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** 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 **Patient-Centred Measurement** Methods Cluster as of March 2022.

Patient-Centred Measurement

Overview

The **Patient-Centred Measurement** Methods Cluster aims to understand what matters most to patients by collecting information on their experiences and outcomes. Through collecting, reporting and incorporating these metrics into research and services, patients and families are able to have an impact on the quality of care that they receive.

Read a blog post by Cluster leads Rick Sawatzky & Lena Cuthbertson: How do we measure what matters to patients... well?

"What is patient-centred measurement? How do we improve it? Why is improvement important— and what, exactly, do we need to improve?"

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

- *Identified **11 priorities** to focus on*
- *Funded **10 projects** to address them*

This Cluster was led by **Rick Sawatzky** and **Lena Cuthbertson**.

Dr. Sawatzky holds a Canada Research Chair in Person-Centred Outcomes at Trinity Western University (TWU) and is a professor in TWU's School of Nursing. He is also Patient-Reported Outcomes (PRO) Lead at the UBC Centre for Health Evaluation and Outcome Sciences (CHEOS).

Dr. Cuthbertson oversees the British Columbia (BC) Canada Office of Patient-Centred Measurement and leads the BC Ministry of Health's strategy for measurement and reporting of patient-centred care.

Patient-Centred Measurement

Navigation

Jump to:

Patient-Centred Measurement

Projects: Overview

Patient-Driven Data Collection and Usage in Chronic Disease Management

Patient-Centred Measurement

This project co-designed a novel digital patient-driven disease measurement tool for hypertension—with patients as partners.

Improving Methods for Using Patient-Centred Data for Clinical Purposes

Patient-Centred Measurement

This study sought to measure where people with different demographics (age, sex, health status) would have different "minimal important difference" values, in gallbladder removal and ankle replacement.

Advancing the Science of Patient-Centred Measurement in Team-Based Care
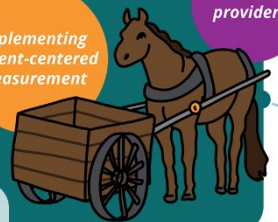
Patient-Centred Measurement

How can patient-generated data be completed, accessed and used by patients and their care team? This study aimed to develop new methods of including patient-generated data in a team-based care clinic.

Incorporating Patient-Reported Outcome (PROMs) and Experience Measures (PREMs) in Practice:

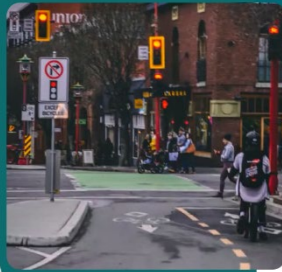**A Resource Guide about What Clinicians Need**

Patient-Centred Measurement

How do we assist health care providers to use patient-centred assessment tools?
And how can health care providers routinely use this information to inform patients' care?

Towards Equity-Informed Care:
Making Visible the Needs of Marginalized Populations

Patient-Centred Measurement

Working alongside people experiencing inequities (e.g., homelessness, poverty, and stigma) and chronic health conditions, this team studied if and how PROMs and PREMs could be used with these populations, and what measures may be most relevant.

A Qualitative Investigation of How to Integrate *Primary Caregiver-Reported Outcomes* Across the *Colorectal Cancer Journey*

Patient-Centred Measurement

What are caregiver experiences and priorities & how can we ensure caregiver-reported outcomes reflect them? Our team interviewed patients with colorectal cancer, their caregivers, & health care professionals for their perspectives.

Decolonizing Birth Research:
Indigenous Researchers, Clinicians, and Community Experts measuring respect, disrespect and mistreatment in Indigenous childbearing communities

Patient-Centred Measurement

This study co-created study questions to capture Indigenous people's lived experiences of respect and cultural safety vs. disrespect, discrimination, and/or mistreatment, in childbearing-related health care in BC.

A Roadmap for Developing *Indigenous Patient-Reported Outcome and Experience Measures*

Patient-Centred Measurement

This team created a "pathways" framework and an inventory of existing culturally relevant PROMs and PREMs for Indigenous families.

Cross-cultural Validation *Methods for Generic Patient-Reported Outcome Measures (PROMs)*

Patient-Centred Measurement

Cultural Safety *in Patient-Centred Measurement Methodologies*

Patient-Centred Measurement

Many PROMs have been translated from English, but are they representative?
This project tested the Chinese translations of the VR-12, and interviewed Chinese-speaking immigrants about their perspectives, experiences, and needs for care.

This project gathered, validated, and refined evidence of culturally safe & appropriate approaches to patient-reported quality and safety assessments of health care experiences of Indigenous Peoples.

Patient-Centred Measurement

Priorities

Each Cluster consulted stakeholders to discuss their priorities for patient-oriented research. The Patient-Centred Measurement Methods Cluster identified **11 priorities** for potential projects.

This Cluster then funded **10 projects** based on these priorities.
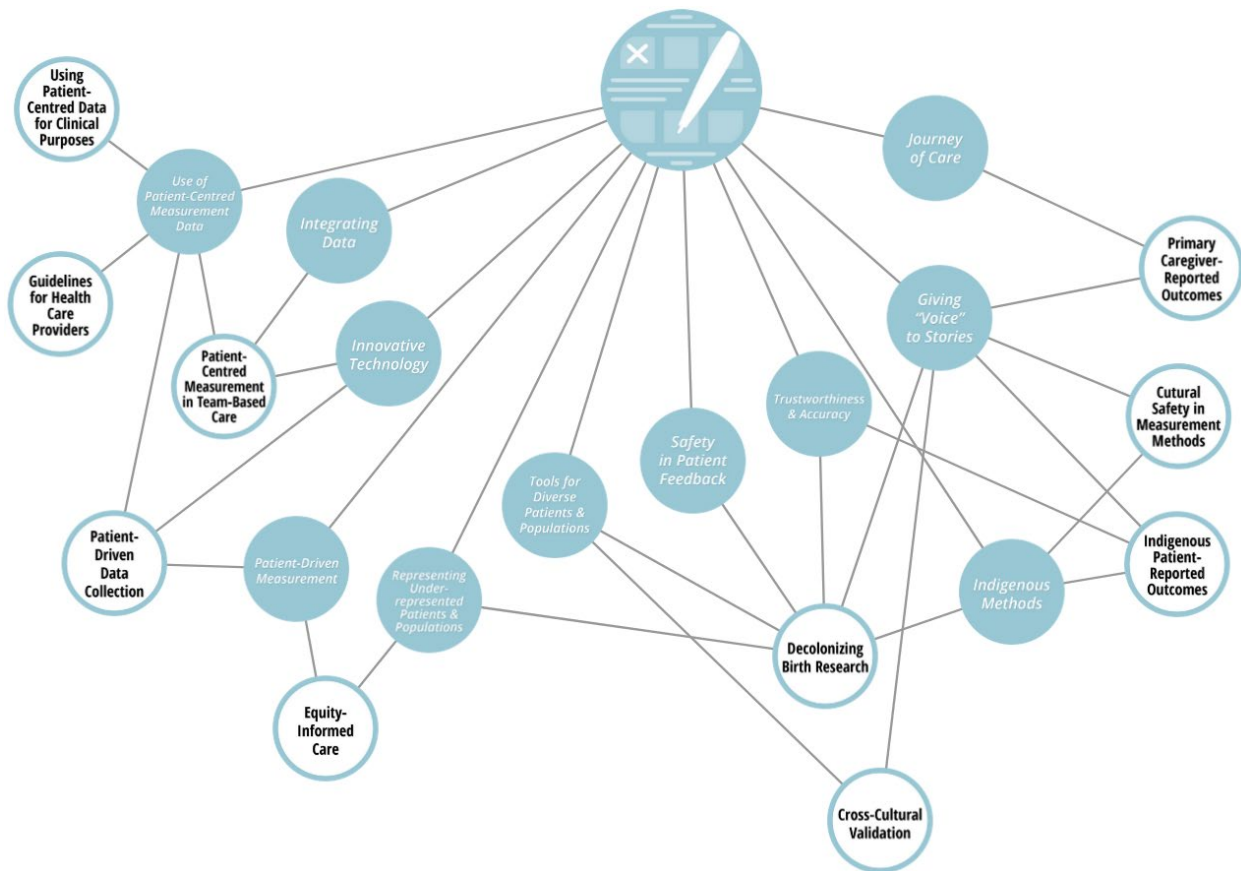
This diagram shows the connections between the priorities (solid blue) and projects (blue outline) of the Patient-Centred Measurement Methods Cluster. A list of the Cluster's priorities, and projects they funded based on them, is below.

Measurement that is patient-driven
The projects that addressed this priority were:
- *Towards equity-informed care: making visible the needs of marginalized populations*
- *Patient-driven data collection and usage in chronic disease management*

Giving 'voice' to patient, family, caregiver, and community stories
The projects that addressed this priority were:
- *Decolonizing birth research: Indigenous researchers, clinicians, and community experts measuring respect, disrespect and mistreatment in Indigenous childbearing communities*
- *Cross-cultural validation methods for generic PROMs*
- *Cultural safety in patient-centred measurement methodologies*
- *A roadmap for developing Indigenous patient-reported outcome and experience measures*
- *A qualitative investigation of how to integrate primary caregiver-reported outcomes across the colorectal cancer journey*

Ensuring patients feel safe to give feedback
The project that addressed this priority was:
- *Decolonizing birth research: Indigenous researchers, clinicians, and community experts measuring respect, disrespect and mistreatment in Indigenous childbearing communities*

Measurement tools that are individualized or tailored for diverse patients and populations
The projects that addressed this priority were:
- *Decolonizing birth research: Indigenous researchers, clinicians, and community experts measuring respect, disrespect and mistreatment in Indigenous childbearing communities*
- *Cross-cultural validation methods for generic PROMs*

Methods for enhancing representation of marginalized, vulnerable, or hard-to-reach populations
The project that addressed this priority was:
- *Decolonizing birth research: Indigenous researchers, clinicians, and community experts measuring respect, disrespect and mistreatment in Indigenous childbearing communities*
- *Towards equity-informed care: making visible the needs of marginalized populations*

Measuring journey across care

The project that addressed this priority was:

- *A qualitative investigation of how to integrate primary caregiver-reported outcomes across the colorectal cancer journey*

Indigenous methodologies for Patient-Centred Measurement

The projects that addressed this priority were:

- *Decolonizing birth research: Indigenous researchers, clinicians, and community experts measuring respect, disrespect and mistreatment in Indigenous childbearing communities*
- *Cultural safety in patient-centred measurement methodologies*
- *A roadmap for developing Indigenous patient-reported outcome and experience measures*

Improving use of PCM data for research, clinical, evaluation, and administrative purposes

The projects that addressed this priority were:

- *Advancing the science of patient-centred measurement in team-based care*
- *Improving methods for using patient-centred data for clinical purposes*
- *Patient-driven data collection and usage in chronic disease management*
- *Incorporating patient-reported outcome (PROMs) and experience measures (PREMs) in practice: a resource guide about what clinicians need*

Integrating of patient-reported data with clinical and administrative data

The project that addressed this priority was:

- *Advancing the science of patient-centred measurement in team-based care*

Advancing methods for ensuring PCM accurately reflects what is important to patients

The projects that addressed this priority were:

- *Decolonizing birth research: Indigenous researchers, clinicians, and community experts measuring respect, disrespect and mistreatment in Indigenous childbearing communities*
- *A roadmap for developing Indigenous patient-reported outcome and experience measures*

Developing and implementation of innovative technology for PCM

Projects:

- *Advancing the science of patient-centred measurement in team-based care*
- *Patient-driven data collection and usage in chronic disease management*

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Patient-Centred Measurement

Projects

Decolonizing birth research: Indigenous researchers, clinicians, and community experts measuring respect, disrespect and mistreatment in Indigenous childbearing communities

This project addressed the priorities:

- *Advancing methods for ensuring PCM accurately reflects what is important to patients*
- *Ensuring patients feel safe to provide feedback*
- *Giving 'voice' to patient, family, caregiver, and community stories*
- *Indigenous methodologies for Patient-Centred Measurement*
- *Measurement tools that are individualized or tailored for diverse patients and populations*
- *Methods for enhancing representation of marginalized, vulnerable, or hard-to-reach populations*

Project summary

The decolonizing birth research project aims to explore the experiences of Indigenous families during pregnancy and childbirth, using participatory methods and measures that reflect the values and needs of the communities. The main objectives are:

1. To identify and/or validate **person-centered measures of respect, disrespect, racism and/or mistreatment** as experienced by Indigenous families during pregnancy and childbirth

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2. To identify wise and decolonizing health research **practices** within the broader context of research that supports Indigenous self-determination

We are working with six communities (Okanagan, Haida Gwaii, Vancouver, Seabird Island, Port Hardy, and Cross Lake, Manitoba), in partnership with community leads who:

- Coordinate local activities for every stage of this project
- Engage Elders, Knowledge Keepers and community leaders to seek approvals and guidance
- Define project goals and objectives
- Develop culturally responsive and safe research methods
- Facilitate community engagement and participate in data analysis, and reporting

Community members have been active participants and have been involved in defining research questions, methods of engagement, and interpretation of results. Through a patient-oriented approach, we were able to recognize and incorporate Indigenous methods and multiple ways of collecting information such as through talking circles, storytelling/journaling, online surveys, and individual interviews with the community leads, and/or trusted community leaders and Elders.

As a result, project results are more reflective, relevant and useful to specific community needs and priorities.

Project findings

Our project showed that to decolonize birth research, researchers must plan for and respond to the three R's: **respect, reciprocity, and relationships.**

In our project, to show **respect,** the research team acknowledged and recognized the community's priorities for learning and knowledge sharing. We decided to modify ways to conduct the research and change timelines in favor of urgent community needs, exercise patience, trust and accept that the work will get done when the community is ready, not when the researcher needs it to be done.

Our work was **reciprocal,** in that we saw each community lead as the expert in the research process, while the principal investigators and research units provided the technical tools and information. We created a process and structure for the research plan for communities to define priorities and research objectives within a larger umbrella of "ways to measure experiences of respectful maternity care".

Our **relationships** to each other, the community leads, and the communities were critical to the progression of this work. We learned that conducting research in good ways in Indigenous communities, with both Indigenous and settler researchers, means to center relational principles, such as humility, critical reflection, willingness to put aside our agendas; and engage in communication that is genuine, authentic, and transparent.

As a result, participants were able to identify measures and metrics that elicit their lived experience. Participants chose **ways to share that did not re-traumatize,** and prioritized measures that describe **strengths-based models of care,** including Indigenous midwives, doulas, and birth on sovereign lands.

We expect that, by the end of March 2022:

- All six communities will have engaged in data collection
- Three communities will have decided on and initiated their knowledge translation and mobilization plans
- Communities will identify specific metrics and culturally safe ways of collecting data on respectful maternity care in Indigenous communities in BC
- We will co-develop a roadmap and strategy for Indigenous communities to lead or meaningfully participate in maternity care research that promotes autonomy cultural safety, and decolonizes birth research

Presentations

"Centering Lived Experience & Expertise: Health Equity and Measurement," December 2021

Runtime: 15:44

Team

Dr. Rachel Olson, Co-PI; Dr. Wanda Phillips-Beck, Co-PI; Elder Roberta Price; Dr. Saraswathi Vedam, Co-PI; Sandra Gosling; Laura Beer; Ali Tatum; Chloe Rickard; Lauren Redman; Rayann Big Plume Harris; Blanche Bell; Ashley Armstrong; Tia Felix; Sage Thomas; Nikki Fraser; Elisha Taylor-Child; Muriel Scott

Cross-cultural validation methods for generic PROMs

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This project addressed the priorities:

- *Giving 'voice' to patient, family, caregiver, and community stories*
- *Measurement tools that are individualized or tailored for diverse patients and populations*

Project summary

Multiculturalism is highly valued and present in Canadian society.

In British Columbia, based on Statistics Canada (2016), more than 200 ethnic groups are reported in Greater Vancouver. About 42% of the population is made up of visible minorities. There is a need for enhancing the representation of culturally diverse populations in patient-centred measurement surveys.

Patient-reported outcome measures (PROMs) are increasingly used in patient surveys to obtain information about patients' perspectives of their health outcomes, including their symptoms and physical, emotional, and social wellbeing.

Although many PROMs have been translated into different languages, it is unknown to what extent these translated versions equivalently represent people's perspectives from different cultural traditions.

One way to measure PROMS is using the Veterans RAND 12-item health survey (VR-12). The VR-12 is a self-administered health survey with 12 items, including general health perceptions, physical functioning, role related to physical and emotional challenges, bodily pain, energy-fatigue, social functioning, changes in physical and emotional health.

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Our project tested the VR-12's Chinese translations using our newly developed psychological measurement methods and engaged Chinese-speaking immigrants to uncover their perspectives on, experiences with, and needs for health care.

Project findings

Our project developed a "patient-oriented cross-cultural measurement validation methodology" using:

- Psychometric *(psychological measurement)* engagement methods
- Community consultation and engagement methods

Psychometric engagement with the VR-12

We developed novel multivariate statistical models, then used them to demonstrate that the two Chinese language versions of the VR-12 equivalently represent the perspectives of respondents who chose either the Simplified or Traditional Chinese language versions.

Further research will test each Chinese language version against the original English version.

Community consultation and engagement

In our community consultation and engagement process, we engaged Chinese-speaking immigrants, who tended to prefer to complete questionnaires in Simplified or Traditional Chinese.

Five main findings emerged:

1: Uncovering health needs and outcomes

In general, the translated two VR-12 Chinese versions are applicable to uncover patients' basic needs (physical & mental health) and health outcomes.

However, more concepts need to be included to uncover more comprehensive health needs and outcomes, such as:

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- Chinese yin-yang health beliefs practices
- Length of stay in Canada
- Acculturation level into Canadian culture
- Values and language abilities

2: Diversity and inclusion in care

Participants expressed their needs from the existing healthcare system in BC to provide **diversity and inclusion care programs** to commensurate their Chinese yin-yang health beliefs embedded in their unique cultural background.

For example, participants emphasized:

- Traditional Chinese Medicine
- Physicians to be educated in their medical school training about patients' lived experiences due to their cultural upbringing

3: Language translation support

Participants expressed a significant need for **language translation support,** especially for new immigrants, for example, the need for Chinese-speaking doctors to understand and communicate with them.

4: Appointment booking

Participants shared their difficulties in **booking an appointment** with their GP or specialist. The resources available to them are limited—especially for new Chinese-speaking immigrants.

5: Mental health needs

The responses to the translated VR-12, and the community consultation and engagement process, uncovered **urgent mental health needs** among the Chinese-speaking participants. The COVID-19 pandemic has enhanced the severity of this

issue and need. Participants expressed a need for mental health professionals who **understand their cultural backgrounds**. Finding appropriate mental health professionals is especially difficult for new immigrants, who have struggled to find Chinese-speaking providers.

Team

Dr. Tina Wu, PI ✉; Dr. Bruno D. Zumbo, PI ✉; Dr. Richard Sawatzky, Co-PI; Sophie Ma Zhu; Xuyan Tang; Kyle Dewsnap; Nancy Zhang; Clark Tang; Qunguanyi Xu; Dr. Keith Chan; Dr. Cynthia Chan

Cultural safety in patient-centred measurement methodologies

Contact: Mathew.Fleury@fnha.ca

This project addressed the priorities:

- *Giving 'voice' to patient, family, caregiver, and community stories*
- *Indigenous methodologies for Patient-Centred Measurement*

Project summary

Findings arising from the In Plain Sight (2020) report confirmed that Indigenous Peoples in British Columbia are faced with discrimination and racism in the healthcare system. Patient-reported experience measurement (PREMs) is essential to understanding the experiences of patients in the healthcare system—but it is important that PREMs for Indigenous Peoples are conducted in culturally safe ways.

"Patient-Reported Experience Measures" (PREMs) use questionnaires to gather information on patients' views of their experience while they are receiving care.

Project findings

To better understand cultural safety in PREMs, this research project had a two-fold approach: a **scoping review** and **key informant interviews.**

The scoping review focused on the methodology of published studies. In total, 79 articles were included and several key factors were found, including:

- Exploring the extent to which Indigenous Peoples were involved in the **research design and implementation** of the study
- Whether the findings were **validated** with Indigenous patient partners or communities

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The research project also included **interviews with key informants.** In total, eleven key informants were interviewed. We discussed how PREMs could be done in a culturally safe way with Indigenous Peoples. The historical and social context of colonization and the subsequent power imbalances between Indigenous patients and the healthcare system was a prominent factor in shaping experiences within healthcare settings.

Some key recommendations emerged, including:

- Research in this area needs to be **led by Indigenous individuals** embedded in Indigenous communities with an understanding of the importance of reciprocity in relationships
- The primacy of **oral traditions and storytelling**
- All research activities need to be **consistent with the principles of Indigenous data governance.**

We anticipate this research will have two main outputs: **the scoping review** as well as **findings from interviews with key informants.**

Team

Advisory committee members:
Elder Syexwaliya, Ann Whonnock; Darlene Wolfe; Victoria English; Christine Hunt; Danielle Behn-Smith; Jessy Dame; Nel Weiman; Becky Palmer; Mark Matthew

Project team members:
Sonia Isaac-Mann, Lead; Megan Misovic, Lead; [Mathew Fleury, Lead ✉](#) Adam Finch; Leena Hasan; Nancy Laliberte; Katie Bauder; Jennifer Leason; Kara Turcotte; Sophia Speier

Historically involved:
In Memoriam of Bill Blackwater; Brittany Barker; Diana Clarke; Delaram Farshad; Namaste Marsden; Alexa Norton; Erika Pulfer; Dion Thevarge; Ashok Krishnamurthy

Project PDF on next page.

Cultural Safety in Patient-Centered Measurement Methodologies

Our team compiled the findings from the interviews into sub-themes, which are organized into four main themes

Theme 1- *Indigenous Health Systems*

The first general themes we found were about acknowledging how Indigenous health and wellness systems have sustained and continue to sustain the health of Indigenous people and communities. The themes included:

- **Emphasizing oral traditions and storytelling**
- **Connection to culture including Indigenous and traditional knowledges, medicines, practices**

Theme 2- *Role of Colonialism*

The next themes describe the role of colonialism in Canada and how it fuels distrust in institutions like health care. There were many comments about the lack of relationship and community values in the Canadian health care system. Many of you also shared these experiences in connection with power imbalances and racism. These themes were:

- **The role of colonialism in Canada and the makeup of the health care system**
- **The colonial health care system doesn't respect Indigenous values and ways of healing**
- **Overt experiences of racism in the health care system**

Theme 3- *Voices for Change*

The third set of themes related to the importance of having your voices heard, for action and system change. These themes also speak to your experiences of frustration over the lack of accountability and action, while also recognizing the progress and good work underway.

- **Indigenous people are interconnected and sharing information**
- **Importance of Indigenous people sharing their health care experiences**
- **Importance of truth telling and real listening**
- **A need for accountability to actually influence policy and practice**
- **Knowing how to navigate the system, advocate and find supports**
- **Balancing the need for new information with what has already been shared**
- **The system is at the root of the problem**

Theme 4- *The Way Forward*

The final set of themes are about the way forward, as Indigenous people are championing health sovereignty and self-determination.

- **Indigenous people determining what is asked and what is shared about their health care**
- **What is done with the information about patient experiences is important for the wellbeing of patients and systems change**
- **Nothing about us without us**
- **Work should reflect the values of Indigenous people and communities**
- **Indigenous data governance principles and self-identification**
- **Methods used for understanding patient experiences**
- **To ensure work around patient experiences and quality affect systems change, it should be Indigenous-led**
- **Resources/What is being done already**
- **Examples/Knowledge to action/Ways forward**
- **When are standardized questionnaires appropriate/helpful**

A roadmap for developing Indigenous patient-reported outcome and experience measures

Contact: ldagincourt@telus.net, jenny32@uvic.ca, SZiabakhsh@cw.bc.ca

This project addressed the priorities:

- *Advancing methods for ensuring PCM accurately reflects what is important to patients*
- *Giving 'voice' to patient, family, caregiver, and community stories*
- *Indigenous methodologies for Patient-Centred Measurement*

Project summary

Patients are often asked to complete surveys or questionnaires about their health and/or care experiences (also known as patient-reported outcome and experience measures, "PROMs" and "PREMs").

However, many researchers and survey makers do not know how to make surveys culturally relevant to Indigenous people—for example, how to ask the types of questions that matter to Indigenous people and communities.

We sought to create pathways (a framework) for developing culturally relevant PROMs and PREMs, as well as an inventory of existing culturally relevant PROMS and PREMs, through:

1. **A literature review:** we looked at other research and published work to see what culturally relevant surveys have already been created, and understand how they were created
2. **Interviews with researchers** who are developing Indigenous-specific PROMs and PREMs, as well as community leaders interested in using these tools
3. **Conversations with Indigenous community members** about their experiences with and perspectives on health and experience surveys

Our work began by creating a [video, posted on YouTube,](#) to introduce our team and the project to potential participants. We viewed this as a form of reciprocal knowledge sharing. Rather than researchers only asking information from the participants, the research team members introduced themselves in the video in a personal way, with the goal of bringing humanity and humility to the research process.

Our research team included Indigenous advisors (one Elder and two Elders-In-Training), who used ceremony to help bring us together and work collaboratively.

Project findings

Our "pathways" framework included 13 protocols:

1. Establish a study team grounded by Indigenous Peoples
2. Build meaningful and reciprocal relationships with Indigenous community partners; recognize the importance of speaking heart to heart
3. Create an "ethical space," meaning that all parties (Indigenous and non-Indigenous) acknowledge their different cultures and worldviews, and work with each other in a respectful and shared space
4. Ensure ceremony and storytelling are a critical part of project from beginning to end
5. Identify Indigenous community-specific priorities; conduct needs assessment, literature review and environmental scan
6. Invite and create content with Indigenous community members, leaders, and experts
7. Apply an Indigenous lens and/or knowledge consistent with Indigenous worldviews to question and content development
8. Ensure Indigenous peoples' knowledge are reflected in the survey tools
9. Validate: Ensure cultural appropriateness, acceptability, relevancy, validity, and reliability of survey questions
10. Ensure ethical data ownership, collection, and storage
11. Administer the survey using culturally appropriate methods (including in-person, or over the phone)
12. Analyze data using both Indigenous and western worldviews

13. Accountability: Ensure results are shared and used to inform changes and communicate how those changes were implemented

As stated above, our Indigenous Elder and Knowledge-Keeper team members were invaluable to this work. Among other insights, these team members demonstrated how ceremony can be included in research itself so that our research process would be both welcoming and respectful of Indigenous knowledge, and Indigenous ways of knowing. Accordingly, in our project, we also found that it is absolutely necessary to include Indigenous Elders in research involving Indigenous peoples.

Elders are frequently called upon to participate in research, yet there are not enough Elders to do the work. As such, it is important that research bodies fund positions to help build this capacity (e.g., supporting Elders-In-Training).

Presentations

March 6, 2021: Indigenous Graduate Student Symposium 2021. Shelby Loft & Tonya Smith: *A Roadmap for Indigenous Patient Reported Outcome and Experience Measures.*

- [Event page](#)
- [Program](#)

Team

[Lori d'Agincourt-Canning, Co-lead](#) ✉; [Jenny Morgan, Co-lead](#) ✉; [Shabnam Ziabakhsh, Co-lead](#) ✉; Elder Sharon Jinkerson-Brass, Co-lead; Soodi Joolaee; Tonya Smith; Shelby Loft; Tosh Mizzau; Natasha Anderson; Malina Dawn; Darci Rosalie; Danielle Harkey; Rochelle Lesueur; Julia Hwang

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A qualitative investigation of how to integrate primary caregiver-reported outcomes across the colorectal cancer journey

This project addressed the priorities:

- *Giving 'voice' to patient, family, caregiver, and community stories*
- *Measuring journey across care*

Project summary

Primary caregivers are family members or friends who take on the work of helping patients throughout their cancer journey with their physical, emotional, disease management and practical needs.

Because the cancer journey includes a long series of stressful events, primary caregivers have high levels of ongoing caregiver burden, including emotional challenges, work and income, and their own health problems.

Which of these outcomes matter most to primary caregivers? When and how is best to perform screening for these caregiver-reported outcomes (CROs)? What assistance might be most helpful?

To answer these questions, we interviewed patients with colorectal cancer, their primary caregivers, as well as health care professionals from nursing, medicine, and social work who are involved in the care of colorectal cancer patients.

Project findings

Caregiver-Reported Outcomes' development, assessment, and implementation will benefit from recognizing:

- The diversity of caregivers

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- o Multiple different family and friends are involved in caregiving, providing different support, and experiencing different challenges
- The diversity of care, including:
    - o specialized care (e.g., help with ostomy bag that collects stool or urine from outside the body)
    - o practical support (e.g., transportation)
    - o emotional support – often unrecognized / "invisible."
    - o spiritual support – often unrecognized / "invisible."
- Shifting self-identity & difficulty engaging in self care
    - o When caregivers spend more time caring and advocating for the other and less time on self-care, this can:
        - ▪ shift their sense of self
        - ▪ contribute to emotional distress
        - ▪ make it harder for them to give care
- The range of emotional challenges
    - o Emotional distress or fear were prominent emotional challenges in relation to cancer treatment
    - o But, as part of their caregiving, caregivers might face other emotional challenges, e.g., interpersonal conflict and grief
- Managing and collecting information
    - o This was an often self-taught and evolving form of advocacy
    - o Learning and doing this helped some caregivers cope, but sometimes also contributed to feeling overwhelmed
- Employment and financial disruption
- Ostomy preparation, management, and adapting to life changes
- Conflicting perspectives about sharing caregiver challenges with the patient
    - o Some believe that transparency is important to support the caregiver
    - o Others believe that patients knowing caregivers' challenges can contribute to caregiver burden
- Clinician time and resource limitations
- Available resources and support for caregivers
    - o e.g., do not ask the questions if there are no supports to be offered!

Publications

Howard, A.F.; Lynch, K.; Beck, S.; Torrejón, M.-J.; Avery, J.; Thorne, S.; Porcino, A.; De Vera, M.; Lambert, L.; Wolff, A.; McDonald, M.; Lee, J.; Hedges, P.; McKenzie, M. At the Heart of It All: Emotions of Consequence for the Conceptualization of Caregiver-Reported Outcomes in the Context of Colorectal Cancer. *Curr. Oncol.* **2021**, *28*, 4184-4202.

Howard, A.F., Torrejón, MJ., Lynch, K. *et al.* To share or not to share: communication of caregiver-reported outcomes when a patient has colorectal cancer. *J Patient Rep Outcomes* **6,** 13 (2022).

Howard, A.F.; Lynch, K.; Thorne, S.; Porcino, A.; Lambert, L.; De Vera, M.A.; Wolff, A.C.; Hedges, P.; Beck, S.M.; Torrejón, M.-J.; Kelly, M.T.; McKenzie, M. Occupational and Financial Setbacks in Caregivers of People with Colorectal Cancer: Considerations for Caregiver-Reported Outcomes. *Curr. Oncol.* **2022**, *29*, 8180-8196.

Presentations

Apr 2021: Oncology Nursing Society (ONS) Annual Research Forum

May 2021: Canadian Centre for Applied Research in Cancer Control (ARCC) Conference

May 2021: The 22nd International Psycho-Oncology Society World Congress (IPOS 2021)

June 2021: Canadian Association of Psychosocial Oncology (CAPO) Conference

June 2021: Multinational Association of Supportive Care in Cancer (MASCC) Meeting

Sept-Oct 2021: Canadian Association of Radiation Oncology (CARO) Annual Scientific Meeting

Oct 2021: The International Society for Quality of Life Research (ISOQOL) Annual Conference

Oct 2021: Canadian Association of Nurses in Oncology (CANO) Annual Conference

Nov 2021: BC Cancer Summit 2021

Apr 2022: Oncology Nursing Society (ONS) Annual Research Forum

Aug-Sept 2022: The 23rd International Psycho-Oncology Society World Congress (IPOS 2022)

Team

Michael McKenzie, Co-PI; Amanda Fuchsia Howard, Co-PI; Sally Thorne; Angela Wolff; Antony Porcino; Shelley Pennington; Melanie McDonald; Joyce Lee; Janine Davies; Leah Lambert; Paul Yong; Mary De Vera; Maria Jose Torrejon; Kelsey Lynch; Scott Beck; Jonathan Avery; Penelope Hedges; Mogens Gade; Leah Wong; Paul Smeltzer

Towards equity-informed care: making visible the needs of marginalized populations

Contact: equitableaccess@uvic.ca

This project addressed the priorities:

- *Measurement that is patient driven*
- *Methods for enhancing representation of marginalized, vulnerable. or hard-to-reach populations*

Project summary

People facing inequities like homelessness, poverty and stigma and who also have chronic health conditions (such as cancer, liver failure, or heart disease) are increasingly disadvantaged as their health is declining.

Research shows this group of people have many barriers to care resulting in unmet health needs, lack of trust in the health care system, and feeling judged due to mental health or substance use issues, poverty, and/or homelessness. Our research suggests that the perspectives of people who face such inequities are seldom considered, especially when interacting with health care providers.

Our project looked at the use of patient-reported outcome measures (PROMs) and patient reported experience measures (PREMs) to better understand if they capture the perspectives of marginalized populations. We worked directly with people experiencing poverty, substance use, mental health issues to figure out how to best to engage them in research, determine if and how current outcome and experience measures could be used, and which measures were most relevant.

Project findings

Some top priorities identified were:

- Experience measures that reflect the priorities and perspectives identified by the advisory committee members
- Relational PROM and PREM measures, including:
  - Being listened to
  - Being treated with dignity
  - Having a trusting relationship with health care providers
  - Having overlapping health issues

Our findings suggest that the engagement process requires **attention and thought** in the planning stages. It is important to budget the necessary time required to build relationships during the research process.

One key example of this relationship is that **how** we engage communities is as important as **what** we do together. Since patient-oriented research is committed to amplifying community voices, flexibility and accessibility are critical to facilitating co-development processes.

The pandemic disrupted our ability to engage community members face-to-face and the research team had to quickly pivot to create opportunities for meaningful conversations. However, it is important to recognize that not everyone has the technology, resources, or ability to move to a virtual platform.

Ultimately, these findings suggest that measurement tools used with marginalized populations need to **reflect the perspectives being measured** and that **experiences of care may have significant impact on health outcomes**.

If someone has a poor experience when seeking care, they may be reluctant to return.

Presentations

Stajduhar, K.I. (2021 November 25). 10 Things you Need to Know in Doing Ethnographic and Community-based Research with Vulnerable and Marginalized Populations in Palliative Cares. *Dutch-Flemish Scientific Palliative Care Conference,* Tiel, The Netherlands (virtual).
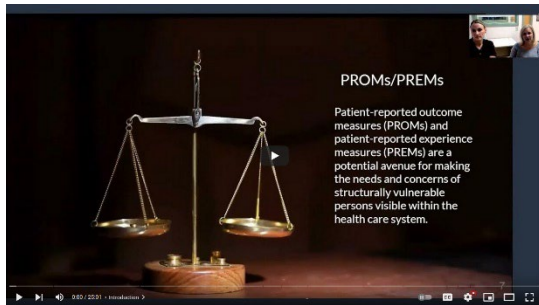
Stajduhar, K., & Whitlock, K. (2021, October). [Advancing the science of patient-centered measurement methods: Making visible the needs of vulnerable and marginalized populations.](#) *28th International Society for Quality of Life Research,* Calgary, AB. (virtual).

Runtime: 25:01

Donald, E., Whitlock, K., Sands, D.J., & Stajduhar, K.I. (2020, October 8). Towards equity-informed care: A co-development process for meaningful patient-reported evaluation of care for persons experiencing structural vulnerability and chronic illness. [Presentation]. *Putting Patients First 2020 Conference*, BC (virtual).

- Two members of the lived experience advisory committee presented our work as a poster in the PPF20 put on by the BC Support unit.

Team

Kelli Stajduhar, PI; Mary Chudley; Rick Sawatzky; Ryan McNeil; Morgan Price; Fraser Black; Jill Gerke; Carolyn Wilkinson; Erin Donald; Carren Dujela; Ashley Mollison; Kara Whitlock

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Incorporating patient-reported outcome (PROMs) and experience measures (PREMs) in practice: a resource guide about what clinicians need

Contact: angela.wolff@twu.ca

This project addressed the priorities:

- *Improving the use of PCM data for research, evaluation, clinical, and administrative purposes*

Project summary

In health care, providing patient-centred care is a hallmark of effective, quality health care. Patient-centred care focuses on the needs and perspectives of the patient. This means care providers are faced with the challenge of focus on what matters to patients during their encounters with the health system.

We wanted to know how to help health care providers to use assessment tools that are patient-centred—also known as patient-centered measurement (**PCM**). We also wanted to know how health care providers routinely use this information to inform patients' care.

To address these questions, we studied how providers can interpret and integrate data from patient-centered measurement assessments (experience and outcome tools) into routine clinical care. To do this, we conducted a systematic review, provider interviews, and stakeholder review of our findings at a deliberative dialogue forum.

Project findings

Our project developed a resource guide for clinicians that complements other existing resources about PCM implementation. We focussed on using PCM to

facilitate shared decision-making between providers, patients and caregivers at the point of care. The guide also identifies strategies facilitate this change in practice and mitigate barriers.

How to use the guide

This *Resource Guide* complements other existing resources about PCM implementation with a specific focus on the healthcare providers who use the PCM tools. The guide shares the benefits of incorporating PCMs into clinicans' practice.

 This guide could be used in various situations:

1. Current implementation of PCM to optimize clinician uptake
2. Planning for implementation of PCM to identify anticipated needs and factors (barriers and facilitators) influencing clinicians
3. Clinicians seeking to use PCMs in their practice
4. Patients advocating for the use of PCMs
5. Educate health professional students about incorporating PCMs into practice

The information is based on clinicians' "real world" experiences that can be adapted to the **local context**. Individuals can determine how to use this information for their own goals and needs based on local/organizational contexts. The guide also identifies strategies to facilitate this change in practice and mitigate barriers.

The findings fall under three headings: capability, motivation, and opportunity.

1. Practical knowledge for health care providers (HCPs) (capability)

- Knowledge is a key factor that influences clinicians' behavior to incorporate PCMs into practice
- General and specific knowledge about PCM within a clinical context/practice area
- Foundational knowledge about PCMs is necessary to scaffold more specific knowledge and skill development
- Pattern recognition necessary clinical judgement based on PCM data

2. Procedural knowledge for HCPs (capability)

- HCPs need to acquire the "know-how" knowledge to be able to incorporate PCMs into the current workflow
- The exact procedures to administer the PCMs are necessary, including how to view the results and understand how it informs patient care

3. Attitude and beliefs of the HCP about PCMs (motivation)

- Personal experiences (providers' self-confidence and self efficacy)
- Beliefs about PCMs in practice as clinically relevant, beneficial to patients, and valuable to support clinical decisions for care planning/treatment
- Burden to patients such having difficulty completing the PCM assessment questions and ensuring PCMs represent what is important to patients

4. Skills/Skill development of HCPs (capability)

- Ability or proficiency acquired through training and/or practice
- Develop clinical competence using PCMs
- Most important skill acquisition is interpretation of PCMs to understand its clinical significance (e.g., summary scores, item or subscale scores, and score changes) to inform care decisions and planning
- Interpersonal skills are necessary to administer PCM tools and discuss the results to inform care

5. Decision-making processes of HCPs (capability)

- PCMs can be used in conjunction with other data elicited by clinicians (e.g., health history, physical assessment, test results) to support clinical judgment, opinions, and decisions
- Interpretation of PCM data/scores can be used to make clinical decisions and review treatment options with patients to tailor their care

6. Environmental context and resources for PCM implementation (opportunity/enabler)

- Resources / material resources necessary for PCM implementation
- Organizational values that are patient-centred
- Address the environmental challenges that impact the integration of PCMs by healthcare providers

Publications

Wolff, A.C., Dresselhuis, A., Hejazi, S. *et al.* Healthcare provider characteristics that influence the implementation of individual-level patient-centered outcome measure (PROM) and patient-reported experience measure (PREM) data across practice settings: a protocol for a mixed methods systematic review with a narrative synthesis. *Syst Rev* **10,** 169 (2021).

08/05/2021: "TWU researchers Abner Kooner, Lillian Li, and Gabriella Collins advance patient-centered practices in Canadian healthcare"

Presentations

December 2021: "Putting the Horse before the Cart: A resource guide about the needs of health care providers for the implementation of patient-centred measurement data in care" *Methods Matters* (BC SUPPORT Unit)

Runtime: 56:16

October 2021: International Society for Quality of Life (ISOQOL) annual conference, three workshops and one group symposium:

- **Workshop 1** "Using PROMs for Screening, presentation:" *Consideration of the Needs of Clinicians to Successfully Implement PROMs Used for Screening Purposes*
- **Workshop 2** "How to Integrate PROs in Routine Care using Complexity Theory," presentation: *Complex Interventions and Implementation Science*
- **Workshop 3** "PROMs data visualization in the clinical setting: what do clinician's need to see?," presentation: *What works for clinicians? A Discussion Panel*
- **Symposium** entitled "Understanding the Needs and Individual Factors Influencing Clinicians' Behaviour to Integrate PROMs in Daily Practice," presentation: *User's Guide for Clinicians to Integrate Patient-Reported Outcome Measures into Daily Practice: A Mixed Method Study*

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October 2021: ISOQOL, Calgary, Oral Presentation, [Using Qualitative Interviews and Deliberative Dialogue to Triangulate Systematic Review Findings about Clinicians Use of Patient-Reported Outcome Measures (PROMs) in Daily Practice](#)

June 2021: University of Sheffield Oral Presentation, *Embedding Patient-Report Outcome Measures in the Curriculum: Lessons Learned from Student Physiotherapy Education based on a Mixed Methods Study*

June 2021: PROMs Down Under, two poster presentations (with audio recording)

- *Healthcare Providers' Experience of Incorporating the Voice of Patients: How to Conduct a Mixed Method Systematic Review of Non-experimental Research Using Nvivo*
- *Supporting Clinicians to Modify their Everyday Practice to Integrate Patient-Reported Outcome Measures*

August 2020: TWU Research and Creativity Symposium, Oral presentation, *Using NVivo™ for Data Extraction and Synthesis in Systematic Reviews*

October 2020: ISOQOL, Prague, Poster Presentation, *Healthcare providers' implementation of patient-report outcome and experience measures in clinical practice: A mixed method systematic review using an implementation science framework*

Subsequent grants

Developing Clinical Decision Tools and Hosting Educational Events to Disseminate an Evidence-based Resource Guide for the Sustained Use of Patient-Centered Measurement Data in Mental Health (2021-2022), MSFHR Reach (15,000). Principal Investigator: Wolff, A.C. Co-investigators: Neptune, A., Yaghoub Zadeh, Z., Musto, L., and Jones, B. (patient partner)

Team

Detailed team list with affiliations on next two pages.

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Abner Kooner Undergraduate Student Research Award (2021)
Lillian Li Undergraduate Student Research Award (2021)
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Advancing the science of patient-centred measurement in team-based care

Contact: daviss@uvic.ca, marcyant@umich.edu

This project addressed the priorities:

- *Developing and implementation of innovative technology for PCM*
- *Improving use of PCM data for research, clinical, evaluation, and administrative purposes*
- *Integrating of patient-reported data with clinical and administrative data*

Project summary

Our study aims to develop new methods of including patient-generated data in a team-based primary care clinic.

Examples of patient-generated data are measures that ask patients about their experience with their care teams, and about their quality of life.

We specifically looked at measures that focus on mental health. Using a knowledge sharing approach (integrated knowledge translation), we explored new methods as to how this patient-generated data could be completed, accessed, and used by patients and their care team.

Project stages

Stage 1: Showing how patient-generated data can support care decisions

For our study, the patient's care team included a doctor, nurse, social worker, and medical office assistant. We created a set of scenarios to show how patient-generated data can support decisions with the care team. The scenarios were

discussed with healthcare providers and patient partners to understand how to integrate patient-generated data into team-based clinic processes.

Stage 2: Developing and implementing a portal

Working with our industry partner and patient partners, we co-developed an online patient-centred platform (i.e. portal) that was specific to our study. We worked with the providers and patient partners in selecting the measures for the portal.

The portal contained two patient-reported outcome measures (PROMs) for mental health (e.g., GAD-7, PHQ-9) and one for self-efficacy (PROMIS® self-efficacy), a patient-reported experience measure, and a depression self-action plan. We also incorporated over thirty articles on evidence-based mental health online educational resources, as well as information on local programs and services.

Our patient partners selected the material, reviewed the articles, and tested the portal.

Stage 3: Using the portal

Patients and providers used the portal for four months. We interviewed them over this time-period to support further iterations of the portal and integration of patient-generated data into team-based care. We asked patients and healthcare providers about how they could use these measures to improve communication and decision-making during care visits and manage care between visits.

Stage 4: Evaluation

The data we have gathered are in the form of documents, interviews, healthcare provider team discussions, care workflow diagrams, and team-based scenario maps. Our analysis of the data resulted in a narrative summary.

Stage 5: Final outputs and sharing results

The final output will be in the form of an online guidance document (in development at PCMinTBC.uvic.ca) that is accessible to patients, healthcare providers, quality improvement analysts, decision-makers, researchers, and technical staff. The guide will provide information on how patient-generated data

can be integrated into team-based primary care using digital health technologies for patients and providers.

Project findings

We conceptualized five team-based PCM methods through this study:

1. **PCM Team Mapping,** as a technique to provide greater clarity of care-team roles and responsibilities in data collected through PCM.
2. **Longitudinal Care Alignment** to guide the care-team on incorporating PCM into ongoing provider-patient interactions.
3. **Digital Tool Exploration** to evaluate care-team members' readiness toward digital tool adoption, and the impact of these tools.
4. **Team-based Quality Improvement** in engaging teams in patient-centered quality improvement.
5. **Shared Learning** promotes provider-patient interactions that validate patient's perspectives of their care.

The adoption of team-based primary care within Patient Medical Homes provides an opportunity to conceptualize team-based PCM methods in new ways to advance patient-oriented research and patient-centered care.

More information about our study is available at PCMinTBC.uvic.ca

Publications

Antonio, M.G., Davis, S., Smith, M. Burgener, P., Price, M., Lavallee, D., Fletcher, S., & Lau, F., (2022). Advancing digital patient-centered measurement methods for team-based care. SAGE Digital Health.

Davis S, Antonio M, Smith M, Burgener P, Lavallee DC, Price M, Fletcher SC, Lau F. Paving the way for electronic patient-centred measurement in team-based primary care: an integrated knowledge translation approach. JMIR Formative Research. 30/12/2021:33584

Presentations
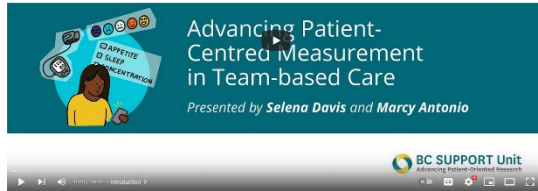
March 2021: "Advancing Patient-Centred Measurement in Team-Based Care" *Methods Matters* (BC SUPPORT Unit)

Runtime: 56:02

Sept 2021: Patient Advisory Committee of the KB Division of Family Practice/Interior Health Collaborative Services Committee

Team

Francis Lau, co-PI; Selena Davis, co-PI ✉; Marcy Antonio, co-I ✉; Mindy Smith; Paul Burgener; Morgan Price; Danielle Lavallee; Sarah Fletcher; Bruce Forde; Leila Dale

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Methods
Clusters

Improving methods for using patient-centred data for clinical purposes

Contact: jason.sutherland@ubc.ca

This project addressed the priorities:

- *Improving use of PCM data for research, clinical, evaluation, and administrative purposes*

Project summary

Our project studied where there were differences in the minimal important difference (MIDs) among patient groups for elective surgeries.

What is an MID?

When patients and doctors are choosing among treatments, one aspect they consider is the patient's perceptions of change. The "minimal important difference" (MID) is the smallest gain in health where the patient is going to report the intervention was effective. To estimate a treatment's MID, we measure, from each patient:

- Their "patient reported outcome" (e.g., health, quality of life) before the treatment
- The same "patient reported outcome" after treatment
- How the patient feels about the change in their "outcome" (e.g., health, quality of life; e.g., much worse, a little worse, the same/no change, a little better, much better)

How are MIDs useful?

When choosing among treatments, or choosing whether to continue with or stop taking a treatment, patients and their doctors may consider the MID as an important threshold to experience important in health-related quality of life. Researchers also use the MID to evaluate the effectiveness of interventions.

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How did our project study MIDs?

The MID is a single value and does not differ by the characteristics of the patient. This study sought to measure where people with different demographics (i.e., age, sex, health status) would have different MID values.

We studied two treatments for which patient-reported outcome data was available: gallbladder removal ("Laparoscopic cholecystectomy"), and ankle replacement ("arthrodesis").

Project findings

From our study on gallbladder removal, we found:

- **Sex:** no statistically significant differences in MID values.
- **Age:** no statistically significant differences in MID values, although our findings suggested there may be significant differences that could be found in a larger group of participants.
- **Baseline health status:** statistically significant differences in MID values. Patients reporting the worst symptoms pre-operatively experienced the most improvement.

From our study on ankle replacement, we found:

- **Sex:** no statistically significant differences in MID values.
- **Age:** statistically significant differences in MID values.
- **Baseline ankle-related health status:** statistically significant differences in MID values. Patients reporting the worst symptoms pre-operatively experienced the most improvement.

Publications

Sutherland, J.M., Albanese, C.M., Crump, T. et al. The minimally important difference of the Gastrointestinal Quality of Life Index for symptomatic gallstone surgery. Surg Endosc (2021).

Sutherland, J.M., Albanese, C.M., Wing, K. et al. Effect of Patient Demographics on Minimally Important Difference of Ankle Osteoarthritis Scale Among End-Stage Ankle Arthritis Patients. Foot & Ankle International. 2021;42(5):624-632.

Team

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Methods
Clusters

Patient-driven data collection and usage in chronic disease management

This project addressed the priorities:

- *Developing and implementation of innovative technology for PCM*
- *Improving use of PCM data for research, clinical, evaluation, and administrative purposes*
- *Measurement that is patient driven*

Project summary

For chronic conditions like hypertension, patients must take an active role in the management of their illness including blood pressure monitoring, evaluating symptoms, tracking medications, changing and monitoring health behaviors, and relaying information to often multiple care providers for coordinated care. Currently, this is poorly done resulting in increased preventable morbidity and mortality. There is an opportunity to advance the science of patient-centered measurement by studying patient-driven data collection, feedback mechanisms, and integration in hypertension clinical practice.

This study identified a process to understand patient-driven priorities on measurement for chronic hypertension management.

Project findings

We conducted focus groups where participants differed in age and sex, in an iterative fashion. This allowed us to identify patient priorities in patient-centered measurements, and understand how to incorporate measures into patient care.

- The patient participants were most interested in monitoring their **medications, side effects,** and their **blood pressure.**

- The patients were interested in monitoring other aspects of their health as well, including **activity levels.**
- The patients had significant variability in **frequency and type** of monitoring and this varied by individual and changing health circumstance.
- The patients were most interested in measuring and collecting data that would help **change their personal management** (for example, if they walked more, would their blood pressure drop) **or their care plan** with the physician.
  - For example, they preferred to measure side effects and use of medications with reductions in blood pressure to determine if medications should be continued or titrated.
- The patients also wanted to receive automated feedback, tailoring of education materials and easy, simplified graphical displays of their data.

We found that an iterative cycle of reviewing findings with patients, physicians, and application designers led to better measurement tools for the patient-provider encounter.

Based on these insights, we were able to develop patient-driven features for a novel hypertension digital health application with our technology partner, Cambian.

These features include:

- Blood pressure measurement (systolic, diastolic, pulse)
- Cardiovascular risk assessment
- Hypertension type indicator (cause, severity, preference)
- Patient-tailored education content that address their management priorities

Publications

Connections Journal (for scientists in the virtual care field)

Presentations

November 2021: Latin American Society of Hypertension

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