

Listening to patients in primary care practice

Using Patient-Reported Measures (PROMs and PREMs)

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Primary Care Strategic Forum
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INTRODUCTIONS



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DISCLOSURES

APERSU receives financial and in-kind support from Alberta Health, Alberta Health Services, the Health Quality Council of Alberta and the EuroQol Research Foundation in the form of operational and research grants.

Simron Sidhu is on the Board of Directors for Imagine Citizens, a financial sponsor of this event. All other presenters have no conflicts of interest or relationships with financial sponsors to declare.

DISCLOSURES

The scientific planning committee has contributed to the consideration of learning needs, the determination of learning objectives, the development of program content, and the choice of speakers or presenters.

No sponsorship funds have been received.

The scientific planning committee has reviewed the content of the presentations and ensured that content presented is evidence-based and free of undue influence.

OUTLINE – 2 x 45 min

Talking about patient-reported outcomes and their utility

Talking about using patient-reported data at the micro, meso, and macro level

Talking about patients involvement in outcome measurement

~BREAK~

Hearing from our panelists experiences with patient-reported outcomes

Hearing from you about your experiences with patient-reported outcomes

Resources / next steps



COMPLETE

Patient Reported Outcomes (PROs)

Patient Reported Outcome Measure
(PROM) – EQ-5D-5L



<https://eq-5d-demo.euroqol.org/?su>

Patient-Reported Experience Measure
(PREM) – HQCA survey



https://redcap.link/HQCA_PCPE_CORE

Under each heading, please tick the ONE box that best describes your health TODAY.

MOBILITY

- I have no problems in walking about
- I have slight problems in walking about
- I have moderate problems in walking about
- I have severe problems in walking about
- I am unable to walk about

SELF-CARE

- I have no problems washing or dressing myself
- I have slight problems washing or dressing myself
- I have moderate problems washing or dressing myself
- I have severe problems washing or dressing myself
- I am unable to wash or dress myself

USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

- I have no problems doing my usual activities
- I have slight problems doing my usual activities
- I have moderate problems doing my usual activities
- I have severe problems doing my usual activities
- I am unable to do my usual activities

PAIN / DISCOMFORT

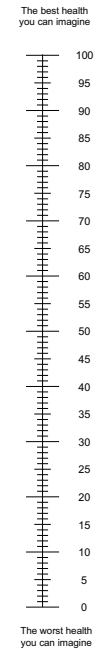
- I have no pain or discomfort
- I have slight pain or discomfort
- I have moderate pain or discomfort
- I have severe pain or discomfort
- I have extreme pain or discomfort

ANXIETY / DEPRESSION

- I am not anxious or depressed
- I am slightly anxious or depressed
- I am moderately anxious or depressed
- I am severely anxious or depressed
- I am extremely anxious or depressed

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine. 0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

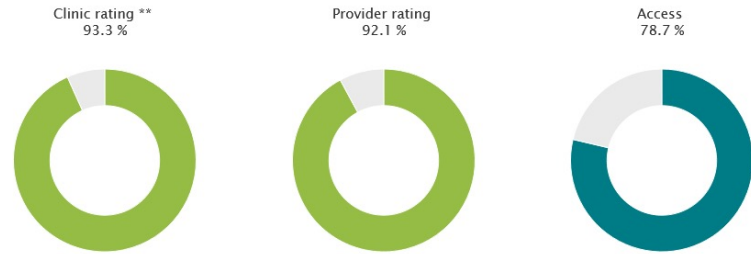
YOUR HEALTH TODAY =



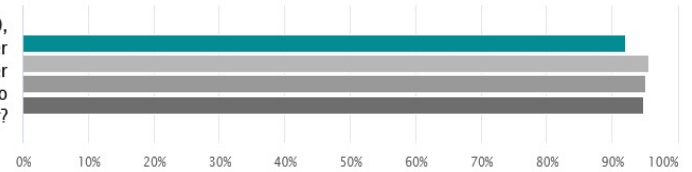
	Score	Lower HRQL	Higher HRQL
EQ-5D-5L Dimensions (Profile)	1 = none 2 = mild 3 = moderate 4 = severe 5 = extreme / unable to e.g.11121	Higher level category (5) = more problems	Lower level category (1) = fewer problems
Index score	-0.148 – 0.949	Closer to -0.148	Closer to 0.949
EQ VAS	0 - 100	Closer to 0	Closer to 100

Dr. Sample
May 2024

Primary Care Patient Experience Survey



Overall, using any number from 0 to 10, where 0 is the worst care provider possible and 10 is the best care provider possible, what number would you use to rate your care provider?



Primary Care Patient Experience Survey Resource List
Quick Wins

Introduction
Purpose of this document
We have identified promising practices to support improvement of the patient experience. This guide is designed to give initial guidance to primary care providers looking for information about improving patient experience.

How the resource lists are organized
Resources are organized by the topic domains in the HCA Primary Care Patient Experience Survey, not easy access to the resources. Keep the top page open and printing it in full may be useful because many of the activities are repetitive and cross-referenced to other resources within the document.

How the resource lists were developed
The resources were compiled in a transparent and collaborative way and suggested by primary care providers and experts in primary care organizations.

What do you mean by Quick Wins?
The resources in this document are either Quick Wins and include checklists, tools and other resources that are relatively quick and easy to test.

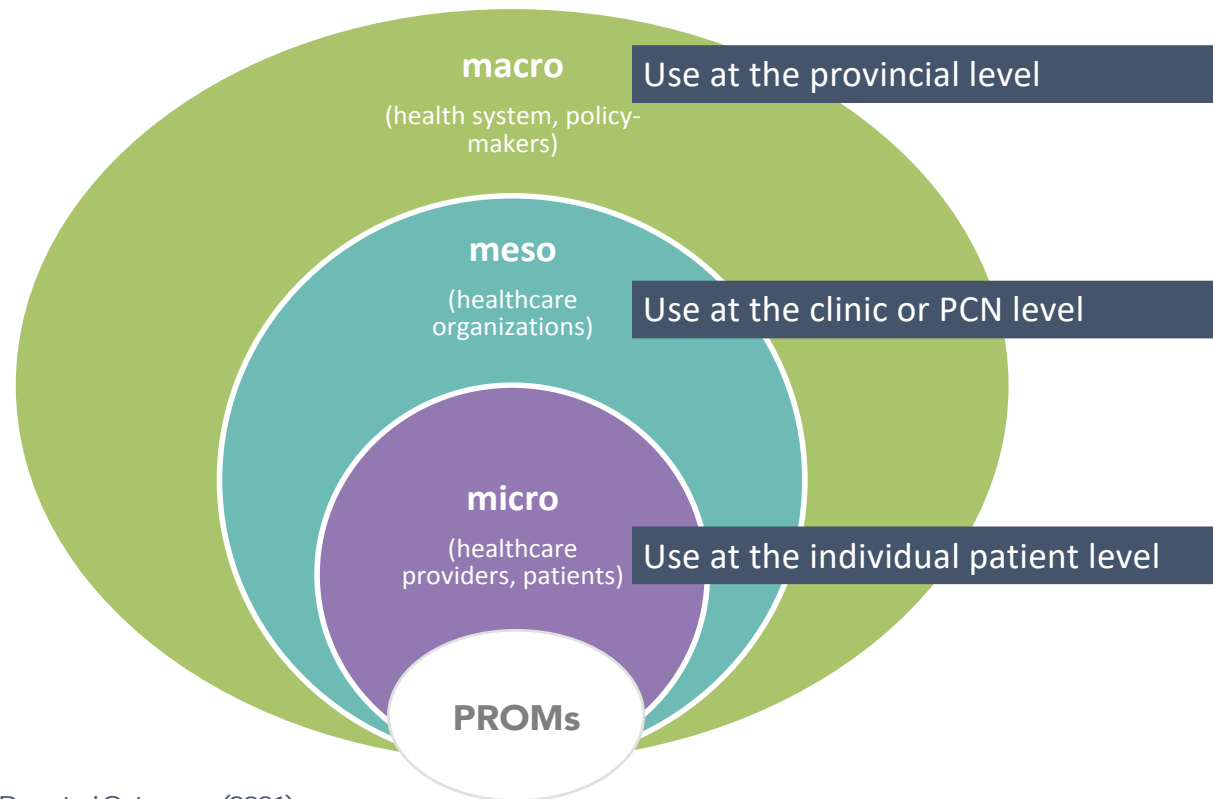
<https://hqca.ca/resources-for-improvement/surveying-patients-about-primary-care-experience/>

DISCUSS

What did you think about these PRO measures?

- What is the tool measuring?
- Have you seen it or used it before? When, where, how?
- Take note of the reference period. When would it be appropriate to measure?
- Are there any dimensions missing? Is anything redundant?
- What was the experience like?
- What are the pros and cons of the tool and/or its data?

USE OF DATA



A multi-level approach, *Journal of Patient Reported Outcomes* (2021)
Fatima Al Sayah, Markus Lahtinen, Gouke J Bonsel, Arto Chinmaa, Jeffrey A Johnson



EuroQol Research Foundation

Master Licensing Agreement

- EQ Foundation & U of A
- Use of instruments/versions
- Research Agenda
- Data sharing
- Sub-licensing to end-users

Alberta



Funding Agreements

- Research Management Team
- Sub-licensing to end-users
- Data-sharing
- Service/Support



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Alberta-based End-users

End-user Agreements

- EQ-5D licensing for Alberta-based non-commercial end-users
- Training
- Resources

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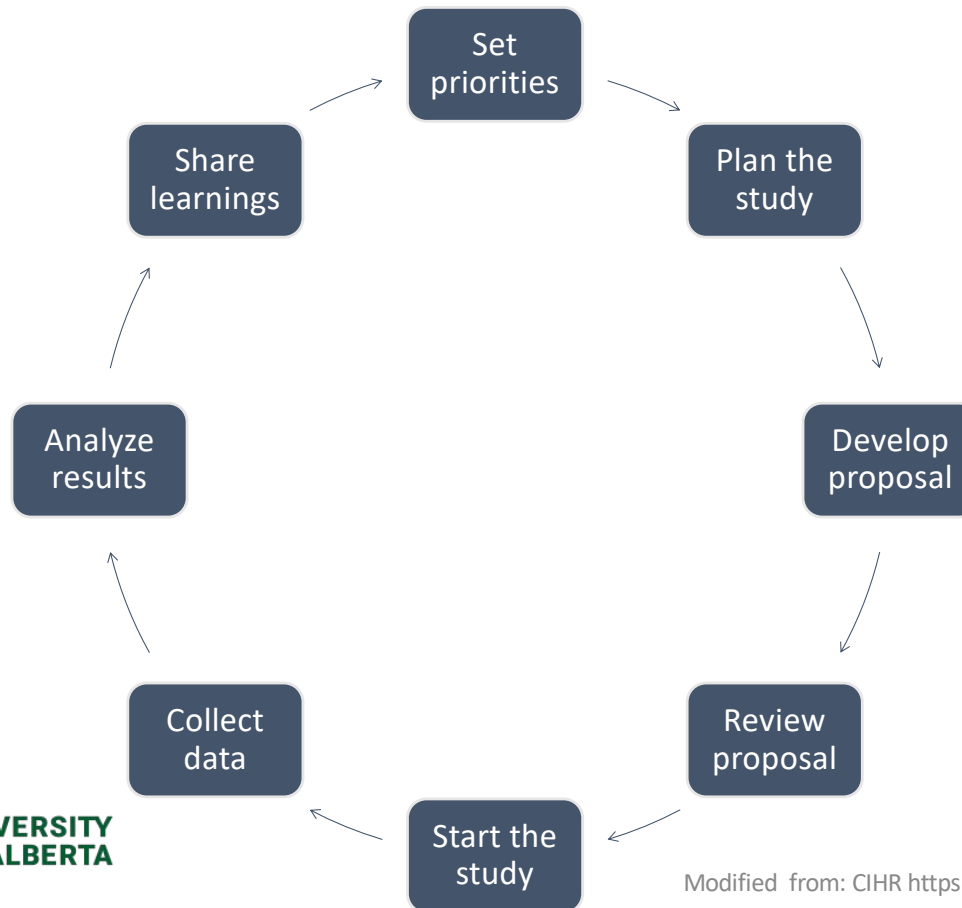
PATIENT INVOLVEMENT

Domains of patient and public engagement in Alberta

- Research and knowledge translation
- Government engagement
- Health policy
- System design
- Program development and implementation
- Healthcare evaluation and feedback
- Local care / clinic level engagement
- Citizen-led advocacy and organizations
- Community-based support & peer-led programs

PATIENT INVOLVEMENT

Research



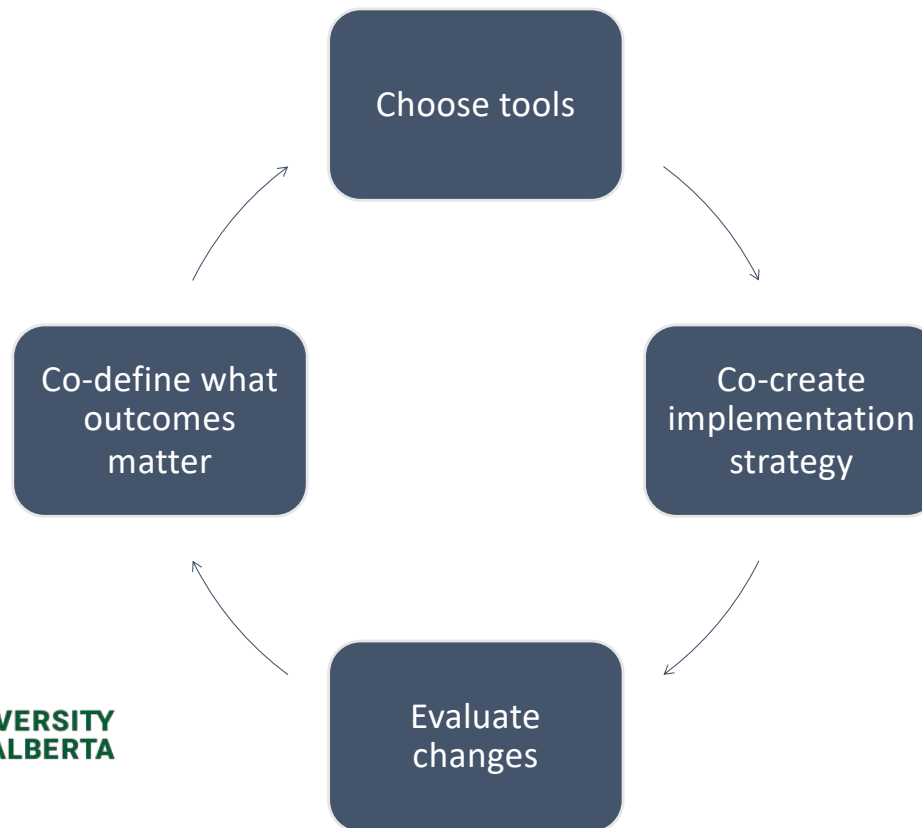
PATIENT INVOLVEMENT

Healthcare



PATIENT INVOLVEMENT

Patient-reported outcomes



PATIENT INVOLVEMENT

APERSU Patient Engagement Network

The value of patient partners is....

- Reminds me why I do this work
- Connecting and asking opinions is not burdensome to me or them
- Patients want to see their data used, understand the hows and why together
- We are stronger together

"listening to learn from each other"




PATIENT INVOLVEMENT

Tip Sheet

Patient Engagement Network
Tip Sheet

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Alberta PROMS and EQ-5D
Research and Support Unit

What are Patient-Reported Outcome Measures and why use them?



- They are **questionnaires that ask about your feelings, daily functioning and more.** They help you and your care team understand how to take the best care of you.
- PROMs put the **patient first.** They make sure your voice is heard, focusing on your unique needs.

Patient Reported Outcome Measures

Improve communication for better care

Patient-reported outcome measures (PROMs) allow you to share symptoms that might not come up naturally in conversation.

Patient-reported outcome measures (PROMs) impact your care by letting you share your care priorities and what matters most to you.

Compare and track changes over time

The results let you compare yourself with other people in similar situations and/or with similar conditions. They let you track your own progress over time.



Patient Engagement Network
Tip Sheet

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Patient Reported Outcome Measures



How do your responses make a difference?

- Feel free to ask your care team how your data is used and request access to track it yourself if you want. (micro)
- Sometimes patient-reported outcome measures (PROMs) help guide decisions in health programming, along with other information. (meso)
- At a larger level, provincial level data may identify vulnerable groups, offering a systems perspective. (macro)

How your responses shape care with sensitivity and respect

- There are no right or wrong answers, and your responses won't negatively impact your care.
- Patient-reported outcome measures (PROMs), along with other tools (like blood pressure for example), help providers make better decisions and be more aware of each patient's unique background and experiences, using respectful language and recognizing diverse backgrounds.



Patient input into the development of PROMs is the next step

QUESTIONS?

~ BREAK ~

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LinkedIn



PANEL

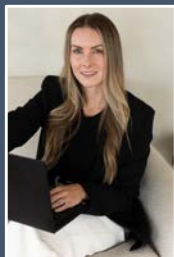
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Moderated by: Allison Soprovich



Krista Brower – Executive Director of EOPCN, PhD in measurement and evaluation, health system innovator and leader.



Veronika Kiryanova – Retired neuroscientist and PACER-trained patient research partner.



Margo Schmitt-Boshnick – Senior Evaluation Lead with Central Zone PCNs, with 14 years of primary care evaluation experience and is a founding member of the APERSU PCN Working Group.



Simron Sidhu – MSc student, implementation science, with an interest in PREMs & PROMs and an equity-driven healthcare advocate



Allison Soprovich – APERSU End-User Lead, who provides support and knowledge translation for implementing PROMs in Alberta.

KEY MESSAGES

- PROMs and PREMs capture the patient voice in systematic ways to help improve patient care.
- Data can be used in primary care at the micro, meso and macro levels.
- Patients are an integral part of research teams, healthcare system implementation and PROMs development.
- APERSU and HQCA both provide support and guidance to administer, collect, analyze and use patient-reported data.

RESOURCES



Alberta PROMS and EQ-5D Research and Support Unit (APERSU)

<http://www.apersu.ca>

Health Quality Council of Alberta, primary care patient experience survey

<https://hqca.ca/resources-for-improvement/surveying-patients-about-primary-care-experience/>

PROMS video and resources from Equitable People Centred Health Measurement (EPHM)

<https://www.healthyqol.com/validation-intro.html>

Manitoba SPOR course about PROMS and PREMS

https://storage.googleapis.com/chi_courses/proms_and_premis/index.html#/

International Society for Quality of Life Research (ISOQOL) – 3 day virtual symposia:

Advancements in the engagement and preparation of healthcare providers for the routine integration of PROMs in clinical practice

<https://www.pathlms.com/isoqol/courses/64045>

AbSPORU course on PROMs and PREMs (upcoming)

<https://absporu.ca/>

Thank you.