The Methods Clusters

In 2016, the BC SUPPORT Unit funded a five-year initiative to study the methods of patient-oriented research: the **"Methods Clusters".**

We started our work by **listening to stakeholders**—including patients, researchers, policy makers, and practitioners. Together, we identified **6 areas** where more methods research was most important. These became the **6 Clusters:**

Knowledge Translation and Implementation Science

Patient-Centered Measurement

Data Science and Health Informatics

Patient Engagement

Health Economics and Simulation Modelling

Real-World Clinical Trials

Each Cluster consulted stakeholders to discuss their **priorities** *(/themes)* for patient-oriented research. **35 priorities** surfaced.

To address these priorities, the Clusters funded **42 different projects.** All of these projects were **patient-oriented:** we **studied** patient-oriented research by **doing** patient-oriented research.

This PDF provides a snapshot of the **Health Economics and Simulation Modelling** Methods Cluster as of March 2022.

Health Economics and Simulation Modelling

Overview

Health economics is a field of study concerned with the connections between health and the resources needed to promote health (e.g., time, people, money and equipment). Because resources are limited, choices need to be made and priorities need to be identified.

By applying economic theories of demand, supply, and social choice, health economics aims to understand the behaviours of decision makers, whether that be individuals, households, health care providers, organizations or governments.

Consulting with researchers, policy makers, and practitioners, this Cluster:

- *Identified **8 themes** to focus on*
- *Funded **12 projects** to address them*

This Cluster was co-led by **David Whitehurst** and **Nick Bansback.**

Dr. Bansback was seconded to the Unit from the School of Population and Public Health at the University of British Columbia (UBC), where he is an Associate Professor. Among many affiliations, he is the Program Head of Decision Sciences at the Centre for Health Evaluation & Outcomes Sciences (CHÉOS), one of the core partner organizations of the BC SUPPORT Unit. Dr. Bansback holds a PhD in health economics from the University of Sheffield (UK), and completed his postdoctoral training at UBC. Currently a Canadian Institutes of Health Research (CIHR) New Investigator, Dr. Bansback's research is focused on using decision science to maximize the value patients and the public gain from health care.

Dr. Whitehurst was seconded to the Unit from the Faculty of Health Sciences at Simon Fraser University (SFU). He is an economist who has specialized in the areas of health and health care throughout his career. Prior to his appointment at SFU in 2012, he held research positions at UBC, and at the Universities of Birmingham and Keele in the UK. His primary research interests focus on the measurement and valuation of quality of life and well-being outcome suitable for use in economic evaluation.

Health Economics and Simulation Modelling
Navigation

Health Economics and Simulation Modelling

Projects: Overview

Most clinical researchers who come up with their ideas do ask others if it's a good idea... but the trouble is they ask other clinicians, and not potential patients. So, we asked patients. What did they want from their treatments?

What are the social value judgements involved in building health economic models?
This project interviewed 22 health economists to find out.

How do we decide how our health dollars are spent? A team of researchers, patient partners, and filmmakers sought to start a conversation about this.

This project explored how Patient-Reported Outcome Measures (PROMs) data could improve patients' adherence to falls prevention recommendations, revealing key considerations including communication, feedback, and patient self-awareness.

Measuring **Out-Of-Pocket Costs** for Rural Patients Accessing Surgical Services in BC
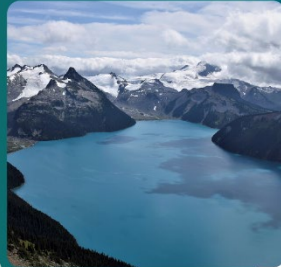
Health Economics & Simulation Modelling Methods Cluster

What are the out-of-pocket costs for rural BC patients seeking health care outside their home community— and how can we measure these costs?
This project found key costs relating to transport, accommodation, wages, and child/animal care.

Can **Natural Language Processing** Estimate Patient Preferences Directly from Patient-Generated Text?

Health Economics & Simulation Modelling Methods Cluster

This project developed a software tool that makes it easier do "social media listening", an emerging approach to analyzing patient experiences and patient preferences that applies text analysis techniques to social media conversations.

How to do Patient Engagement in **Rapid-Cycle** Health Technology Assessments **(HTA)**
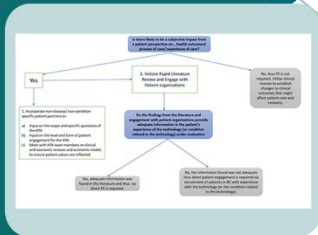
Health Economics & Simulation Modelling Methods Cluster

This project developed a detailed tool, in the form of a series of questions, to guide a research team on how, when, and where members of the public can best be engaged in health technology assessments.

Incorporating patient preferences and values into the **design and evaluation of technologies**

Health Economics & Simulation Modelling Methods Cluster

This project designed and tested a Discrete Choice Experiment to measure patient preferences about different aspects of preventative therapies for COPD (Chronic Obstructive Pulmonary Disease).

Measuring work productivity losses in patients and caregivers

Health Economics & Simulation Modelling Methods Cluster

How do we measure work productivity losses in people with health problems—and their caregivers?
This study adapted and validated the "Valuation of Lost Productivity" (VOLP) for use by caregivers.

You talk, we listen
Gathering rural and remote communities' knowledge and experiences in health care decision making

Health Economics & Simulation Modelling Methods Cluster

Efficient health resource allocation in BC needs more input from rural and remote communities.
This project aimed to establish a connection between health economists, mostly from the Lower Mainland, & rural/remote BC communities.

The Peer Models Network
A Novel Mechanism to Support Transformative Model Interrogation in Patient-Oriented Health Economics
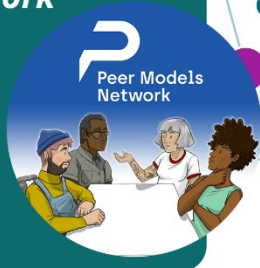
Health Economics & Simulation Modelling Methods Cluster

More and more, healthcare decisions are being informed by scientific computer models. The Peer Models Network is passionate about computer modelling—and passionate about engaging patients and members of the public!

Advancing the Methods for Using Routinely Collected Health Data
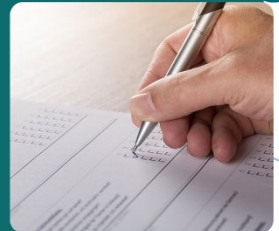
Health Economics & Simulation Modelling Methods Cluster

This project developed guidelines on how we can use routinely collected health data (e.g., administrative data; PROMs) to conduct economic analyses, and investigated the costs and needs of high-cost, high-need patients.

Health Economics and Simulation Modelling

Themes

Each Cluster consulted stakeholders to discuss their priorities for patient-oriented research. The Health Economics and Simulation Modelling Methods Cluster identified **8 themes** for potential projects.

This Cluster then funded **12 projects** based on these priorities.
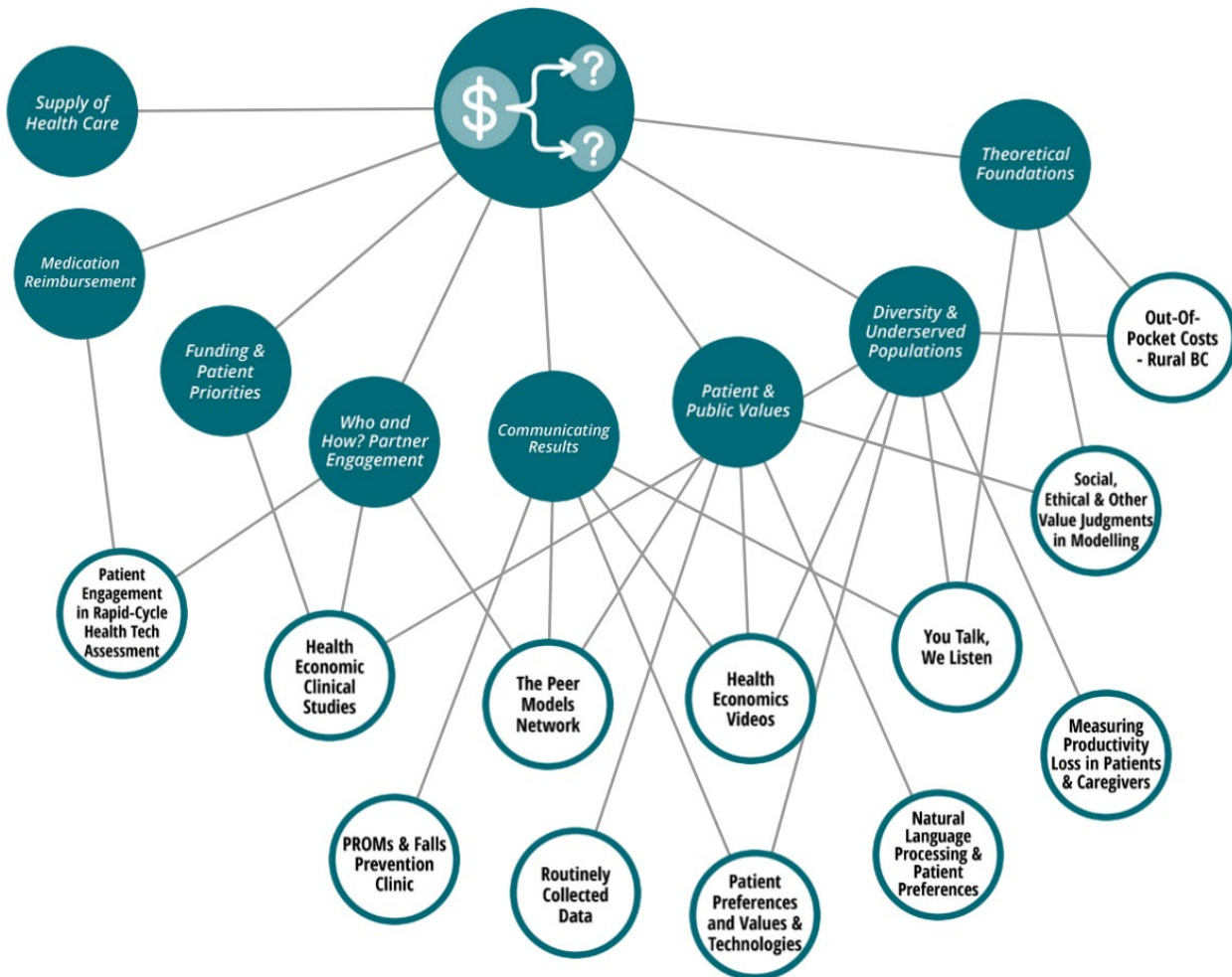
This diagram shows the connections between the priorities (solid teal) and projects (teal outline) of the Health Economics and Social Modelling Methods Cluster. A list of the Cluster's priorities, and projects they funded based on them, is below.

Aligning research funding with patient priorities

The project that addressed this priority was:

- *Using health economic methods to design clinical studies*

Communicating results

The projects that addressed this priority were:

- *You talk, we listen: advancing health economics methods for rural and remote health research by gathering local communities' knowledge and experiences in health care decision making*
- *The Peer Models Network: a novel mechanism to support transformative model interrogation in patient-oriented health economics*
- *Examining the utility of educational videos for increasing knowledge and enhancing the experiences of patient partners in health economics research*
- *Can patient preferences and values be objectively incorporated into the design and evaluation of technologies? A conceptual framework and a proof-of-concept study*
- *Using patient-reported outcome measures (PROMs) to support adherence to falls prevention clinic*

Diversity and underserved populations

The projects that addressed this priority were:

- *You talk, we listen: advancing health economics methods for rural and remote health research by gathering local communities' knowledge and experiences in health care decision making*
- *The development and pilot-testing of an instrument to measure out-of-pocket costs for rural patients accessing surgical services in British Columbia*
- *Examining the utility of educational videos for increasing knowledge and enhancing the experiences of patient partners in health economics research*
- *Using health economic methods to design clinical studies*
- *Improving the methods to measure work productivity losses in patients and caregivers*
- *can patient preferences and values be objectively incorporated into the design and evaluation of technologies? a conceptual framework and a proof-of-concept study*

Medication reimbursement

The project that addressed this priority was:

- *How to do patient engagement in rapid-cycle HTA*

Patient and public values in research
The projects that addressed this priority were:
- *Advancing the methods for using routinely collected health data*
- *The Peer Models Network: a novel mechanism to support transformative model interrogation in patient-oriented health economics*
- *Can natural language processing estimate patient preferences?*
- *Examining the utility of educational videos for increasing knowledge and enhancing the experiences of patient partners in health economics research*
- *Social, ethical, and other value judgments in health economics modelling*
- *Using patient-reported outcome measures (PROMs) to support adherence to falls prevention clinic*

Supply of health care
No projects addressed this theme.

Theoretical foundations
The projects that addressed this priority were:
- *You talk, we listen: advancing health economics methods for rural and remote health research by gathering local communities' knowledge and experiences in health care decision making*
- *The development and pilot-testing of an instrument to measure out-of-pocket costs for rural patients accessing surgical services in British Columbia*
- *Social, ethical, and other value judgments in health economics modelling*

Who and how? Methods of partner engagement
The projects that addressed this priority were:
- *The Peer Models Network: a novel mechanism to support transformative model interrogation in patient-oriented health economics*
- *How to do patient engagement in rapid-cycle HTA*
- *Using health economic methods to design clinical studies*

Health Economics and Simulation Modelling

Projects

Using Health Economic Methods to Design Clinical Studies

Contact: mjharri@mail.ubc.ca

This project addressed the priorities:

- *Aligning research funding with patient priorities*
- *Diversity and underserved populations*
- *Who and how? – methods of partner engagement*

Project summary

Our project was trying to find out what are the most important factors to people with scleroderma who might be trying to decide whether to undergo stem-cell transplant, a treatment that offers exciting benefits but with considerable risks. By talking to people with scleroderma, we found that although risks and benefits are important, there are many other considerations in treatment decisions that should be considered.

These included:

- Burden to patients of cost and distance to the treatment center
- The way that treatment is delivered
- The experience of physicians of treating people like them
- The extent to which multidisciplinary, holistic care would be available to support medical and non-medical needs through the treatment

Project findings

Our survey confirmed that these factors are important in the decisions people with scleroderma would make when deciding when to undergo stem cell treatment.

The two main trials of stem cell treatment for scleroderma have been hindered by a lack of people wanting to participate. Our results suggest that if trials of the same treatments were designed with patient priorities in mind, the amount of people willing to participate in trials—and the chance of results improving the care of scleroderma patients in the future—would be increased.

This approach of patient involvement in the design of research studies could be used in any disease area for any treatment.

Blogs

May 18, 2021 – Nick Bansback & Mark Harrison: "Rethinking how we design clinical studies" *Health Research BC.*

Publications

Aguiar, M., Laba, TL., Munro, S. *et al.* Co-production of randomized clinical trials with patients: a case study in autologous hematopoietic stem cell transplant for patients with scleroderma. *Trials* **22,** 611 (2021).

Aguiar M, Harrison M, Munro S, Burch T, Kaal KJ, Hudson M, Bansback N, LabaT. Designing discrete choice experiments using a patient-oriented approach. Patient 2020.

11

Burch T. Patient Commentary: [Added value and validity to research outcomes through thoughtful multifaceted patient-oriented research.](#) Patient 2020.

Presentations

February 2021: [BC AHSN Patient Engagement in Clinical Trials Community of Practice and Clinical Trials BC](#)

March 2020: [#CRArthritis Interview at the Arthritis Broadcast Network Booth](#), at the Canadian Rheumatology Society conference

October 2019: [Scleroderma Association of British Columbia's (SABC) Annual General Meeting](#)

Team

[Mark Harrison, co-PI ✉,](#) Tracey-Lea Laba, co-PI, Tiasha Burch, Nick Bansback, Magda Aguiar, Julia Kaal, Sarah Munro, Jennifer Beckett

Social, ethical, and other value judgments in health economics modelling

Contact: stephanie.harvard@ubc.ca

This project addressed the priorities:

- Patient and public values in research
- Theoretical foundations

Project summary

In many research areas, scientists use computer models to study things of interest in the world. Recently, some studies have looked closely at computer models, and asked whether building them requires researchers to make 'social value judgments' (decisions about what is good for society, not just good from a scientific point of view). These studies showed that **computer modelling does involve making social value judgments.** However, they did not look specifically at health economics models, used to study health and healthcare spending.

In this project, researchers looked at social value judgements involved in building health economics models specifically. To do this, the researchers interviewed twenty-two health economists between February and May, 2019.

Project findings

The project findings suggest that social value judgments are involved throughout health economics modelling.

Specifically, these judgments influence:

- early modelling decisions *(like what to model)*
- model assumptions *(like when to assume that different patient groups will have the same experiences, despite their differences)*

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- decisions about trade-offs between desirable model features *(like whether it is more important for the model to be simple to understand, or more important for it to include all possible information)*
- setting standards of evidence *(like deciding how 'strong' evidence needs to be before researchers conclude that something is true)*

These results point to decisions that researchers should pay special attention to in health economics, particularly research that aims to incorporate patient and public values.

Publications

Harvard S, Werker G, Silva D. [Social, ethical, and other value judgments in health economics modelling.](#) Social Science & Medicine. Volume 253, 2020, 112975, ISSN 0277-9536.

Harvard S., Werker G., 2021. [Health Economists on involving patients in modeling: potential benefits, harms, and variables of interest.](#) PharmacoEconomics.

Team

[Stephanie Harvard, Principal Investigator ✉](#) , Gregory R. Werker, Co-Investigator, Diego S. Silva, Co-Investigator, Alison Mclean, Patient Partner, Don Grant, Patient Partner

Examining the utility of educational videos for increasing knowledge and enhancing the experiences of patient partners in health economics research

Contact: david_whitehurst@sfu.ca

This project addressed the priorities:

- *Communicating results*
- *Diversity and underserved populations*
- *Patient and public values in research*

Project summary

Patients, caregivers, and the public have a right to help decide how our health dollars are spent.

In 2021, the public sector paid for almost 75% of health services in Canada (about $230 billion). Deciding what the public purse should pay for can be complicated because the resources we have from the land and from our tax dollars aren't enough to cover the health services that the public wants. Funding some health services means sacrificing others, so Canadians should know what is most important to them when it comes to health care.

In this project, a team of researchers, patient partners, and filmmakers are seeking to start a conversation about these issues through a series of short educational videos. These videos explore different ideas about health and health care costs and ask audiences to take part in imagining how Canada's health system can be the best it can be.

As part of a collaboration with another project funded by the Health Economics and Simulation Modelling Cluster (The Peer Models Network), funds have also been

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used to produce a 24-minute film on the value-laden processes of modelling in the social sciences and the case for greater public involvement in research.

[Watch Professor Eric Winsberg](#) share his views on COVID-19 models, including their moral significance and influence on society in [this video on YouTube.](#)

Runtime: 24:06

Below, we provide further details about two video series – *Challenges in Funding Healthcare* (three videos) and *Values & Healthcare* (four videos). The *Values & Healthcare* videos are part of an ongoing evaluation.

All short educational videos created as part of this project are available [at this YouTube playlist](#).

Videos: "Challenges in Funding Healthcare"

Funding the healthcare system isn't a straightforward process. Because we don't have unlimited funds, we can't have everything we want. This creates a series of challenges where decisions need to be made about what gets funding, and what doesn't.

These videos explain some of the issues that policymakers must balance.
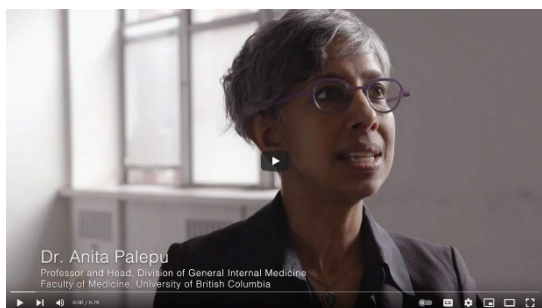
[CHALLENGES IN FUNDING HEALTHCARE | short documentary](#)

Runtime: 5:26

16

[FUNDING HEALTHCARE: WHAT IS 'HEALTH'? | public service announcement](#)

Runtime: 1:04
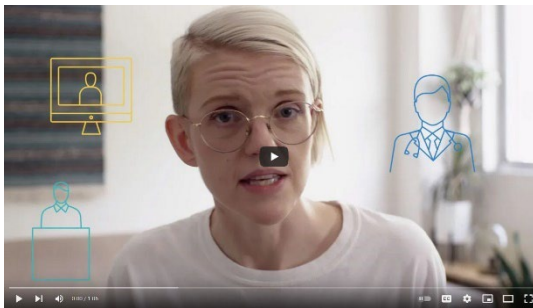
[FUNDING HEALTHCARE: A CHANGING ENVIRONMENT | public service announcement](#)

Runtime: 1:06

Videos: "Values & Healthcare"

Our values help us consider trade-offs and make decisions, whether that be in deciding where we live, what we eat, or how we spend our leisure time.

But what does this mean in the context of healthcare, and how does this relate to research that looks at 'value for money'?

[1. VALUES & HEALTHCARE: AN INTRODUCTION | whiteboard animation](#)

Runtime: 1:35

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[2. VALUES & HEALTHCARE: CHOOSING YOUR OWN TREATMENT | whiteboard animation](#)

Runtime: 1:38

[3. VALUES & HEALTHCARE: PLANNING THE HEALTHCARE SYSTEM | whiteboard animation](#)

Runtime: 1:28

[HEALTH ECONOMICS 'LISTEN' VIDEO | whiteboard animation](#)

Runtime: 1:44

Team

[David Whitehurst, PI](#) ✉, Nick Bansback, co-PI, Stephanie Harvard, Iskwé, Radha Lochan, Julianna Moore, Linda Li, Kim McGrail, Erin Michalak, Rick Sawatzky, Hubert Wong

And, special thanks to all those involved in the creation and execution of the materials developed in this project.

Using patient-reported outcome measures (PROMs) to support adherence to falls prevention clinic

Contact: **jennifer.davis@ubc.ca**

This project addressed the priorities:

- *Communicating results*
- *Patient and public values in research*

Project summary

The goal of this project was to create an approach that uses Patient-Reported Outcome Measures (PROMs) data to help improve patients' adherence to falls prevention recommendations.

PROMs provide data on patients' quality of life through questions about symptoms, functionality, and physical, mental and social health. One PROM tool is the "EuroQol 5 domain – 5 level" (EQ-5D-5L), which measures five health dimensions: mobility, self-care, usual activities, pain and discomfort, and anxiety and depression.

Better patient adherence to falls prevention recommendations would lead to fewer falls over time, and thus, save health care dollars.

The project took place at the Falls Prevention Clinic, based out of the Vancouver General Hospital.

1. We conducted a qualitative study, designed with patient partners who received care previously from the Falls Prevention Clinic. Our goal was to understand whether individualized PROMs data, such as the *"EuroQol 5 domain – 5 level" (EQ-5D-5L)* PROM, could be used to facilitate improved adherence to Falls Prevention Clinic recommendations.

   The purpose of improving adherence to evidence based recommendations was to prevent more falls. This study explored Falls Prevention Clinic patient participants' perspectives on PROMs, and how PROMs might impact their own adherence to

"mult-imodal" fall prevention recommendations (i.e., recommendations combining different treatment methods).

2. We gained valuable feedback from the patient partners on their views of the *EQ-5D-5L* PROM, as well as their perspectives on our focus group questions. Access a summary of our findings here.

Project findings

This project revealed key considerations for implementing PROMs in this setting:

- Communication with the patient's health care provider is important. It is especially important to provide understandable feedback along with other clinical feedback. This will support patient adherence when using the *EQ-5D-5L* PROM.
- Timely feedback on a patient's health status, assessed using the *EQ-5D-5L*, is important.
- Completing the *EQ-5D-5L* PROM may increase patients' self-awareness, through receiving its results. This may also support patient adherence.

Publications

Tai D, Li E, Liu-Ambrose T, Bansback N, Sadatsafavi M, Davis JC. Patient-Reported Outcome Measures (PROMs) to Support Adherence to Falls Prevention Clinic Recommendations: A Qualitative Study. *Patient Prefer Adherence*. 2020;14:2105-2121

Presentations
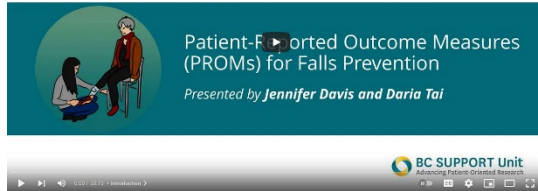
June 2021: "Patient-Reported Outcome Measures (PROMS) for Falls Prevention"
Methods Matters (BC SUPPORT Unit)

Runtime: 50:13

Team

Elodie Portales-Casamar; Ali Eslami, Co-I; Raymond Ng, Co-I; Giuseppe Carenini, Co-I; Ali Mussavi Rizi, Co-I
Ahmed Abura'ed, postdoctoral fellow; Yuqian Zhuang, data scientist; Ariel Qi, patient partner; Alison Taylor, patient partner; Omar Bseiso, patient partner

Alumni:
Rebecca Lin, Esther Lin, Amy George, Cindy Ou Yang

Project poster on next page.

Patient-Reported Outcome Measures (PROMs) to Support Adherence to Falls Prevention Clinic Recommendations

Daria Tai[1,2,3,4]; Eric Li[1]; Teresa Liu-Ambrose[2,3,4]; Nick Bansback[5,6]; Mohsen Sadatsafavi[6,7]; Jennifer Davis[1,2,3,4]

[1]Social & Economic Change Laboratory, [2]Center for Hip Health and Mobility, [3]Aging, Mobility, and Cognitive Neuroscience Lab, [4]Djavad Mowafaghian Centre for Brain Health, [5]School of Population and Public Health, Centre for Health Evaluation & Outcome Studies, [6]Faculty of Pharmaceutical Sciences, [7]Collaboration for Outcomes Research and Evaluation

Introduction

- PROMs are increasingly recognized for their role in primary care clinical settings.[1]
- Patient benefits from interventions can be limited by failure to adhere to recommendations.[2]
- Patient- physician communication is a significant predictor of treatment adherence because it facilitates shared decision-making
- Can encapsulate the personal impact of conditions and provide an objective measure that can be used during discussions to set expectations

Purpose: We examined how patient-reported outcome measures (PROMs) support patients' adherence to fall prevention recommendations in a novel primary care setting – the Falls Prevention Clinic.

Methods

Setting	• Vancouver Falls Prevention Clinic
Patient Partnership	• Involved in study design • Have lived experiences in the Falls Prevention Clinic
Study Design	• Focus groups of 4-6 • Semi-structured interviews
Data Analysis	• Coded in 3 stages: 1) open 2) axial 3) selective

Baseline Demographics

Variables	Mean (SD)
Age	81.1 (6.5)
SPPB	9.8 (1.6)
MMSE	28.9 (1.2)
EQ-5L-5D	0.8 (0.3)

Results

Theme 1: Usefulness of a patient-reported outcome measure (EQ-5D-5L) to patients

Opportunity
Gaining the patient perspective
  How patients are feeling
  How patients' conditions affect their daily living
Gaining self-awareness
  Brining issues to patient's attention
For comparison
  Follow up purposes
  Possible trends
Development
Care pathway
  Role in provider's/physician's decision of treatment plan

Theme 2: EQ-5D-5L administration and feedback timing

Frequency
When to receive feedback
  Real-time
  Patient preference
Administration of questionnaire
  Often is more helpful

Theme 3: Tracking health status over time – the relationship to adherence

Benefits
Comparison
  Able to see if there are changes throughout time
  To understand the treatment process
Motivation
  Able to see improvements or declines
Challenges
Data presentation
  May be a cause for confusion
Target audience
  Patient vs Provider vs Research
Patients' understanding
Interpretation of the graph
Reasons for decline/incline

Theme 4: Comparison of PROM data with peers

Relevance of data
Relevance to self
  Performance of others not relevant
  Evidence for benefits from recommendations
  Already knowing their own level of adherence
  Need to be similar in demographics/conditions
Usefulness of data
For Patient
  For motivation
  For self-awareness
  Figure out why they are in a certain group
For Provider
  Find and provide reason for different levels of compliance

Theme 5: Patient perspectives on promoting their own adherence

Performance
Direct feedback from the provider
  Report of/asking how compliant they were
Resources
  Lists
Recreation/exercise programs
  Directly from provider Ask what patients need
Knowledge
Effect of comorbidities
  How it can hinder compliance
Self-reflection
  Prompts to think about reasons they have not been complying

Theme 6: Potential role for the EQ-5D-5L in promoting adherence

Role in behaviour change
Not having a role
  Already knowing own state of wellbeing
  More important for provider
Reasons for its ability to change behaviour
  Improving self-awareness
  Positive reinforcement

Key Quotes

Theme 1:
- *Opportunity*: "I think it encourages us support that we see what's happening, we're improving or slipping and it might just give us a little kick in the back in the bottom."

Theme 2:
- *Frequency*: "I just found that [it is] helpful is to have the person tell me how I respond to them on that particular day."

Theme 3:
- *Benefits*: "I would expect… improvement . . . That's what I would like my graph to look like… My expectation would be, [that if] I am reasonably compliant, I'd progress. Hopefully, it would shame me, if I didn't progress."

Theme 6:
- *Reasons for ability to change behaviour:* "Well, and the reason I want to see the long-term answer sheets is, I'm curious to know whether the exercise program, that I've put myself through, is changing any of these answers, as the year progresses. And so that seems to me, that, that would give really good feedback to adherence . . . "

Discussion

- Highlights the importance of productive provider feedback to facilitate patient understanding and to promote self-awareness
- Patient experiences are dynamic and should be recorded frequently to capture this
- Can be a useful tool for providers to gain a patient's perspectives on their conditions, record any trends, increase self-awareness and assist in directing the provider's treatment plan

References

1. Black N. Patient reported outcome measures could help transform healthcare. BMJ. 2013;346(jan28 1):f167. doi:10.1136/bmj.f167
2. Osterberg L, Blaschke T. Adherence to medication. N Engl J Med. 2005;353(5):487–497. doi:10.1056/NEJMra050100

THE UNIVERSITY OF BRITISH COLUMBIA
Faculty of Management

BC SUPPORT Unit
Advancing Patient-Oriented Research
British Columbia Academic Health Science Network

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CENTRE for HIP Health and Mobility

Djavad Mowafaghian CENTRE FOR BRAIN HEALTH

CORE Collaboration for Outcomes Research and Evaluation

Michael Smith
Health
Research BC
BC SUPPORT UNIT

Methods
Clusters

The development and pilot-testing of an instrument to measure out-of-pocket costs for rural patients accessing surgical services in British Columbia

Contact: jude.kornelsen@familymed.ubc.ca

This project addressed the priorities:

- *Diversity and underserved populations*
- *Theoretical foundations*

Project summary

This project studied out-of-pocket costs for rural BC patients seeking health care outside their home community.

We wanted to:

1. Explore the themes and categories of these out-of-pocket costs
2. Develop and use a survey tool to get data about the nature and extent of these out-of-pocket costs, including absence-related costs such as childcare or lost wages.

To do this, we:

1. Conducted focus groups and connected with other research projects at the Centre for Rural Health Research, and
2. Developed and used a survey tool, in collaboration with our patient partners

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Project findings

From our focus groups and investigations into other research projects, we found that themes highlighted out-of-pocket costs of:

- Transportation
- Accommodation and meals
- Traveling with a companion
- Lost wages
- Child/animal care

From our survey, we found that:

- On average, rural residents pay $2,234 per person on travel related out-of-pocket spending for health.
- The majority of respondents reported difficulty in paying for the costs of accessing care outside their community.
- For many respondents, time spent away from home meant losing out on wages.
- Very few respondents received any type of system-level financial support to help cover costs.
- Those who reported spending more on traveling for health care also reported experiencing higher levels of stress and anxiety.
- Higher-income respondents experienced less stress on average.

These findings underscore just how significant traveling for health care is for rural residents, both financially as well as psychologically and emotionally. Low-wage, elderly and other marginalized rural residents are particularly impacted by the costs of traveling, with few supports available to them.

Overall, this study closes the knowledge gap about out-of-pocket costs for rural residents accessing health services in BC.

Publications

Kornelsen, J., Khowaja, A.R., Av-Gay, G. *et al.* The rural tax: comprehensive out-of-pocket costs associated with patient travel in British Columbia. *BMC Health Serv Res* **21,** 854 (2021).

Team

Elodie Portales-Casamar, Lead ✉; Ali Eslami, Co-I; Raymond Ng, Co-I; Giuseppe Carenini, Co-I; Ali Mussavi Rizi, Co-I
Ahmed Abura'ed, postdoctoral fellow; Yuqian Zhuang, data scientist; Ariel Qi, patient partner; Alison Taylor, patient partner; Omar Bseiso, patient partner

Alumni:
Rebecca Lin, Esther Lin, Amy George, Cindy Ou Yang

Jude Kornelsen

Co-Director, Centre for Rural Health Research, Department of Family Practice, UBC

Introduction

Many rural patients in BC are required to travel out of their community to access diagnostic and specialist care. Most patients pay for this 'out of pocket', and for some, this is a difficult burden.

Methods and Approach:

Engaged survey development, dissemination and interpretation with four rural patient partners from across the province;
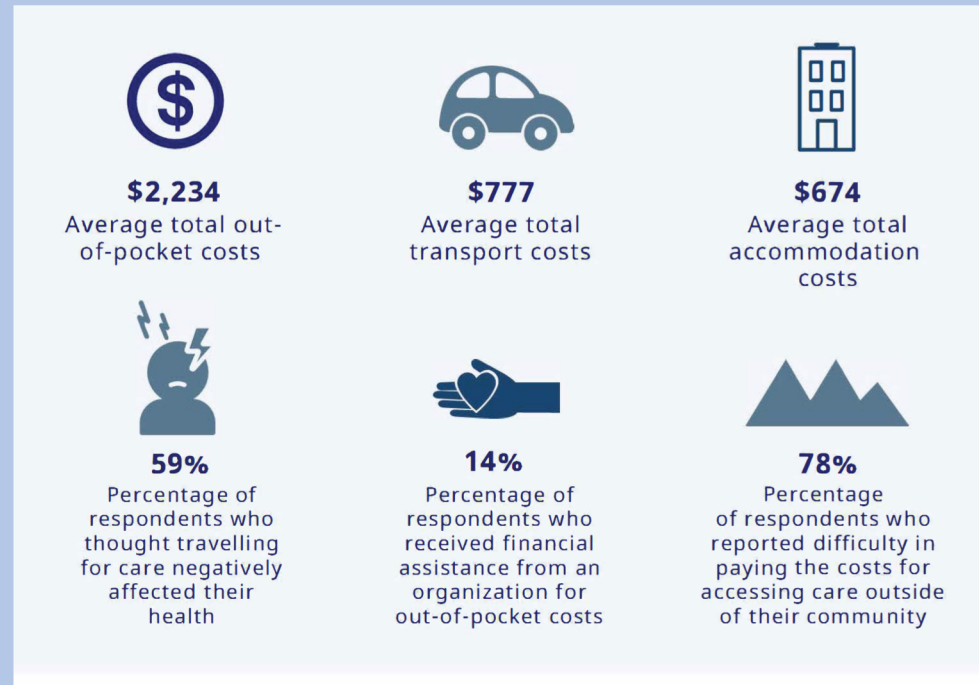
On-line survey research targeting 186 Rural Physician Subsidiary Agreement Communities Nov 2019 – February 2020;

Findings

381 respondents across rural BC

Take-home findings:

"Rural patients in BC traveling out of their home community for health care are burdened with high financial and psychosocial costs."

The financial impact of **traveling to access health care** for rural residents amounts to a **rural tax on health care.**

$2,234
Average total out-of-pocket costs

$777
Average total transport costs

$674
Average total accommodation costs

59%
Percentage of respondents who thought travelling for care negatively affected their health

14%
Percentage of respondents who received financial assistance from an organization for out-of-pocket costs

78%
Percentage of respondents who reported difficulty in paying the costs for accessing care outside of their community

Next Steps

Develop action plans with patient partners and rural key stake- and right-holders

Convene provincial stakeholders in a deliberative dialogue to determine equitable solutions

Project Funders

Health Economic & Simulation Modelling Methods Cluster | BC SPOR Support Unit

BC SUPPORT Unit
Advancing Patient-Oriented Research

Project Team

Asif Khowaja, PhD & Jude Kornelsen PhD, Co-Principle Investigators

Patient Partners:

Marjorie Dunnebacke (Trail, BC)
Dorothy Egan (Kitimat, BC)
Mickey Balas (Golden, BC)
Peggy Williamson (Williams Lake, BC)

CRHR Research Team:

Eva Sullivan | Gal Av-Gay | Anshu Parajulee

The Centre For Rural Health Research

Michael Smith
Health
Research BC
BC SUPPORT UNIT

**Methods
Clusters**

Can natural language processing estimate patient preferences?

This project addressed the priorities:

- *Patient and public values in research*

Project summary

When researchers want to understand patient preferences, we often use interviews and focus groups. But, these have some limitations. For example, they often only involve a small number of participants, and can take a lot of work for recruitment and analysis. It is also difficult to explore changes in patient preferences over time.

"Social media listening" is a new method of gathering information about patient preferences that overcomes some of these limitations, by drawing from patient discussions held over social media, such as Reddit forums. However, social media listening can still require a lot of work to analyse the data, since there is usually a lot of text available for analysis.

To try to address this problem we developed a "natural language processing" tool *(EXPECT-NLP (EXploration of Patient Experiences in Collected Texts using Natural Language Processing)*. This tool can automatically extract key themes from discussions, group them by sentiment, relatedness, and topic, and allows users to explore the underlying body of text.

Project findings

Validity: We used this tool do a "preference exploration"—specifically, we analysed Reddit discussions about different drug therapies for multiple sclerosis. The results were similar to results researchers found before, which suggests that our natural language processing tool works for this purpose.

Scalability: To use the tool on these Reddit discussions, we had to build a lexicon (word bank) of relevant terms using the tool and some human curation. This was a practical step, because patients using social media express opinions about a limited number of concepts. In our case, the initial list of "aspect-opinion pairs" extracted using our tool was around 1000, even as more text was added. This suggests our tool is usable at larger scales.

Versatility: We also found that these curated lexicons could be used for other areas of health, suggesting that this tool can be versatile. Specifically, we used the lexicon curated from MS, rheumatoid arthritis, and cancer forums to instead analyse data on COVID-19 forms successfully.

Limitations: Finally, one limitation of the tool is that it will likely be much more challenging to use to understand patient "trade-offs" (e.g., whether they would prefer a less effective but cheaper treatment vs a more effective but more expensive treatment).

Overall, our hope is that this will allow potential users to easily and quickly use the vast amount of social media data available to generate insights and hypotheses on patient experiences and preferences, and this will inform the development of new medical products, health services, and policies.

Presentations

May 2021: "Natural Language Processing & Social Media Listening in Patient-Oriented Research" *Methods Matters* (BC SUPPORT Unit)

Runtime: 57:50

Oct 2020: SMDM (Society for Medical Decision Making) 42nd Annual North American Meeting: "Relationships in Medical Decision Making." [Presentation Abstract](#)

Team

Larry Lynd, PI, Nick Dragojlovic, Raymond Ng, Giuseppe Carenini, David Johnson, Nicola Kopac, Marilyn Lenzen, Sarah le Huray, Yifu (Charles) Chen, Samantha Pollard, Mark Harrison, Dean Regier, Kennedy Borle, Amy George

How to do patient engagement in rapid-cycle HTA

Contact: craig.mitton@ubc.ca

This project addressed the priorities:

- *Medication reimbursement, who and how?*
- *Methods of partner engagement*

Project summary

"Health technology assessment" is a type of analysis that provides information on the costs and benefits of various health technologies and services. One recent advance in health technology assessment has been the involvement of patients or public members in providing insight into the use of the given technology or service, as well as the relevant outcomes from such use.

This study examined how members of the public can best be engaged in these types of assessments, particularly in cases where there is a timeline of 100 days or less from project initiation to completion.

There are many challenges in obtaining meaningful public involvement in such a short timeline, but our study resulted in a detailed tool, in the form of a series of questions, to guide a given research team in this activity.

Project findings

The tool that we developed provided new insight into this field around how, when and where public involvement is best utilized.

Team

Craig Mitton, PI ✉ , Meghan Donaldson, Neale Smith, Selva Bayat, Vivian Sandberg

Project tool on next page.

Is there likely to be a subjective impact from a patient perspective on... health outcomes/ process of care/ experience of care?

Yes

2. Initiate Rapid Literature Review and Engage with Patient organizations

No, thus PE is not required. Utilize clinical reviews to establish changes to clinical outcomes that might affect patient-care and recovery.

1. Incorporate non-disease/ non-condition specific patient partners to:

a) Input on the scope and specific questions of the HTA
b) Input on the level and form of patient engagement for the HTA
c) Meet with HTA team members re clinical and economic reviews and economic model, to ensure patient values are reflected

Do the findings from the literature and engagement with patient organizations provide adequate information re the patient's experience of the technology (or condition related to the technology) under evaluation

Yes, adequate information was found in the literature and thus no direct PE is required.

No, the information found was not adequate thus direct patient engagement is required via recruitment of patients in BC with experience with the technology (or the condition related to the technology).

Can patient preferences and values be objectively incorporated into the design and evaluation of technologies? A conceptual framework and a proof-of-concept study

Contact: mohsen.sadatsafavi@ubc.ca amir.khakban@ubc.ca

This project addressed the priorities:

- *Communicating results*
- *Diversity and underserved populations*

Project summary

Whether or not to start a new treatment is an important decision that patients often take in consultation with their doctors. To help patients and doctors make these decisions, guidelines often recommend "treatment algorithms" that consider the risks and benefits of treatment. These treatment algorithms often classify patients as "high risk" versus "low risk", and the treatment is recommended only for the "high risk" group.

This classification of a patient into "high" versus "low" risk is often done based on the opinion of the few scientists who develop such guidelines, without consulting patients who may actually take the treatment.
One example is the use of long-term antibiotic therapy for preventing lung attacks in patients with Chronic Obstructive Pulmonary Disease (COPD). Antibiotics reduce the risk of lung attacks, but their long-term use is associated with risk of adverse events, such as hearing loss.

However, we do not know patient "trade-offs" between the risk of lung attacks and the risk of adverse treatment events. For example, we do not know the acceptable risk of hearing loss to patients to avoid one lung attack. Current guidelines establish the trade-offs based on the opinion of clinicians.

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To address this problem, this project designed a way to measuring and considering patients' values and preferences. Using focus groups and follow-up conversations, we designed and tested a Discrete Choice Experiment to measure patient preferences about different aspects of preventative therapies for COPD.

Project findings

We found that:

- Patient preferences for different aspects of antibiotic therapy can reliably be measured
- These differences can be used in creating treatment algorithms that reflects patient preferences

We hope that guideline development committees such as the Canadian Thoracic Society will be motivated by the findings of this study to use a patient-centred approach in developing the next version of their guidelines.

Team

Mohsen Sadatsafavi, Co-lead ✉, Stephen Schechter, Co-lead, Amir Khakban ✉

Improving the methods to measure work productivity losses in patients and caregivers

Contact: wzhang@cheos.ubc.ca

This project addressed the priorities:

- *Diversity and underserved populations*

Project summary

The "Valuation of Lost Productivity" (VOLP) questionnaire was initially developed to measure and value work productivity losses in people with health problems. These losses include work stoppage, absenteeism and presenteeism (reduced work productivity while at work).

However, people with health problems often require time from their family members or friends (caregivers) to take care of them. These caregiving responsibilities can affect the caregivers' work productivity. Existing questionnaires that assess the time spent by caregivers on caregiving responsibilities and caregiver work productivity losses have limitations.

Using a patient-oriented research approach, we adapted the VOLP into a caregiver version to capture time spent on caregiving and work productivity losses of caregivers.

Developing the questionnaire

After reviewing the VOLP and other existing questionnaires measuring caregiver work productivity losses, our team developed a draft of the questionnaire, which included the addition of volunteer activities and lost job opportunities. This questionnaire draft was improved using one-on-one interviews with caregivers, converted to an online survey, and improved with further one-on-one caregiver tests and interviews.

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Testing the questionnaire

We then tested the feasibility and validity of our tool, by comparing it to the results of a previously validated questionnaire, the "Work Productivity and Activity Impairment" questionnaire (WPAI), as well as a previous VOLP validation study.

Project findings

Our study results provide evidence on the feasibility and validity of the VOLP caregiver questionnaire.

Publications

Gelfand A, Sou J, Sawatzky R, Prescott K, Pearce A, Anis AH, Lee C, Zhang W. Valuation of Lost Productivity in Caregivers: A Validation Study. Frontiers in Psychology. 2021;12:727871.

Presentations

October 2020: Putting Patients First 2020, BC SUPPORT Unit

July 2021: International Health Economics Association Congress, oral presentation

Team

Wei Zhang, Co-PI ✉, Christine Lee, Co-PI, Julie Sou, Aaron Gelfand, Katrina Prescott, Lee Boyko, Rick Sawatzky, Alison Pearce, Aslam Anis

You talk, we listen: advancing health economics methods for rural and remote health research by gathering local communities' knowledge and experiences in health care decision making

This project addressed the priorities:

- *Communicating results*
- *Diversity and underserved populations*
- *Theoretical foundations*

Project summary

Health economics is the study of resource allocation in health care. Resources might be monetary, such as private or governmental funds, as well as non-monetary, such as health professionals and other staff, equipment and social support.

Health resources are scarce and policy makers are faced daily with complex decisions of how to allocate these resources to improve the health and well-being of the populations they serve.

The goal is for the allocation to be efficient—in other words, for the available resources to be used where they can produce the "best possible outcomes." What is meant by "best possible outcome" is context-specific and depends, amongst other things, on the population values and contextual factors such as demographics, culture and geography.

Health care resources can be scarce even in affluent urban areas, and this scarcity is exacerbated in rural and remote settings. The very low population density, harsh climates and long distances from main treatment centers pose obvious problems.

The challenges and solutions for accessing health resources in rural and remote communities isn't always clear to researchers in urban areas.

This work starts from the premise that efficient resource allocation in BC needs more input from rural and remote communities. Our work also aims to establish a connection between health economists predominantly based in the Lower Mainland and communities in rural and remote BC.

Our goals were:

1. To establish links between the health economics community, predominantly based in the Lower Mainland, with communities, policy-makers and researchers in northern BC
2. To create an opportunity for health economists to learn from rural and remote communities about resource allocation and health priorities in BC
3. To explore novel ways of communicating and engaging with a diverse audience with the principles of resource allocation and prioritization in health care through arts-based research and knowledge translation activities
4. To empower communities in rural and remote BC to communicate their priorities to relevant audiences including researchers, decision-makers and the general public

Project findings

We learned from participants located in 18 communities across northern BC, through:

- Three online focus group sessions with nine community members
  - This included an interactive hypothetical resource allocation activity
- Three 'photovoice sessions,' a photography-based research method that engages participants as co-analysts of the data they gather.
  - Two online with community members and Indigenous women studying at UNBC
  - One in-person with members of The New Hope Society in Prince George
- One-on-one telephone interviews with thirty-one decision makers (municipal officers, healthcare professionals, non-governmental organizations)

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Our results show that community members across northern BC have a significant awareness of the reality of resource constraints and understand the bureaucratic and political realities that shape the need for trade-offs. However, from this deep understanding they do not accept these realties as an excuse for shortcomings. Rather, they believe there should be a core suite of services that are accessible to everyone including those in rural and remote regions.

They note that funding models need to facilitate the provision of core services in a way that reflects an understanding of the unique needs of rural and remote northern communities and designed to maximize equity in access. Additionally, they noted that community members should be able to access financial and logistical support when accessing services outside community to guarantee equity in access to health services.

Our findings revealed and challenged actual and potential biases in decisions made, and priorities set, for these areas when allocating health care resources. This includes nuanced understanding of how per capita funding, designed to provide equitable access to health care does not support such equity in northern BC.

Based on our photovoice activity and results, we produced a photobook (a hardcopy plain language document) which was shared with our participants, as well as various community partners and decision makers. Every library in northern BC will also receive a copy.

Team

Magda Aguiar, Lead, Glory Apantaku, Theresa Healy, John Grogan, Lara Frederick, Jasmine Thomas, Caitlin Chew, Jiahui Zhang, Mark Harrison, Attilio Fiumarella, Sarah de Leeuw

The Peer Models Network: A novel mechanism to support transformative model interrogation in patient-oriented health economics

Contact: stephanie.harvard@ubc.ca

This project addressed the priorities:

- *Communicating results*
- *Patient and public values in research, who and how?*
- *Methods of partner engagement*

Project summary

In Canada's public health care system, governments must decide which treatments and programs to fund with a limited budget. To help make these decisions, decision-makers often rely on information from "health economic models". These are computer models that inform decision-making by giving information about costs and effects of different treatments and programs. Although health economic models inform very important decisions, it is always not easy to see how they are built.

To help make health economics models more transparent, understandable, and open to feedback, our research team launched a project called the Peer Models Network, which included a website, Twitter, and YouTube page.

- The website introduced a **new technical infrastructure** called 'PRISM' that allows health economic models to be hosted online, making them accessible to everyone.
- To invite patients and the public learn about modelling and give feedback to researchers, the website included a **blog, private message** feature, and **discussion forum.**
- The website also introduced the **'Peer Models Network Panel'**, a group of patients and the public who wish to be contacted about research opportunities.
- Our Twitter account, @PeerModels, aimed to raise awareness and start conversations about public engagement in modelling.

- The YouTube paged hosted **'model companion videos'**, short educational videos that aim to introduce modelling to broader audiences, including a six-part video series on the EPIC model.
- We also conducted a **survey** to ask patients and members of the public what they think of the Peer Models Network. The results included both encouraging and critical feedback that will inform future research about transparency and patient engagement in health economic modelling.

Project findings

Throughout conducting this project, we found that patient partners and researchers had a good and productive experience working together, even on a specialized topic such as health economic modelling.

In our engagement, we found a need to identify the levels of familiarity with health economic modelling among different people, and to establish what the connection is between modelling and the concerns most relevant to them.

Patient partners and researchers were also able to identify common concerns relevant to the project. We identified that **anti-racist practices can be incorporated into all forms of patient-oriented research.** We also found that conversations about modeling can present an opportunity to address the problem of racist bias in health research, which was a priority for our team.

Further project findings will be communicated via the PeerModels Network website, Twitter, and YouTube pages, as well as an academic manuscript.

Publications

Harvard, S., Adibi, A., Easterbrook, A. *et al.* Developing an Online Infrastructure to Enhance Model Accessibility and Validation: The Peer Models Network. *PharmacoEconomics* (2022).
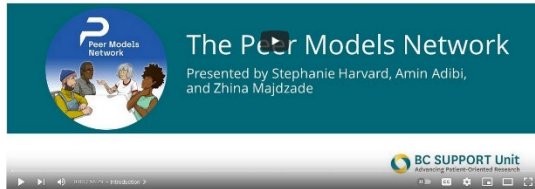
Presentations

Oct 2020: [Putting Patients First: Connecting Face to Face in Virtual Space](#) (#PPF20)

May 2021: ["The Peer Models Network"](#)
Methods Matters (BC SUPPORT Unit)

Runtime: 56:29

Team

[Stephanie Harvard, Lead ✉](#), Alison Mclean, Don Grant, Greg Werker, David Murphy, Amin Adibi, Mohsen Sadatsafavi

Advancing the methods for using routinely collected health data

This project addressed the priorities:

- *Patient and public values in research*

Project summary

Routinely collected data, or "administrative data," is created through visits to care providers and medication prescriptions. This data helps us understand the costs and benefits of providing services in different ways to different people.

However, these data—have limitations. For example, they do not typically capture how patients feel about the care that they receive.

Recently, in BC, there have been initiatives that have asked patients to complete surveys about their hospital care. These data can now be linked with routinely collected "administrative data," providing an opportunity to answer questions that could not be answered before.

However, work is needed to understand how best to do this.

This project will develop guidelines on which methods will ensure administrative data can answer important questions to patients while balancing costs and available funding.

Team

Logan Trenaman, Mark Harrison, Kim McGrail