Partnerships across the Line: Arthritis research in a First Nations community

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Acknowledgements

- Tsleil-Waututh Nation
  - Community Advisory Committee
  - Research Assistants
  - Participants
  - Chief and Council
- UBC supervisory committee
- CIHR, MSFHR, APN Chair
Outline

- Background
  - Aboriginal health
  - Decolonizing research
- Arthritis in First Nations
  - What happened
  - Community perspectives
  - Lessons learned
Why Bother?

- Aboriginal health: colonization
  - Past legacy of research
    - Bad blood research
- Promising examples of how to do it right
Decolonizing Methodologies

- Past research
  - Representation of peoples (savage/noble)
  - Interpretations
  - Harvesting indigenous knowledge
  - Best intentions
    - Whose problems?
    - Whose solutions?
Decolonizing Methodologies

- Current predicament
  - Neo-colonialism
  - Health disparities
  - Culture = disease
- Boundaries
  - Researched to death
  - Only Aboriginals ought to do Aboriginal research
Decolonizing Methodologies

- Linda Tuhiwai Smith: Self determination
  - Culturally appropriate
  - non exploitive
  - empowering
  - productive
Other Guidelines

- OCAP
- CIHR
- BC ACADRE

Paradigm of inquiry: Critical
- Post colonial feminist + Aboriginal epistemology
- Two-eyed seeing
Arthritis in First Nations

- Understanding the health gap
  - Historical practices
  - Current conditions
  - The health system
    - Organization
    - Delivery
    - Utilization
Ethnographic Methods

- Researcher as instrument
- Prolonged engagement
- Reflective journaling/Fieldnotes
- PO and interviews
  - 15-25 Community members
  - 15-25 HCP
- Document analysis
Arthritis in First Nations

- Becoming known and providing service
- Community Advisory Committee
  - Memo of understanding
  - Culturally relevant; productive
- Research Assistants
  - Training
  - Empowering?
Community Perspectives

- Go little white girl go
  - Accepted and optimistic about outcomes

- What are we getting out of it?
  - Learning about arthritis (personal) and the health system (feeling like I’m not alone, chance to talk about my experiences)
  - Training about research
  - Employment
  - Research! (answers?) (improved health services?)
  - An opportunity to participate in a community program
Community Perspectives

- Margaret
  - One of first researches where there will actually be results.
  - Opens the door to better use of the system
  - People learning how to work with our own people
  - Issues of confidentiality
Community Perspectives

- Claudette
  - Personal growth
  - Interview processes
    - The benefits of our tag team approach
Community Perspectives

- Cheyenne
  - Learning to be respectful of people’s boundaries
  - Learning about the health system
Community Perspectives

- Connie
  - Emotional effects
  - Training/gaining skills
  - Support
  - This is important work
Lessons learned

- Who does the interviews?
- Interview protocols
- Who is in control?
  - Community way of life/values
- Learning and growing together
  - Takes time
- Remain open
Final thought

- The goal of this research is to learn something ‘from’ rather than ‘about’ First Nations peoples (Marker, 2003)