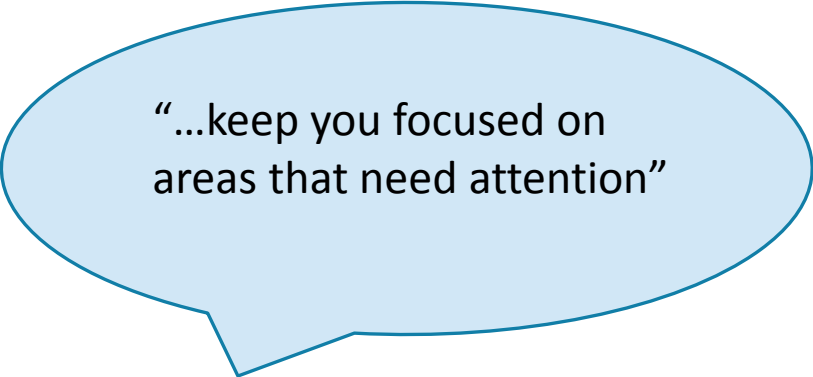
We also need:

- Access to specific information about OA progression and corresponding self-management strategies
- An ongoing partnership with our physicians that supports our self-management

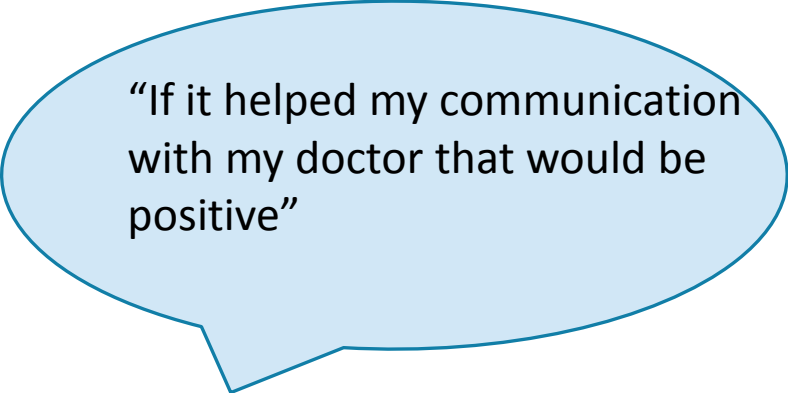
# Patients views on an eHealth tool

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- Provide access to reliable information about OA and how to manage it
- Let them enter information
- Help them monitor their progress
- Be “mutually available” to them and their physicians



“...keep you focused on areas that need attention”



“If it helped my communication with my doctor that would be positive”



**I don't know, I just feel my OA is not that important to him....compared to my heart problem**

**In terms of the global scale of medical problems OA is not the highest one on my list**


**I often talk about OA as a progressive condition, and we manage it symptom-wise as things go.**

**I've never heard about what stage I am, no one has ever mentioned that to me**

**I asked about taking turmeric and my physician told me I don't want to hear you talking about that stuff, it's not in my protocol.**

**Alternative approaches that help you function may be worthwhile, depending on the cost versus the benefit.**





**I don't keep going back as there's nothing he can do. You just learn to cope, that's really what it's about.**

**If OA isn't significantly limiting what they do then I'm happy. Usually the patient is reasonably happy, and so just carry on.**

**I find those diets, I just can't do them. I'm thinking about food all the time: it makes me crazy...because diets make me food obsessed.**

**Out of all the treatments I can offer weight loss is probably what can make a difference. But I almost don't expect patients to lose weight, because so few of them do.**

# The funny thing that happened

Goal of Original Proposal	Family Physicians & Patients Perspectives	Revised Goal
<p>Create a risk management tool that:</p> <ul style="list-style-type: none"><li>• is a quantitative measure of clear, expected course of OA</li><li>• promotes self-management strategies to slow disease progression</li></ul>	<ul style="list-style-type: none"><li>• Family physicians did not see the utility of a risk measurement tool</li><li>• Patients need specific up-to-date information and help in managing their OA</li></ul>	<p>Create a self-management tool that:</p> <ul style="list-style-type: none"><li>• includes risk prediction factors</li><li>• provides patients with evidence-based information, and planning and monitoring capabilities</li><li>• enhances patient/physician engagement for a healthier outcome</li></ul>

# The Co-Design Process

Session	Purpose	Outcome
Session 1	<ul style="list-style-type: none"><li>•What patients &amp; physicians want the app to include</li><li>•How the app would be used for patient-physician communication &amp; patient self-management</li></ul>	<ul style="list-style-type: none"><li>•A digital tool for: early diagnosis; tracking symptoms, activity &amp; red flags; weight &amp; pain management; aids, exercises &amp; resources</li></ul>
Session 2	<ul style="list-style-type: none"><li>•Develop &amp; refine features</li><li>•Assign functionalities to the features</li></ul>	<ul style="list-style-type: none"><li>•Refined features: goal setting; symptom &amp; activity tracking; red flags; pain management; reminders; summaries for patients &amp; physicians.</li></ul>

# The Co-Design Process

Session	Purpose	Outcome
Session 3	<ul style="list-style-type: none"><li>•Critically discuss the app prototype &amp; give feedback to the app developer</li><li>•Finalize app features</li><li>•achieve validity &amp; priorities using surveys &amp; voting exercises</li></ul>	<ul style="list-style-type: none"><li>•User perspectives of the importance, desirability, &amp; usability of app features</li><li>•Priorities for app feature development identified</li></ul>

## ...at the end of this project we will have a co-designed app

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- Family physicians will have OA progression risk information
- Patients will:
  - 1) have access to intervention information
  - 2) increase their capacity for self-management of their KOA
- Patients and physicians will have a platform for more productive communication

# The Challenge

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How do differences in patient and physician perspectives impact care in your setting?

How might something like an app help put patients and physicians on the same page?

How could the idea of co-design be useful in your setting?

What kind of culture change would this require?

Would the results be what you expect?

Thank you



THE KOASKTEAM