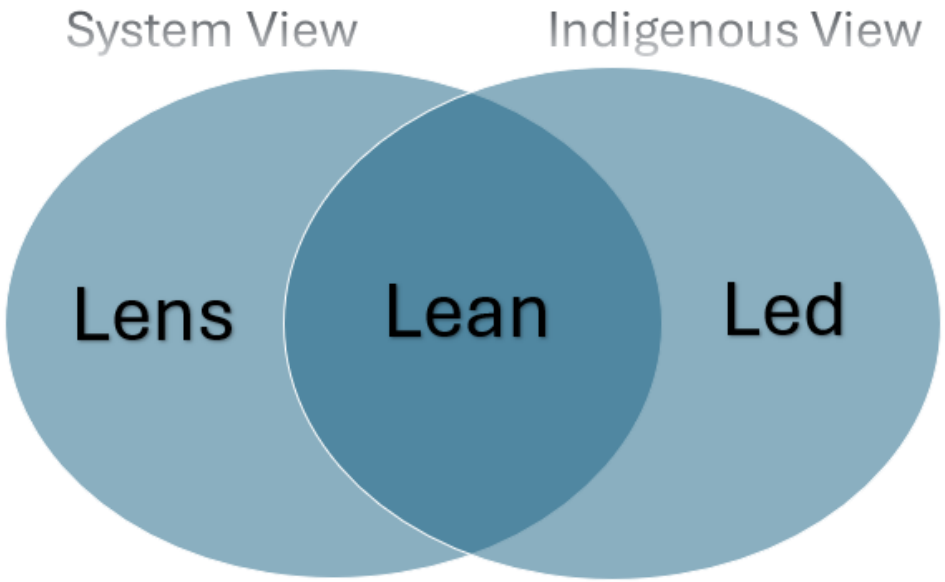
Xyemstés re xqweqwĺúten-kt

All of our voices are respected.

All of our voices are heard.

All of our voices matter.

A Conceptual Framework for Indigenous Approaches in Patient-Centred Measurement



This Conceptual Framework was developed by the British Columbia Patient-Centred Measurement Indigenous Advisory Committee

Questions and inquieries about this work can be directed to: **info.bcpcm@providencehealth.bc.ca**

The Development and Use of this Conceptual Framework

This *Conceptual Framework* for Indigenous Approaches in Patient-Centred Measurement is the outcome of four years of discussions by members of the British Columbia Patient-Centred Measurement Steering Committee's Indigenous Advisory Committee (the IAC). For more information about the IAC, please visit our website at www.bcpcm.ca/indigenous-pcm. The IAC is now ready to share both the use and ongoing development of the Conceptual Framework with Indigenous and health systems partners. The documentation of the Conceptual Framework, along with its socialization within the broader academic, Indigenous, and health systems communities, marks the first step in this process. The foundation of this *Conceptual Framework* is the mandate provided by the ***Declaration on the Rights of Indigenous People's Act*** **(***DRIPA*) for health systems to uphold self-determination, BC First Nations Right and Title and inherent Indigenous rights.

How we conceptualize patient-reported experience and outcome measurements is important as they play a significant role in the advancement of Indigenous rights and wellbeing through embedding and prioritizing *Indigenous knowledge systems* and methods into the design and delivery of health and wellness services.

When this *Conceptual Framework* talks about applying an 'Indigenous Lens (Review and Reflect)', it is acknowledging that system-led work requires the guidance of Indigenous peoples. The 'Indigenous Lean (Co-Design)' work is carried outby the system and Indigenous partners. And, importantly, non-Indigenous organizations have a responsibility to make space for and provide support to the elements of this work that is 'Indigenous Led (Self-Determination)'.

Commitment to Self-Determination

The goals of an Indigenous-specific approach to patient-centered measurement are to gather and distribute knowledge that contributes towards Indigenous self-determination, the elimination of Indigenous-specific racism and discrimination, and the "equal right to the enjoyment of the highest attainable standard of physical and mental health" (*DRIPA*). Canada and British Columbia's health systems have legal obligations outlined in *Section 35 of the Constitution Act*, and the *Declaration on the Rights of Indigenous People's Act* (*DRIPA*), including to "take the necessary steps with a view to achieving progressively the full realization of this right" (ibid) to access health and social services without discrimination.

This Conceptual Framework aims to support this commitment to self-determination and recognizes that Indigenous approaches will be as diverse as Indigenous Peoples, and are rooted in First Nations, Métis, and Inuit traditions and knowledges. It promotes the use of a common language to identify opportunities for Indigenous perspectives to contribute to the broader patient experience measurement ecosystem within the approach of including the Indigenous Lens. For more information on Indigenous Self-Determination, see Appendix A.

Using a Distinctions-Based Approach

This *Conceptual Framework* promotes a Distinctions-Based Approach to data collection and reporting, as required and outlined in the Government of BC's *Distinctions-Based Primer*[1], which recognizes the importance of working independently with First Nations, Métis, and Inuit in recognition of their unique communities, the Rights and Title of the First Nations of BC, and Rights as defined under Section 35 of the *Constitution Act* (1982), and affirmed by more recent court decisions. That said, it is also recognized that there are times when a collective Indigenous perspective may strategically advance this work within the health care system more efficiently and effectively. We invite learners to hold this complexity as they navigate how best to apply a distinctions-based approach when contemplating operational planning, changes, or funding. For more information on using a distinctions-based approach please see Appendix B.

Recognizing Unique Relationships

We acknowledge the unique relationships between First Nations, Métis, and Inuit and governmental institutions. It is crucial to address both historical and current colonial harms from Indigenous-specific racism and discrimination, structural norms, and policies. It is also important to work towards adherence with legislation, including but not limited to the Declaration on the Rights of Indigenous Peoples Act (*DRIPA*), legislation that targets Indigenous-specific racism in the health system, and Anti-Racism Data Act. Rights, and when appropriate Title, recognition is foundational to creating a framework that supports self-determination and respects Indigenous ways of knowing and being.

[1] https://www2.gov.bc.ca/assets/gov/british-columbians-our-governments/indigenous-people/aboriginal-peoples-documents/distinctions_based_approach_primer.pdf

Statement on Inclusivity, Collaboration, and Evolution of the Model

As the *Conceptual Framework* remains a "work in progress", the IAC believes that it is essential to share iterative drafts of it for review by other groups, fostering inclusivity and diverse perspectives. Identifying and inviting contributors for these reviews ensures that the *Conceptual Framework* reflects a broad range of insights and experiences.

Scope Statement

While this *Conceptual Framework* was created to strengthen practices and knowledge relating to Indigenous patient-centred measurement, these concepts may be relevant to other areas of collaboration and research relating to First Nations, Métis, and Inuit peoples.

Contents

The Development and Use of this Conceptual Framework **2**
Commitment to Self-Determination ..... **Error! Bookmark not defined.**
Using a Distinctions-Based Approach 3
Recognizing Unique Relationships 3
Statement on Inclusivity, Collaboration, and Evolution of the Model 4
Scope Statement 4

The Conceptual Framework for Indigenous Approaches in Patient-Centred Measurement **6**
Patient Self-Reported Experiences and Outcomes of Care are Important Indicators of Health System Performance 7

Conceptual Overview **9**
The Conceptual Framework for Indigenous Approaches in Patient-Centred Measurement and System Transformation 9
Differentiating Indigenous Lens, Lean, and Led 10

Survey Design: Applying Indigenous Lens, Lean, Led Approaches **15**
1. Be grounded in Indigenous Peoples Community-Based Approaches 15
2. Build Meaningful and Reciprocal Relationships Over Time 15
3. Invite and Create Content with Indigenous Community Members 16
4. Identify Indigenous-Specific Priorities (e.g., Inclusion/Exclusion Criteria) 16
5. Administer the Survey Using Culturally-Appropriate Methods 17
6. Hire and Train Locally, Build Local Nation/Community Capacity 17
7. Ensure Indigenous Peoples' Knowledges are Reflected in Approach (e.g., Images, Truth telling, Ceremony, Protocols) 18
8. Establish Accurate and Meaningful Information on Indigenous Patient Experiences and Outcomes 18

Conclusion **20**

Appendices **21**
Appendix A – Explanation of Commitment to Self-Determination 21
Appendix B – Explanation of Distinction-Based Approach 22
Appendix C – Explanation of Patient-Centred Measurement 24
Appendix D – Diagram showing a brief overview of the three related approaches 27

The Conceptual Framework for Indigenous Approaches in Patient-Centred Measurement

Patient-Centred Measurement (PCM) is intended to foster an inclusive, respectful, and culturally relevant healthcare system for all patients through its question design, data collection and use. This **Conceptual Framework for Indigenous Approaches in Patient-Centred Measurement** outlines and explains three domains applied to PCM practices. The domains discussed here are **not** a set of steps to achieve, but rather, are a pathway to understanding and growth.

The Conceptual Framework illustrates the life cycle of PCM work through three interconnected approaches: Indigenous Lens (Review and Reflect), Indigenous Lean (Co-Design), and Indigenous Led (Self-Determination). These approaches represent a shift in orientation, moving from conventional measurement approaches to those deeply rooted in Indigenous knowledges and ways of being.

3 Key Considerations for Use of this Conceptual Framework:

- Patient-centred measurement is distinct from research, in its aim to prioritize and incorporate patients' voices directly into the evaluation of healthcare, fostering a continuous improvement process.
- The approaches presented can be used in combination, as applied to different stages of PCM work; they are **not** to be viewed as sequential step-by-step instructions.
- The Conceptual Framework is a guide for different approaches to meaningful measurement of Indigenous experiences and outcomes, as well as an opportunity for engagement and discussion; it is not a criticism/commentary of current approaches or work underway.

The three domains of the Conceptual Framework—Indigenous Lens, Indigenous Lean, and Indigenous Led—reflect a spectrum of Indigenous involvement and decision making to the process. Use of the Conceptual Framework can support gathering more accurate information on Indigenous patient experiences and outcomes in BC and elsewhere. This approach is not about achieving specific measurement outcomes, but rather about fostering a deep, ongoing understanding that supports the growth and transformation of healthcare systems to be more inclusive and respectful of Indigenous Peoples, their views, knowledges, Title, Rights and cultures.

Patient Self-Reported Experiences and Outcomes of Care are Important Indicators of Health System Performance

Patient-centred measurement (PCM) is healthcare performance measurement driven by patients' expressed preferences, needs and values. It is about measuring health care quality, safety, cost and patient-reported outcomes and experiences of care in ways that reflect—or are centered on—the needs and values of patients. It is important to note that while PCM results can inform or contribute to health research, PCM is **not** a research process, rather it is meant to be part of an ongoing process supporting a learning health system delivering the highest possible quality care to patients.

What distinguishes patient-reported measures from other measures is that PCM involves partnering with patients to decide what we measure, how we measure it, how we report the information, and how we use the results of measurement. Furthermore, the hallmark of PCM is that the patient's assessment of the quality and the safety - including cultural safety - of their care comes directly from the patient themselves. PCM provides these patient perspectives on the healthcare system as a balancing or equal indicator to other clinical and administrative measures that when taken together should improve the ability of measurement to drive meaningful change.

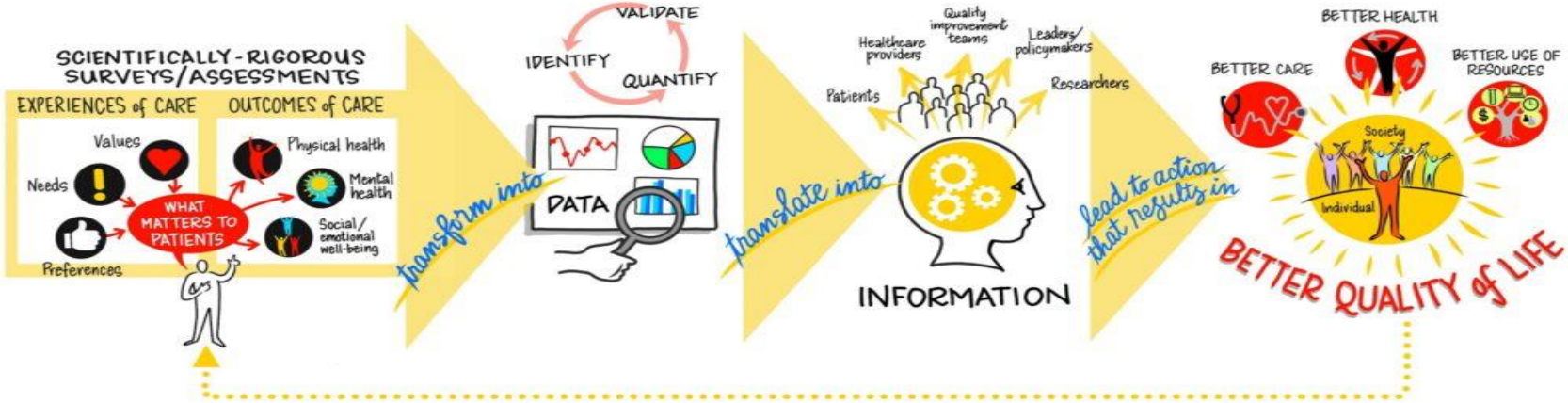


Figure 1: Cuthbertson, Lena; Sawatzky, Richard (2023). Cuthbertson, Lena; Dixon, Duncan; Schmidt, Faye; Sawatzky, Richard (2023). Graphic illustration of "Towards a working-definition of patient-centred Measurement: A review of literature". figshare. Online resource. https://doi.org/10.6084/m9.figshare.22228072.v1

Understanding the self-reported satisfaction, experiences, and health-related quality of life, or outcomes, of the people who use healthcare services in BC is a strategic priority for our health system. The measurement of patient experiences and outcomes gives those who use healthcare services a voice in evaluating the quality and safety of their care and is a means to evaluate progress towards providing care that is patient-centred, compassionate, and free of racism and discrimination.

Statement on Principles of Patient-Centred Measurement:

PCM should be driven by patients' expressed needs – not assumptions about what matters to them. By engaging patients at every step of the PCM value chain, the focus of measurement is on what matters to patients, and the results, in turn, allow a focus on improvement activities that will be key drivers of change and improvement in the quality and safety of care for all patients.

PCM best practices are based on good measurement practices that are inclusive of patients at each step:

- Robust tool design;
- Comprehensive and ongoing psychometric evaluation of items, tools and measures;
- Sound fielding protocols, including sampling plans;
- Sound data analysis/interpretation;
- Ensuring a clear, direct patient voice in the use of the data.

This description of the patient-centred measurement process and best practices within the existing system is provided for reflection on current practices and stages where the identified approaches can be engaged or applied. See page 15 for an outline of Indigenous Lens, Lean, and Led approaches applied at each stage of PCM.

For more information on PCM processes and practices, please see Appendix C and/or visit our website at www.bcpcm.ca.

Conceptual Overview

The *Conceptual Framework for Indigenous Approaches in Patient-Centred Measurement* includes three approaches that exist on a spectrum of inclusiveness and are conditional upon recognition of self-determination by colonial institutions engaging with Indigenous Peoples that may not yet reflect the current reality. They are: Indigenous Lens (Review and Reflection), Indigenous Lean (Co-Design), and Indigenous Led (Self-Determination).

Each approach reflects a distinct approach in shaping how systems support, understand and interact with Indigenous patient experiences and outcomes at individual, population and collective levels. To set the stage for understanding these approaches and how they function, we explain what they are and how they, individually and/or collectively, can be used to drive system transformation and aid in the elimination of Indigenous-specific racism.

The Conceptual Framework for Indigenous Approaches in Patient-Centred Measurement and System Transformation

Our approach to transforming systems is reflected across the three approaches which are not always mutually exclusive, can overlap, and while not linear, do work towards an end state that respects data and research sovereignty that is grounded in nation-based and community driven approaches. While the IAC began its work in the approach of Indigenous Lens, there is commitment by IAC leadership to work towards facilitating an Indigenous Led approach.

The IAC acknowledges that some PCM methods may reside in one approach, however, the intent of this work is to facilitate learning, knowledge exchange and innovation that will support more work in the development of Indigenous Led methods. This Framework acknowledges system competency, levels of learning and readiness for engaging in ways that Indigenous Peoples would like to see regarding their members' health outcomes and experiences of health care. Importantly, this is **not** a linear, step-by-step guide, nor a mere achievement of engagement checklists and minimum representation. Rather it is a spectrum that aims to encourage working towards deep, principled understanding of relationship-based partnerships with Indigenous Peoples.

- **Indigenous Lens (Review and Reflect):**
  This approach involves viewing all processes in the PCM value chain and data through a culturally relevant, and where possible, safe and accurate perspective that respects and integrates Indigenous knowledges and ways of being to tools, methods and interpretation of data. It ensures that the work reflects the realities of Indigenous Peoples, honouring their traditions and experiences.

- **Indigenous Lean (Co-Design):**
  Co-design involves working in partnership with Indigenous communities in the design and development of processes and approaches while privileging and honouring Indigenous ways of knowing and being in the patient experience measurement work. This collaborative effort ensures that the methods used are relevant and acceptable to the communities, fostering shared decision-making and mutual respect. Respectful partnerships and protocols including ethics and engagement are foundational to this approach, accompanied by appropriate resourcing.

- **Indigenous Led (Self-Determination):**
  This approach upholds the right of Indigenous communities to lead and control the processes that affect them. Methods are nation-based and community-driven and the knowledge production cycle is based in self-determination and sovereignty over knowledge, data and methods. Indigenous Peoples have ownership over the data collected and the ways it is used to improve health, services and other priorities, reflecting their unique contexts and cultures. Significant resourcing is required.

Differentiating Indigenous Lens, Lean, and Led

A clear understanding of each approach is crucial, as they are often mistaken for one another amongst those working with Indigenous Peoples; practitioners can confuse them, feel capable of doing approaches that they are not ready for, or not engage Indigenous Peoples respectfully. Specifically, Indigenous Led (Self-Determination) and Lean (Co-Design) can be confused by those external to the Nations/communities.

Some clarifying points on these approaches:

- **Indigenous Lens (Review and Reflection)** is about perspective and accuracy, ensuring cultural safety and relevance in all processes that remain largely out of the control of Indigenous Peoples.
- **Indigenous Lean (Co-Design)** is about collaborative and equal development, engaging Nations/communities in creating and refining PCM approaches that will be applied to their peoples and being involved in decisions regarding data use, storage and access.
- **Indigenous Led (Self-Determination)** is characterized by Indigenous leadership and ownership of the entire process and method(s). Nations/communities guide and control the processes and outcomes and seek western expertise in service to their methods, not the other way around which is the standard in most health research conducted by research institutions.

Examples and illustrations will be provided throughout this document to highlight these differences clearly and help convey their distinct roles.

The Conceptual Framework for Indigenous Approaches in Patient-Centred Measurement – The three Approaches

The journey to creating Indigenous Lens, Lean, and Led approaches, processes and projects is not straightforward. While there might be a single process for applying the Indigenous Lens in a given project, there could be multiple processes for Co-Design of an approach, project or tool to improve Indigenous patient experience and/or outcomes, and a multitude of potential methods for Indigenous Led, tailored to the specific needs and contexts of each Nation. This approach recognizes the diversity among Indigenous partners and avoids a one-size-fits-all approach, respecting the unique characteristics and requirements of each Nation/community.

This conceptual Framework sets the foundation for understanding how the principles of Lens, Lean, and Led collectively contribute to a more inclusive, respectful, and effective healthcare system for Indigenous Peoples.

1. Indigenous Lens (Review and Reflection)

Purpose	To enhance existing patient centred measurement (PCM) processes and policies by integrating Indigenous knowledges and terminology, and where applicable, engaging Indigenous peoples and practitioners specifically.
Key Concepts	• **Enhancement of Existing Systems**: Improve conventional PCM processes, policies, and practices by integrating Indigenous perspectives. • **Terminology Integration**: Incorporate Indigenous-relevant terminology to make PCM more inclusive. • **Policy Revisions**: Identify and remove ineffective, harmful or irrelevant policies and practices, and replacing them with more relevant ones. • **Promotion of Indigenous Knowledges**: Advocate for the inclusion and recognition of Indigenous ways of knowing and being within PCM and broader healthcare systems, such as the establishment of an Indigenous advisory committee.
Goals	• Foster cultural safety for Indigenous patient participants. • Ensure PCM systems are more relevant and responsive to Indigenous needs. • Promote understanding and respect for Indigenous health perspectives.
System Resource Considerations/ Examples	• Resources for Indigenous participation (i.e. compensation) • Investments in staff training

2. Indigenous Lean (Co-Design)

Purpose	To collaboratively design PCM systems through shared decision-making and accountability with Indigenous partners.
Key Concepts	• **Shared Governance**: Establish joint decision-making structures to ensure Indigenous voices are respected and integral to governance processes. • **Co-Designed Investment Controls**: Develop and manage PCM investments collaboratively to align with Indigenous priorities. • **Success Measures & Reporting**: Create co-designed surveys, metrics and reporting mechanisms that reflect Indigenous definitions of success. • **Leadership & Capacity Building**: Actively support Indigenous leadership and build capacity within Indigenous communities to sustain healthcare improvements.
Goals	• Strengthen partnerships between Indigenous: First Nations, Métis and Inuit communities and healthcare systems. • Ensure investments and outcomes are aligned with Indigenous priorities. • Foster accountability and transparency in PCM processes and broader healthcare governance.
System Resource Considerations/ Examples	• Resources for changes and addition of organizational staffing • Investment in sessions and events to establish relationships • Co-Investment in training, survey design and reporting

3. Indigenous Led (Self-Determination)

Purpose	To hold and resource space for Indigenous: First Nations, Métis and Inuit communities to define PCM processes and lead the work according to their own ways of knowing and being.
Key Concepts	• **Dialogue Grounded in Indigenous Knowledges**: Initiate processes with dialogue rooted in First Nations, Métis, and Inuit knowledges and practices. • **Indigenous-Centered Content**: Uphold PCM and broader healthcare processes and policies that may not necessarily align with conventional Western models but are consistent with Indigenous values. • **Community Ownership**: Invest in communities to retain ownership and control over their data and the outcomes of their initiatives.
Goals	• Uphold self-determination and Indigenous leadership in healthcare. • Develop PCM practices and policies that are culturally relevant and effective for Indigenous communities. • Ensure PCM systems are adaptable and respectful of Indigenous ways of knowing.
System Resource Considerations/ Examples	• Investment for organizational change and restructure (potential new teams) • Investment for stand alone funding for Indigenous capacity • Investment in promotion of reporting

Survey Design: Applying Indigenous Lens, Lean, Led Approaches

The following application of Indigenous Lens, Lean and Led to survey design includes good and/or standard practices within each of these domains to illustrate differences in these approaches. System resources allocation will need to be equitably considered throughout each of the approaches. It is to be understood that a working within a Lens, Lean, and Led approach will require unique and in the case of Led, significant investment to be done in a good way.

1. Be grounded in Indigenous Peoples Community-Based Approaches

Indigenous Lens (Review and Reflection):

- Ensure that community-based approaches are inclusive of Indigenous perspectives and respect cultural protocol, laws, and practices.
- Incorporate Indigenous ways of knowing and being in the design and implementation of community-based approaches.

Indigenous Lean (Co-Design):

- Engage Nation/community members in the co-design of survey methods, ensuring their input and governance shape the process.
- Establish shared decision-making structures to guide community-based approaches.

Indigenous Led (Self-Determination):

- Facilitate Nations/communities' ability to define the priority/methods based on their knowledge and cultural practices.
- PCM process is entirely driven and controlled by the Nation/community, reflecting their unique context, culture(s) and priorities.

2. Build Meaningful and Reciprocal Relationships Over Time

Indigenous Lens (Review and Reflection):

- Recognize the importance of trust-building and long-term relationship development within Indigenous communities.
- Approach relationship-building with cultural sensitivity and respect for Indigenous traditions and values.

Indigenous Lean (Co-Design):

- Co-develop partnership frameworks and ethical spaces that ensure mutual respect and shared governance.
- Collaboratively set goals and expectations for the partnership, emphasizing ongoing communication and trust.

Indigenous Led (Self-Determination):

- Uphold Indigenous Rights to take the lead in defining and guiding the work.
- Ensure PCM activities are rooted in community-driven priorities and objectives, with Indigenous leadership at the forefront.

3. Invite and Create Content with Indigenous Community Members

Indigenous Lens (Review and Reflection):

- Ensure survey questions reflect Indigenous priorities, knowledges, and cultural contexts.
- Use culturally appropriate methods to gather input from community members.

Indigenous Lean (Co-Design):

- Co-create survey questions with community members, ensuring their perspectives and needs are central to the process.
- Establish joint decision-making mechanisms to prioritize and finalize PCM questions and reporting process.

Indigenous Led (Self-Determination):

- Uphold the community's right to define the PCM priorities and ability to develop questions that are relevant to their experiences.
- Ensure the process of gathering questions is entirely community-driven and reflects Indigenous ways of knowing.

4. Identify Indigenous-Specific Priorities (e.g., Inclusion/Exclusion Criteria)

Indigenous Lens (Review and Reflection):

- Respectfully seek and incorporate Indigenous input on inclusion and exclusion criteria.
- Ensure criteria reflect the cultural and social realities of common Indigenous experiences or perspectives.

Indigenous Lean (Co-Design):

- Collaboratively develop inclusion and exclusion criteria with community partners.
- Ensure the criteria are co-created and agreed upon through shared governance structures.

Indigenous Led (Self-Determination):

- Uphold the Nation/community's right to set and define inclusion and exclusion criteria based on their unique context and priorities.
- Priorities and processes are defined by Indigenous leadership and community.

5. Administer the Survey Using Culturally Appropriate Methods

Indigenous Lens (Review and Reflection):

- Ensure the consent process respects cultural norms and practices around informed consent.
- Use culturally relevant language and methods to obtain consent.

Indigenous Lean (Co-Design):

- Co-design the consent process with community members, ensuring it reflects their values and expectations.
- Establish shared accountability for the ethical aspects of the consent process.

Indigenous Led (Self-Determination):

- Uphold the community's right to lead the creation of the consent process, ensuring it aligns with their cultural and ethical standards.
- Ensure the consent process is driven by community norms and practices, with full community ownership.
- Uphold cultural and ethical standards and decisions based upon them in colonial and mainstream institutions.

6. Hire and Train Locally, Build Local Nation/Community Capacity

Indigenous Lens (Review and Reflection):

- Prioritize local hiring and training individuals who acknowledge and respect the Indigenous perspectives, knowledges and skills.
- Provide Indigenous cultural safety and Indigenous-specific anti-racism training programs.

Indigenous Lean (Co-Design):

- Collaboratively develop hiring and training process with community input and oversight.
- Establish shared governance in capacity-building efforts, ensuring local needs and priorities are addressed.

Indigenous Led (Self-Determination):

- Invest in hiring and training processes that are defined and controlled by the community.
- Focus on building local capacity in a way that aligns with community goals and aspirations, driven by Indigenous leadership.

7. Ensure Indigenous Peoples' Knowledges are Reflected in Approach (e.g., Images, Truth telling, Ceremony, Protocols)

Indigenous Lens (Review and Reflection):

- Integrate culturally relevant elements into survey design to ensure it resonates with the community.
- Respect and incorporate Indigenous aesthetics and symbols in survey materials.

Indigenous Lean (Co-Design):

- Co-create survey materials or other appropriate information gathering methods with community members, ensuring cultural relevance and appropriateness.
- Establish shared decision-making for the design and implementation of culturally relevant approaches.

Indigenous Led (Self-Determination):

- Uphold the community's right to define and design culturally relevant approaches, ensuring they reflect their traditions and values.
- Ensure the entire process is led by community cultural practices, with full ownership and control.

8. Establish Accurate and Meaningful Information on Indigenous Patient Experiences and Outcomes

Purpose: To collectively gather and interpret data on Indigenous patient experiences and outcomes that are accurate, culturally appropriate, and reflective of Indigenous realities. To ensure ethical data ownership, collection, storage, access

and reporting within each area of the Conceptual Framework. To ensure results are shared and used to inform changes which benefit Indigenous health care experiences and outcomes.

Indigenous Lens (Review and Reflection)

- **Accuracy and Cultural Relevance**: Ensure the data accurately represents Indigenous patient experiences and outcomes by integrating Indigenous knowledges and perspectives. This involves understanding and respecting cultural nuances that may impact patient experiences and outcomes.
- **Culturally Safe Methods**: Promote the use of data collection, analytics, and reporting methods that are culturally relevant. This includes using language, policies, and practices that are meaningful and respectful to Indigenous communities.

Indigenous Lean (Co-Design)

- **Community Participation**: Actively engage Indigenous communities in the co-design of data collection and interpretation processes. This ensures that the methods used are relevant and acceptable to the community and that the data gathered is truly reflective of their experiences.
- **Mutual Data Sets**: Establish data sets that are mutually informed by Indigenous processes and conventional scientific rigor. This hybrid approach ensures that data collection methods are both culturally appropriate and scientifically robust, providing a comprehensive understanding of Indigenous patient experiences.

Indigenous Led (Self-Determination)

- **Community Leadership**: Uphold the right of Indigenous communities to create, lead and implement the data collection and interpretation processes. This empowers Nations/communities to define what information is important to them and how it should be collected and used.
- **Ownership and Control**: Ensure that the data collected is owned and controlled by Indigenous communities. This reflects their unique contexts and priorities and supports self-determination and sovereignty through Nations/ communities deciding how to use the data in ways that benefit them most.

Conclusion

This Conceptual Framework emphasizes and ensures the importance of culturally safe and community-driven measurement methods, including but not limited to tool selection or development, analysis/interpretation of results, and decision-making or actions based on results. Incorporating the component of establishing more accurate information on Indigenous patient experiences and outcomes is crucial for the overall *Conceptual Framework*. By ensuring the accuracy and cultural relevance of data through the Indigenous Lens, actively engaging Nations/communities in co-design processes through Indigenous Lean and upholding the leadership and ownership rights of Indigenous communities through Indigenous Led principles, this *Conceptual Framework* spans comprehensive approaches to patient-centered measurement that should be chosen to be applied in consultation with Indigenous Peoples.

Approaches presented in this *Conceptual Framework* ensure that the data collected not only reflects Indigenous patient experiences and outcomes accurately, but also respects and honours Indigenous ways of knowing and being. It promotes sovereignty and self-determination by supporting Indigenous Nations/communities' control over their data and its use. By integrating these principles throughout survey design, data collection and analysis processes, and decision-making or policy actions based on results, we move towards a healthcare system that is more inclusive, respectful, and responsive to the needs and realities of Indigenous patients. Significant commitments and resourcing are required to move this *Conceptual Framework* from theory to practice such that Indigenous perspectives, ways of knowing, design and leadership are pillars in the healthcare landscape.

When data is applied and utilized in ethical ways, it can lead to a more equitable healthcare system that recognizes and addresses the unique challenges and strengths of Indigenous Peoples. Trending of data over time will be a necessary component to determine if these improvement initiatives have been successful or require adjustment. In this way, the information gathered through this *Conceptual Framework's* approaches can inform policy changes, improve healthcare practices, and ultimately lead to better healthcare experiences and health outcomes for Indigenous patients, families and Nations/ communities.

Appendices

Appendix A – Explanation of Commitment to Self-Determination

The goals of an Indigenous-specific approach to patient-centered measurement are to gather and distribute knowledge that contributes towards Indigenous self-determination, the elimination of Indigenous-specific racism and discrimination, and the "equal right to the enjoyment of the highest attainable standard of physical and mental health" (*DRIPA*). Canada and British Columbia's health systems have legal obligations outlined in Section 35 of the Constitution Act, and the Declaration on the Rights of Indigenous People's Act (*DRIPA*), including to "take the necessary steps with a view to achieving progressively the full realization of this right" (ibid) to access health and social services without discrimination. To achieve these legal obligations, health and social service organizations in BC have certain responsibilities to which we are accountable. While our responsibilities are not always immediately clear, they are currently outlined in the *DRIPA Action Plan* and the *In Plain Sight Report* recommendations, and they continue to develop through ongoing dialogues with First Nations, Metis, and Inuit peoples about how to fully implement *DRIPA* without unintentionally using colonial processes, or reinforcing colonial norms and stereotypes, that undermine self-determination through the very process of decolonization.

The foundation of this conceptual framework is the mandate provided by *DRIPA* for health systems to support self-determination, Indigenous rights, and First Nations land-based rights and title. How we conceptualize patient-reported experience and outcome measurements plays a significant role in the advancement of Indigenous rights and wellbeing through embedding and prioritizing *Indigenous knowledge systems* into the design and delivery of health and wellness services. The first steps in developing Indigenous approaches to Patient-Centered Measurement are to determine which elements of achieving self-determination are the responsibility of the health system to Indigenous individuals and Nations, which elements are the responsibilities of Nations to their membership and guests living on their traditional territories, and which responsibilities are shared. These are our *reciprocal accountabilities* to health system improvements and Indigenous self-determination. When this conceptual framework talks about applying an 'Indigenous Lens' it is acknowledging that system-led work requires the guidance of Indigenous peoples. The 'Indigenous lean (co-design)' work is carried out by the system and Indigenous partners. And, importantly, non-Indigenous organizations have a responsibility to make space for and provide support to the elements of this work that is Indigenous led. This conceptual framework puts forward a plan for how non-Indigenous and Indigenous partners can walk together towards a shared goal.

Appendix B – Explanation of Distinction-Based Approach

This Conceptual Framework includes the Province's requirement to take a distinctions-based approach, as outlined in the Government of BC's *Distinctions-Based Primer*,8 which recognizes the importance of working independently with First Nations, Métis, Inuit and peoples in recognition of their unique attributes and Rights as defined under Section 35 of the *Constitution Act* (1982), and affirmed by more recent court decisions. That said, it is also recognized that there are times when a collective Indigenous perspective may strategically advance this work within the health care system more efficiently and effectively. We invite learners to hold this complexity as they navigate how best to apply a distinctions-based approach when contemplating operational planning, changes, or funding.

As per the *Distinctions-Based Primer*, a distinctions-based approach, and appropriate respect for First Nations laws and jurisdictions, means that the scope of rights enjoyed by First Nations People is contextual and that the Province's relations and dealings with First Nations, Métis, and Inuit will be conducted in a manner that is appropriate for the specific context, recognizing and respecting the distinct and different rights, laws, legal systems, and systems of governance of each. This approach, in relation to addressing Indigenous-specific racism, must ensure First Nations, Métis, Inuit are represented at all levels of decision making in a means that aligns with the legal obligations and decolonizing commitments of the Provincial and Federal governments. A distinctions-based approach furthers efforts toward reconciliation with First Nations, Métis, Inuit through self-determination in their needs, priorities, and implementation strategies. A distinctions-based approach includes but is not limited to the following considerations:

- "Not all rights are uniform or the same among or between all Indigenous Peoples. These rights are diverse, distinct, and contextual under both domestic Canadian law and international law, arising from and in relation to their unique histories, circumstances, laws, legal systems, and systems of governance. As such, the relationship and engagement with First Nations, Métis, and Inuit will require different approaches and result in different outcomes" (Distinctions-Based Primer).
- "As part of the political and social work of addressing the legacy of colonialism and systemic racism in British Columbia, the Province works with Métis Nation British Columbia in respect of Métis who have settled and are living in British Columbia and to recognize and value Métis culture. This work is distinct in scope, nature, and purpose from government-to-government relations the Province has with First Nations. It is important that this work occurs in a manner which recognizes the inherent, human, and constitutional rights of First Nations and upholds the laws, legal systems, and systems of government of First Nations" (Distinctions-Based Primer).

- BC First Nations are geographically and culturally diverse; with over 349 self-determining cultural and linguistic populations throughout the province across 203 communities. First Nations, as territorial title and rights-holders and the pre-existing sovereign societies that used and occupied lands and resources in British Columbia prior to contact, have their own laws, legal systems, and systems of governance that apply to those lands, resources, and territories. In the context of governance and decision-making, understanding the uniqueness of the First Nations or Nations in your service area is critical to ensuring appropriate implementation of a distinctions-based approach.
- The BC Association of Aboriginal Friendships Centres and other Urban organizations often can serve to provide perspectives of non-Status and away-from home First Nations populations. However, these service organizations still operate within territory-based Nations which need to be recognized and also represent their members who are away from home, and guests on their traditional territories.
- Métis in BC share collective cultural practices, kinship ties and history as a Nation. However, the Métis have often faced erasure due to the historical and ongoing nature of colonization and colonial policy and have been frequently left out of Indigenous-specific health care policies and programs. Métis Nation of BC is their provincial representative organization.
- Inuit in BC are limited in their inclusion due to limited population numbers and no formal provincial organization to elevate their collective voice. However, there is potential in seeking alignment with the health work of the national group Inuit Tapiriit Kanatami10.
- While a distinctions-based approach reminds us that a pan-Indigenous perspective tends to erase the real voices of First Nations, Métis, and Inuit, there are shared viewpoints and colonial experiences across Indigenous cultures and peoples that support collective action.

Appendix C – Explanation of Patient-Centred Measurement

What is Patient-Centred Measurement?

Patient-centred measurement (PCM) is healthcare performance measurement driven by patients' expressed preferences, needs and values. What distinguishes PCM from other measures is that PCM involves partnering with patients to decide what we measure, how we measure it, how we report the information, and how we use the results of measurement. Important to note is that while PCM results can inform or contribute to health research, the work of PCM is **not** a research process, rather it is meant to be part of an ongoing process supporting a learning health system delivering highest possible quality care to patients.

PCM is not about assessing the patient-centeredness of *care*. It is about measuring health care quality, safety, value, patient self-reported outcomes and *patient experiences of care* in ways that reflects—or centers on—the needs and values of patients. PCM is not just about developing and using measures reported by patients, such as patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs); it involves considering patient-centeredness not only in measure development, but also data collection, data reporting, and decisions about how measures are used. And finally, while PCM recognizes and emphasizes the importance of patient preferences and values, it does not ignore the needs and concerns of other key contributors, such as health care providers, health care organizations, policymakers, and others. PCM provides the patient perspective on the healthcare system as a balancing or equal indicator to other clinical and administrative measures that when taken together improve the ability of measurement to drive meaningful change toward better health, better care, more satisfied patients, families and care providers, a more equitable health system and lower costs (the tenets of the IHI's Quintuple Aim)[2].

It is important not to take a narrow view of PCM. For example, PCM should not be equated as being solely the development and collection of PROMs, PREMs or other approaches where the focus is limited to the use of a measurement tool to assess patient-centred care. PCM requires a wholistic approach where the voice of patients is not only gathered through a soundly applied measurement activity (as is used in PREMs or PROMs), but where this voice is also used throughout the continuum of measurement activities with patients meaningfully involved during all stages (i.e., tool design/selection, gap analysis, fielding, analyzes, reporting, and use of the data), including the collection of qualitative data in the form of stories and narratives.

[2] https://www.ihi.org/resources/publications/quintuple-aim-health-care-improvement-new-imperative-advance-health-equity

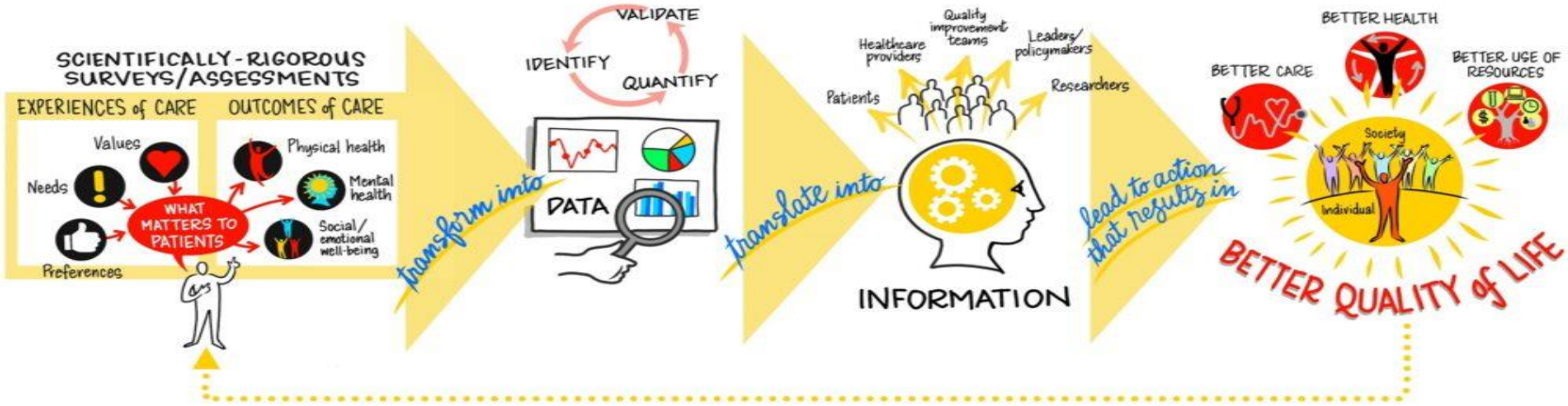


Figure 1: Cuthbertson, Lena; Sawatzky, Richard (2023). Cuthbertson, Lena; Dixon, Duncan; Schmidt, Faye; Sawatzky, Richard (2023). Graphic illustration of "Towards a working-definition of patient-centred Measurement: A review of literature". figshare. Online resource. https://doi.org/10.6084/m9.figshare.22228072.v1

Why is it important to have patient-reported measures of the performance of the health system over time?

Understanding the self-reported satisfaction, experiences, and health-related quality of life/outcomes of the people who use healthcare services in BC is a strategic priority for our health system. The measurement of patient experiences and outcomes gives those who use healthcare services a voice in evaluating the quality and safety of their care and is a means to evaluate progress towards providing care that is patient-centred, compassionate and free of racism and discrimination.

The hallmark of PCM is that the status of a patient's health condition and their assessment of the quality and the safety - including cultural safety, of their care comes directly from the patient themselves. Similar to the description of cultural safety in First Nations Health Authority's Policy Statement[3] that – *We will know we have achieved cultural safety when First Nations tell us we have*.

Not only does PCM need to be based on good measurement practices that are inclusive of patients (i.e., good tool design, comprehensive psychometric evaluation of measures, sound fielding and data analysis, etc.), it must also ensure a clear,

[3] https://www.fnha.ca/documents/fnha-policy-statement-cultural-safety-and-humility.pdf

direct patient voice in the interpretation and use of the data. PCM should be driven by patients' expressed needs – not assumptions about what matters to them – and should focus on structure, processes and outcomes that patients care about, not what the system says they should care about. By engaging patients at every step of the PCM value chain, the focus of measurement is on what matters to patients, and the results, in turn, allow a focus on improvement activities that will be key drivers of change and improvement in the quality and safety of care. Trending of data over time will be necessary to determine if improvement initiatives have been successful or require adjustment.

A key learning from the PCM Methods Cluster work conducted with CIHR SPOR funds in BC was the realization that tensions can arise from differing views from analysis on how to interpret measurement data and that it is important to ensure that patients are involved with users of the data, so that the process of interpretation brings all voices into consideration in ways that are patient-centred. This is comparable to the approach used in experience-based co-design, an approach that enables staff and patients (or other service users) to co-design services and/or care pathways, together in partnership.

Although PCM data is often considered to be the result of evaluative ratings that generate quantitative data, BCPCM has increasingly invested in approaches to solicit narrative comments, including the development of a Natural Language Processing (NLP) platform and Large Language Models (LLMs). This inclusion of qualitative input serves to interpret gaps in knowledge and provide a more fulsome picture of patient experience.

PCM data in BC is available through BC's central data warehouse, Healthideas, and available to inform local and system level quality improvement, program evaluation, performance monitoring and accountability and research. In addition, various reporting templates make descriptive results available at local, regional and system levels. For example, BCPCM's Dynamic Analysis and Reporting Tool (the DART) is an online platform, which provides "close to real time" survey results reflecting the experiences and self-reported outcomes and health-related quality of life of patients at unit, facility, health authority, and provincial levels, presented as aggregate, de-identified results. Please contact us at www.bcpcm.ca if you would like more information on anything discussed here.

Appendix D – Diagram showing a brief overview of the three related approaches