

Conceptualizing “patient-oriented” for population health research

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Learning Objectives

- Identify strategies to support the engagement of community members from northern BC on research teams
- Explore how (and if) principles defined in the Strategy for Patient-Oriented Research (SPOR) can be applied to population health research
- Explore the importance of multi-sector collaborative research teams and strategies to ensure productive partnerships

Disclosures

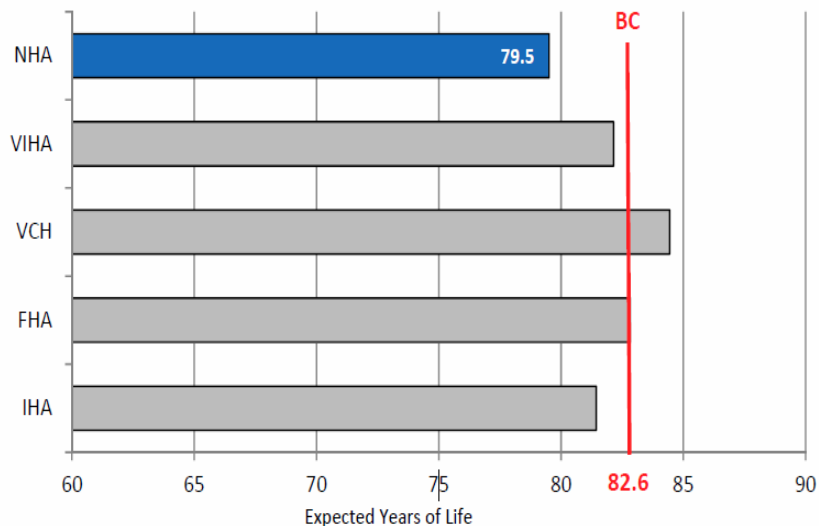
Dr. Chelsea Pelletier – Nothing to disclose.

Dr. Anne Pousette – Nothing to disclose.

Presentation Objectives

- Describe how our team of researchers, researcher-users, and community members worked together to complete this qualitative research project
- Describe the outcomes of this project which provide guidance and a framework for community-engaged research based on the perspectives of community members

Life Expectancy at Birth for BC Health Authorities 2011 - 2015

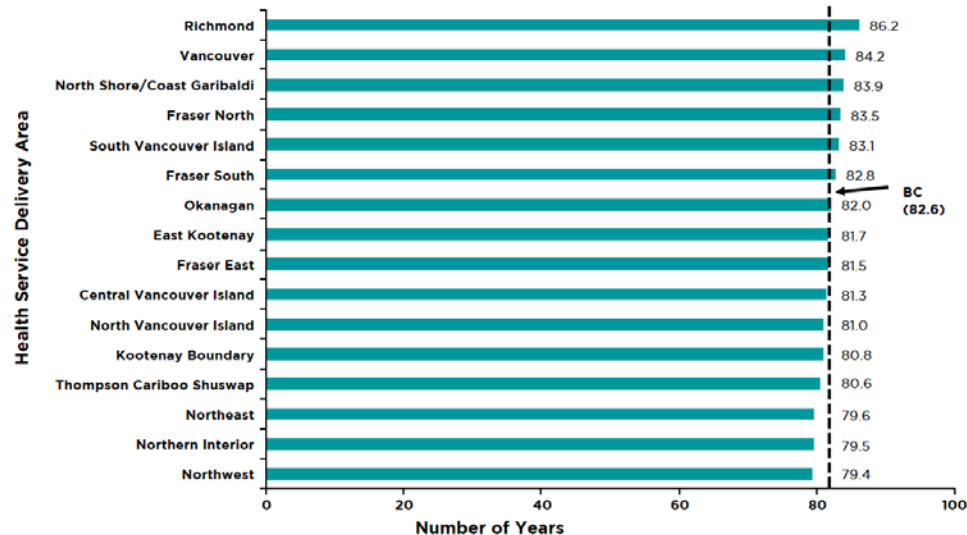


Source: BC Stats: Vital Statistics: Life Expectancy at Birth; Accessed January 6, 2017.
<http://www.bcstats.gov.bc.ca/StatisticsBySubject/Demography/VitalStatistics.aspx>

Northern Health has the lowest life expectancy of all the Health Authorities and HSDAs

How healthy are we?

FIG 2.3 Life Expectancy at Birth, by Health Service Delivery Area, BC, 2011-15



Notes: "Life expectancy" is the expected number of years of life remaining at a given age; in this case, at birth. Health service delivery area is based on the residence of the individual. See Appendix B for more information about these data sources.

Sources: BC Vital Statistics Agency (Deaths); BC Stats (Population Data). Prepared by BC Stats, June 2015; and Population Health Surveillance and Epidemiology, BC Office of the Provincial Health Officer, BC Ministry of Health, May 2017.

How do we move the north?

- Physical inactivity is one of the top-four strategies for prevention and management of noncommunicable diseases
- Population health:** an approach to health that aims to improve the health of the entire population and to reduce health inequities among population groups. In order to reach these objectives, it looks at and acts upon the broad range of factors and conditions that have a strong influence on our health (PHAC, 2012)

Noncommunicable Diseases
4 Diseases, 4 Modifiable Shared Risk Factors

	Tobacco Use	Unhealthy diets	Physical Inactivity	Harmful Use of Alcohol
Cardio-vascular				
Diabetes				
Cancer				
Chronic Respiratory				

How to include patient or community members on our team?

Physical Activity Strategy for the North

Global Action Plan (2018):

6 Guiding Principles

4 Strategic Objectives:

- 1) Create Active Societies
- 2) Create Active Environments
- 3) Create Active People
- 4) Create Active Systems

Aboriginal Sport, Recreation & Physical Activity Strategy (2009):

5 Pillars:

- 1) Active Communities
- 2) Leadership & Capacity
- 3) Excellence
- 4) System Development
- 5) Sustainability

Areas of Overlap:

- Access
- Equity
- Physical Literacy
- Life-Course Approach
- Measurement/Evaluation
 - Cultural Norms
- Supportive Environments
 - Capacity Building
 - Partnerships

Canada's Common Vision (2018):

5 Foundational Principles

6 Areas of Focus:

- 1) Cultural Norms
- 2) Spaces & Places
- 3) Public Engagement
- 4) Partnerships
- 5) Leadership & Learning
- 6) Progress

BC Physical Activity Strategy & Action Plan 1.0 (2015):

Active People:

- 1) Children & Youth
- 2) Older Adults
- 3) Indigenous Peoples

Active Places:

- 1) Communities

Strategy for Patient-Oriented Research (SPOR)

- Patient partners actively engaged in governance, priority setting, developing research questions, performing aspects of research
- Ensures research is relevant, valuable to people it impacts
 - Create sustainable, accessible, equitable health care system
- **Patient:** an overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends

SPOR – Guiding Principles

Inclusiveness

Mutual
Respect

Support

Co-Build



CIHR IRSC

Canadian Institutes of Health Research Instituts de recherche en santé du Canada

Study Objectives & Research Questions

- What does patient-oriented mean for population health research?
- What are the needs of community and patient partners to better enable participation on a research team?
 - What is the best way to engage patient and community partners in physical activity research in northern BC?

Team & Funding



- Developing Northern Research Collaborations Award, BC SUPPORT Unit Northern Centre
- Team Members
 - Chelsea Pelletier, Assistant Professor, UNBC (Researcher)
 - Kelsey Yarmish, Regional Director, Population Health Programs, Northern Health (Health System Partner)
 - Gloria Fox, Physical Activity Lead, Northern Health (Health System Partner)
 - Anne Pousette, Executive Director, Promotion of Wellness in Northern BC (Community Partner)
 - Kirsten Ward, Undergraduate Honours Student (Research Assistant)

Methods – Team Process & Engagement

- All team members completed Foundations of Patient-Oriented Research Course (<https://bcsupportunit.ca/foundations-of-por>)
- Collaboratively development of:
 - Research questions & methodology
 - Recruitment matrix
 - Interview guide
 - Analysis plan
- Used existing network for recruitment
- Interviews conducted by trained research assistant and one other team member in person or via telephone

Methods – Data Collection & Analysis

- **Community member (or “patient”):** anyone living in northern BC (defined as Northern Health Authority Region) for a period of at least 1-year and have experience engaging in their community related to physical activity and/or health research
- 12 semi-structured interviews
- Purposeful sampling based on representation targets & recruitment matrix

Methods – Data Collection & Analysis

- Inductive thematic analysis
- Coding & pattern identification completed by researcher team members (3 independent coders)
- Initial themes and categories discussed by entire team for interpretation
- Themes and sub-themes finalized and approved by entire team

Findings - Themes

Relevance

Communication

Empowering
involvement on
research team

Theme 1: Relevance

Community

Individual

- To engage partners on research teams the projects need to be relevant for individuals
 - Individuals have a vested interest based on their work (paid or volunteer) or personal interest
- Projects and outcomes are relevant to the communities
 - For individuals to want to be involved it has to have an impact in their community
 - Needs to measure or explore something that the community values and cares about
- More than personal gain or compensation, people want to be involved in things that lead to change in their community

Theme 1: Relevance

*“.....I think in order for people to commit to getting involved, y’know, they generally need **something**, some reason that they can and even sometimes just to **justify the time** if they’re working or just enough to make it worth their personal while to be involved y’know seeing the benefit or the potential” (Participant 1)*

Theme 1: Relevance

*“...there’s a much more fundamental question and that is what is the research about? I don’t think that people are going to be interested in a research question that doesn’t apply to them so people would be engaged if they could see some point to the research and see that it applies in some way to their community and might lead to a **benefit** for their community, so if it’s simply an academic kind of question that would be interesting to people in an academic setting I think it would be my sense very difficult to engage members of the community” (Participant 7)*

Theme 2: Communication

- Participants commonly stated that if they had been involved in research, they often never hear about where things go
- Discuss expectations – when and how partners would want to hear updates about the project (*retention*)
- To *recruit* partners, need to identify preferred communication mechanisms for context/community

Use existing networks &
create partnerships

Clarify expectations

Identify preferred mechanism

Theme 2: Communication

“ I think you would have to have a clear concise picture of what it is you’re looking for and then try to sell it. We don’t have a newspaper, we have a very engaged radio and council’s very engaged. So if you were looking at my community you could say this is what we’re doing, do a presentation to council, this is the research we’re looking for and we’re looking for some key community members, and then they would come to you and say here’s some names that you should check because they know the community and they have a passion....then it’s kind of a prestigious thing, council recommended me to be a part of this research...they would be able to link you to the right community members” (Participant 5)

Theme 2: Communication

“It’s just really about communication back, it has to be that there might not be anything to communicate back to be honest, but it could be a simple hey just to let you know here’s an update” (Participant 8)

*“sometimes projects are based around somebody’s research field of study and then they move on and it gets **shelved** and nothing comes of it so that part is always **disappointing**” (Participant 1)*

“...options for participating so if it’s inclement weather you can skype in that kind of thing because if you can accommodate that there are people of a certain age in smaller communities, winter sets in and they’ll drive say between Vanderhoof and Prince George when the weather is ok, but they’re not going to venture out otherwise” (Participant 9)

Theme 3: Empowering Involvement on Research Teams

- Participants are valued and appreciated as knowledge holders, the experts
 - Trust, relationship building
- Mentorship and training support
 - Clear roles and responsibilities
 - Understanding of the research process
 - Information is accessible
- Understand application of research for communities & individuals

Being valued & appreciated

Support

Application of Research

Theme 3: Empowering involvement on research teams

“being First Nations, that is always a battle that you’re fighting with research, I think a lot of research falls flat because of that is because people sort of roll their eyes and go oh my god yeah we have to have a First Nations person on it and you often want to battle that perception, you want to know that you’re there for your brain, you want to know that you’re there because you belong” (Participant 6)

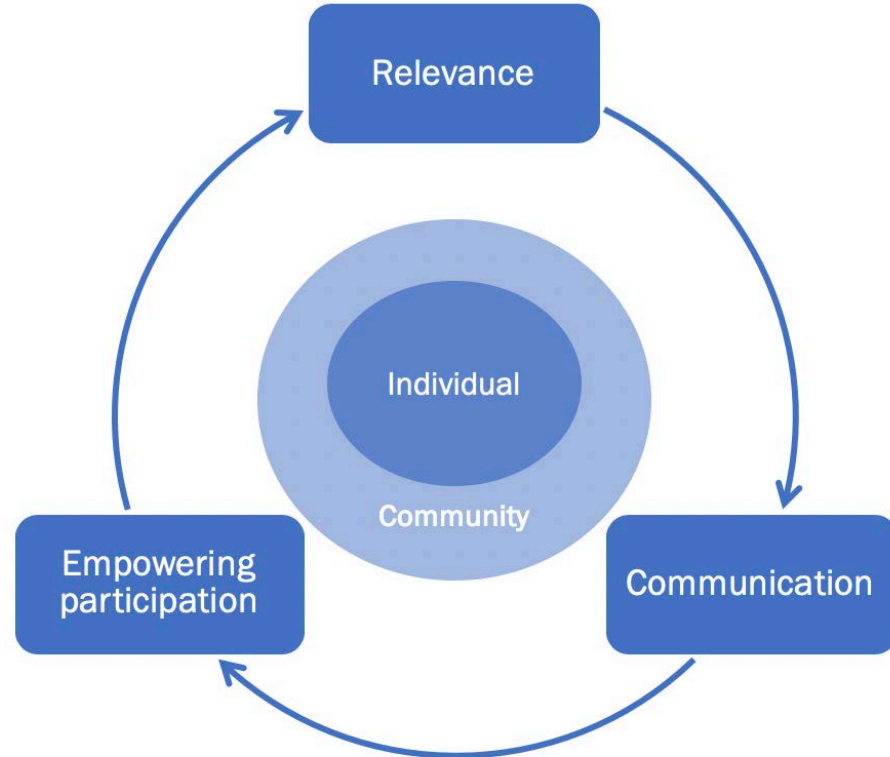
Theme 3: Empowering Involvement on Research Teams

*“for the people if they wanted to volunteer for that they might want a little bit of training and what’s going on and how the research works and stuff like that – yeah cause if they didn’t understand the process they probably wouldn’t be as likely to stick with it I imagine, so they’d need training”
(Participant 4)*

“once you get them there, appreciation keeps them there, you don’t have to pay them, you don’t have to buy them gifts but appreciate them, thank them, recognize them, that’s what keeps volunteers” (Participant 10)

How and why do we support community members in population health research?

- Research questions need to be driven by community identified issues
- Understand community needs & context
- Acknowledge that community members are the experts on their own approach
- Share results, progress
 - Ask about preferred communication mechanism



Lessons Learned & Future Directions

- Training to make sure everyone on the same page
- Communication
 - Speak the same language
- Taking the time to build relationships & trust
 - Patience
- Future directions:
 - Complete ongoing evaluation of team and engagement
 - Unpack research partnerships and collaboration
 - Meaning of physical activity for individuals and their communities



How do we best partner with community members in physical activity research in northern BC?

Increasing participation in physical activity could help improve health in northern BC. When researchers partner with community members, it helps to make research more relevant and ensures we ask the right questions. In this study we were trying to understand how to better support and work with community members from across northern BC in physical activity research.

Questions?

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WHAT DID WE DO?

To find out how to engage community members, we interviewed 12 adults, all of whom have lived in northern BC for at least 12 years. We asked participants questions and discussed health research and physical activity. We used the interview transcripts to identify main themes and guidelines.

WHAT DID WE FIND?

We found 3 main factors that are important for research partnerships:

1. The project must be **relevant** to the community and to the individuals taking part in it;
2. **Communication** between researchers and community members must be frequent, appropriate, and in a language that everyone understands;
3. Community members should be **empowered** as part of the research team through supports such as training, acknowledging and valuing their work, building strong relationships, and using the information from the project to support decision-making in the future.

WHAT IS SPOR?

The Strategy for Patient-Oriented Research (SPOR) is a way of doing research where the 'patients', or people who have personal lived experience of a particular health issue, work together with researchers to answer questions that are important to the patients and will lead to improvements in health or health care.

For more information check out:

<https://bcsupportunit.ca/>

<https://www.msfr.org/our-work/patient-oriented-research>

WHAT NOW?

We will use this information as a guide to help us better partner with community members on our research team. Our overall research goal is to *Move the North*, increasing physical activity in northern BC, which can only be achieved if we work together.

For more information contact
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Community Size (population)*	Age						
	18 - 24	25-34	35-44	45-54	55-64	65-74	75+
< 500							
500 - 1000			✓				✓
1000 - 5000				✓x2	✓		
5000 – 10,000					✓		
10,000 – 20,000							
20,000 – 29,000							✓
30, 000 – 99,000			✓x2	✓x2		✓	

Self-identified gender (male:female)

- Goal 50:50
- Will accept 30:70
- Current: 5 males, 7 females

Northern Health HSDA

- Northern Interior, 50% of sample
- Northwest, 25% of sample
- Northeast, 25% of sample
- Current: 2NE, 2NW, 7NI

Lenses

- Employment status:
 - o Parents ✓
 - o Retired ✓
 - o Working adults ✓
- Disability status ✓
- Role in community: varied
- Length of time living in northern BC all are ≥ 12 years
- Previous involvement in research: yes ✓ no ✓
- Self-identified cultural identity/ethnicity: **Canadian**, Caucasian, First Nations, several European countries
- Education: high school only ✓ some post-secondary ✓ post-graduate ✓

Theme	Subthemes	Codes
Relevance	Community	<ul style="list-style-type: none"> • Benefit and value to community • Collaborative development • Community ownership and capacity building
	Individual	<ul style="list-style-type: none"> • Vested or personal interest • Opportunity to be involved and make impact for community
Communication	Use existing networks and create partnerships	<ul style="list-style-type: none"> • Identify local champions • Partner with existing organizations already doing the work in area of interest
	Clarify expectations	<ul style="list-style-type: none"> • Define project, role, and time commitment • Share progress and findings • Ensure information is accessible
	Identify preferred mechanism	<ul style="list-style-type: none"> • Understand local norms and context • Provide communication options for participation
Empowering involvement on research team	Being valued and appreciated	<ul style="list-style-type: none"> • Acknowledgement and recognition for contribution • Trust and relationship building
	Support	<ul style="list-style-type: none"> • Mentorship and training • Maintain environment of inclusiveness • Remove barriers to participation
	Application of research	<ul style="list-style-type: none"> • Evidence to support decision making • A tool to understand options and benefits for healthy living