

**Consumer** action in Canadian  
Osteoarthritis research:  
*From study participants to  
knowledge transfer agents*

AAC 2015 Consumer Panel

# Our time together ....

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- ▶ Setting the stage
- ▶ Diving Deeper
- ▶ Pulling it Together
- ▶ Realizing the Dream

# Setting the stage: Diversity

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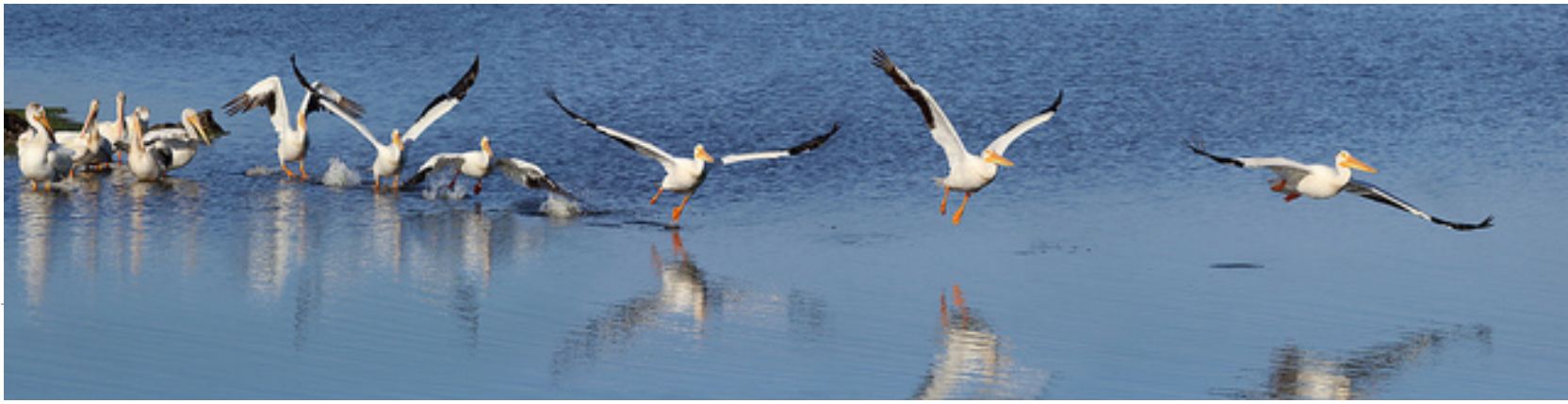
- ▶ Who are the patients?
  - ▶ 20 year old post ACL injury leading to OA
  - ▶ 80 year old with hip OA
  - ▶ 35-55 year old with IA & secondary OA



# Setting the Stage: Disease

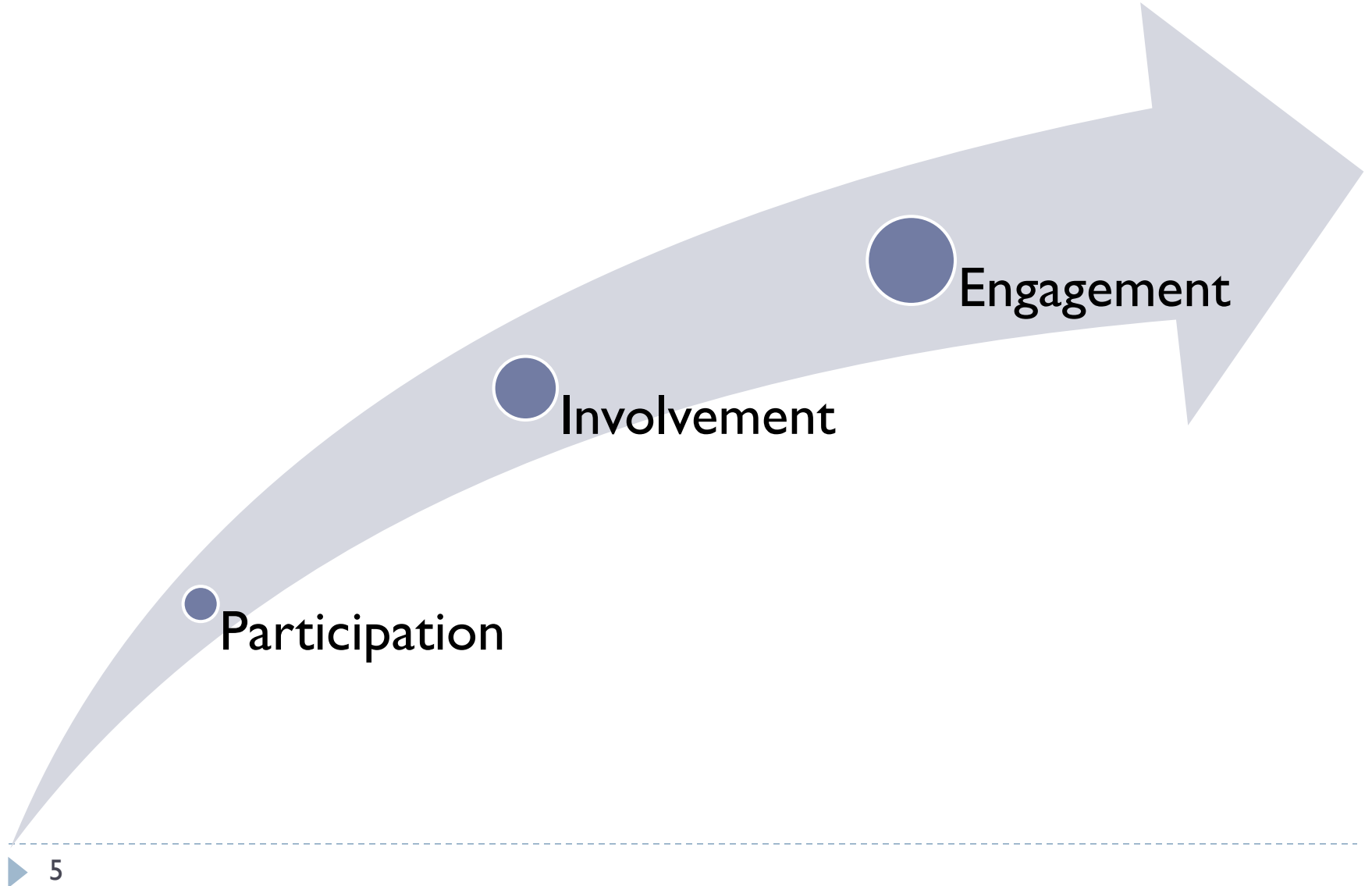
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- ▶ Consumer perspectives
  - ▶ “ I didn’t know”
  - ▶ Told: “It’s just your joints wearing out”
  - ▶ Told: “Nothing can be done”
- ▶ It’s ‘beyond the cartilage’
- ▶ It’s a disease *process*



# Setting the Stage: Definitions

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# Setting the Stage: Roles

- Translate or implement findings



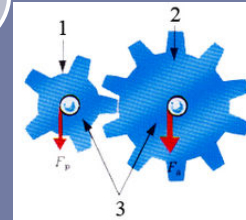
- Identify priorities & questions, inform design



- Interpret findings



- Implement study



Funding

Funding

# ‘By and With’ rather than ‘for’

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# Setting the Stage: Funding

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- ▶ OA research – the ‘poor cousin’?





# Diving Deeper

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- ▶ We are 'more' than our disease
  - ▶ **John Coderre**
    - ▶ B. Engineering, MSc (Operational Research)
    - ▶ Military Engineering Officer
    - ▶ Community Volunteer: Ontario Senior Games
    - ▶ Patient Advocate: CAN, Patient Partner in Arthritis, Can Clinic Trials Coordinating Centre
  - ▶ **Jean Miller**
    - ▶ BScN, PhD Nrsng, MA Curriculum & Instruction
    - ▶ Patient engagement researcher PaCER
    - ▶ Alberta Health Service's Bone & Joint Strategic Clinical Network Core Cmtte
    - ▶ Retired Nurse Educator
  - ▶ **Anne Fouillard**
    - ▶ OA patient over 20 years
    - ▶ Masters Environmental Management
    - ▶ International development consulting professional in 40 countries over 3 decades

# Anne Fouillard

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## ▶ Experience within the quadrants

- ▶ Co-Chair Consumer Advisory Council CAN
  - ▶ identifying priorities, questions and design of research projects
- ▶ Project peer-review teams CAN
  - ▶ Influenced research priorities & funding
- ▶ CAN, CAPA, CAS and CARE Conference
  - ▶ KTE patient advocate

## ▶ Key messages

- ▶ 1. It's not new (2007-2015)
- ▶ 2. Needs: Openness, dialogue, information, training & time (\$)
- ▶ 3. Think big picture: Facilitate arthritis friendly environment

# John Coderre

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## ▶ Experience within the quadrants

- ▶ Peer-review team: research priorities & funding
- ▶ Member: multi-year, multi-institutional project
- ▶ Organized & hosted KTE seminar for general public

## ▶ Key messages

- ▶ 1. Pts have already participated in & established value in all quadrants
- ▶ 2. Pt involvement is enhanced when training is provided
- ▶ 3. Dedicated funding to patient engagement is necessary

# Jean Miller

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- ▶ **Experience within the quadrants**
  - ▶ PaCER Program
    - ▶ partners with academic and community researchers
    - ▶ pt engagement in all quadrants:
      - design, carry out, analyse & interpret findings, make recommendations for implementation
- ▶ **Key messages**
  - ▶ 1. Start with patient priorities
  - ▶ 2. Focus research on helping pts manage their OA over time
  - ▶ 3. Push *engagement to action*

# Pulling it Together

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- ▶ Rich history to build on
- ▶ Greater focus on the diversity of the disease & on day-to-day self management
- ▶ Capitalize on the **full capacity** of patient partners
  - ▶ Don't underestimate the potential contributions e.g. Occupations / life skills / personal networks
  - ▶ Build on the learnings and activities of previous / current organizations and initiatives
- ▶ Budget accordingly
  - ▶ Consumer engagement requires funding & coordination
  - ▶ (Thanks to AAC for bringing us together in Kananaskis 😊)

# Realizing the Dream

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- ▶ **Build capacity**
  - ▶ Recruit / build champions
- ▶ **Ensure sustainability**
  - ▶ Create awareness, appetite & infrastructure
    - Pts: Seek opportunities in OA research
    - Researchers: Provide opportunities in all quadrants

