WHITE PAPER

Enhancing the Use of Patient-reported Outcome Measures (PROMs) in the Healthcare System in Alberta

Alberta PROMs and EQ-5D Research and Support Unit (APERSU)
School of Public Health
University of Alberta

Contact
Alberta PROMs and EQ-5D Research and Support Unit (APERSU)
2-040 Li Ka Shing Centre for Health Research Innovation
University of Alberta
Edmonton, AB T6G 2E1

Phone: 780-248-1010
Fax: 780-492-7455
E-mail: apersu@ualberta.ca
Website: www.apersu.ca

Version 1.0
January 2020

Acknowledgements

Disclosures

Fatima Al Sayah, Jeffrey A. Johnson, Arto Ohinmaa, and Xuejing Jin are members of the EuroQol Group.

Jeffrey A. Johnson is a member of the Board of Directors for the EuroQol Research Foundation.

Contributors

Fatima Al Sayah
Jeffrey A. Johnson
Arto Ohinmaa
Stafford Dean
Markus Lahtinen
Deborah Marshall
Xuejing Jin
Lisa Warner
Katie Churchill
Linda Watson
Colin Bruce Josephson
Margo Schmitt-Boshnick

TABLE OF CONTENTS

CONTRIBUTORS

Fatima Al Sayah, PhD

Research Manager, APERSU, University of Alberta, Edmonton AB
Consultant, EuroQol Research Foundation, Rotterdam, NL
falsayah@ualberta.ca

Jeffrey A. Johnson, PhD

Professor, School of Public Health, University of Alberta, Edmonton AB
Co-Director, APERSU, University of Alberta, Edmonton AB
jeff.johnson@ualberta.ca

Arto Ohinmaa, PhD

Professor, School of Public Health, University of Alberta, Edmonton AB
Co-Director, APERSU, University of Alberta, Edmonton AB
arto.ohinmaa@ualberta.ca

Stafford Dean, PhD

Chief Analytics Officer, Alberta Health Services
Stafford.Dean@albertahealthservices.ca

Markus Lahtinen, PhD

Director, Health Systems Analytics, Health Quality Council of Alberta
markus.lahtinen@hqca.ca

Deborah Marshall, PhD

Professor, University of Calgary, Calgary AB
damarsha@ucalgary.ca

Xuejing Jin, PhD

Post-doctoral Fellow, APERSU, University of Alberta, Edmonton AB
xuejing3@ualberta.ca

Lisa Warner, M.Sc., R.S-L.

Director of Community Rehabilitation, Allied Health Professional Practice &
Education, Alberta Health Services
Lisa.Warner@albertahealthservices.ca

Katie Churchill, MSc.OT

Senior Practice Lead, Practice Based Research, Allied Health Professional Practice & Education, Alberta Health Services
Katie.Churchill@albertahealthservices.ca

Margo Schmitt-Boshnick, BA, MEd

Program Evaluator, Red Deer Primary Care Network
Margo.Schmitt-Boshnick@rdpcn.com

Linda Watson, PhD, RN

Scientific Director, Applied Research and Patient Experience, CancerControl Alberta - Alberta Health Services; Adjunct Assistant Professor, Faculty of Nursing, University of Calgary
Linda.Watson@albertahealthservices.ca

Colin Bruce Josephson, MD, MSc, FRCP(C), CSCN (EEG)

Assistant Professor of Neurology and Community Health Sciences, O'Brien Institute for Public Health & Hotchkiss Brain Institute
Epilepsy Fellowship Director, Department of Clinical Neurosciences, Cumming School of Medicine, University of Calgary
cbjoseph@ucalgary.ca

1. About this White Paper

There is a growing recognition throughout the world that the patient's perspective is highly relevant to efforts to improve the quality and effectiveness of healthcare. At an OECD conference in January 2017, Ministers of Health from around the world – including Canada – stated, "We need to invest in measures that will help us assess whether our health systems deliver what matters most to people" [1]. The introduction of **patient-reported outcome measures** (PROMs) is one strategy to ensure that patients' perspectives are incorporated into the approaches of delivering healthcare services and valuing the performance of the healthcare system [2-5].

The purpose of this white paper is to provide a brief overview of PROMs and their use in Alberta, and guidance to enhance the use of these measures within the healthcare system in the province. This paper also provides a justification of past and future activities for our sponsors and scientific support group.

The use of PROMs in the province of Alberta has markedly increased with the establishment of the *Alberta PROMs and EQ-5D Research and Support Unit* (APERSU) in 2015. APERSU is a collaborative initiative between the University of Alberta, provincial health authorities (Alberta Health, Alberta Health Services, and Health Quality Council of Alberta), and the EuroQol Research Foundation. APERSU aims to support and enhance the use of PROMs in the province, where the EQ-5D is the recommended generic preference-based PROM. Users, however, use other PROMs, especially disease-specific measures, alongside the EQ-5D, for good reasons.

Since 2015, APERSU has worked with 228 PROMs end-users in Alberta, and registered 137 projects utilizing the EQ-5D. End-users include individual clinicians, managers, administrators or researchers leading PROMs programs at their organizations. As of August 2019, 215,315 administrations of EQ-5D have been completed by different patients, in various clinical settings. This extensive and comprehensive collection of PROMs data highlights a significant need for strategies to utilize this data within the healthcare system.

This paper is intended for PROMs end-users and stakeholders within the healthcare system, including clinicians, managers, patient advisors, system administrators, researchers, and policy makers. By the end of this paper, the reader should have a direction for planning a proper implementation of PROMs, and an understanding of the role of PROMs in informing clinical practice, enhancing patient-centered care and decision-making, health services programming, performance measurement, comparative effectiveness analysis, and quality improvement initiatives. Guidance for the use of PROMs data at the **micro** (e.g., patients, clinicians), **meso** (e.g., healthcare organizations), and **macro** (e.g., health system, policy makers) levels is also provided.

2. Foreword by Alberta Health Services

Alberta Health Services (AHS) is focused on ensuring Albertans get full value for their money from the publicly funded health care system. In order to meaningfully assess value, measuring outcomes – especially those that matter to patients – is imperative.

AHS has embarked on a data acquisition strategy across the domains of the triple aim: cost, experience, and clinical outcomes. Patient-reported outcome measures (PROMs) add a critical dimension by measuring outcomes from the patient's perspective, which allow us to assess what we produce in terms of health impact, not just healthcare utilization.

Our initial applications of PROMs are focused on pre/post quality of life assessments for planned interventions (e.g., surgery). Over time, we will leverage the patient portal to assess outcomes for other health conditions (in both inpatient and outpatient settings), as well as unplanned interventions. We also plan to use PROMs for economic analysis as a means of comparing relative value across services.

Stafford Dean
Chief Analytics Officer, Alberta Health Services

3. Foreword by Health Quality Council of Alberta

One of the many things we've learned at the Health Quality Council of Alberta (HQCA) is the value you get from understanding the patient perspective.

Over the years, we've seen rich discussions ensue from our work to capture the experiences of Albertans in areas such as primary care, home care, long term care, designated supportive living, and emergency department care.

In fact, thousands of Albertans share their perspectives with us every year so we can represent their voice in our work. And we know it leads to better, more informed decisions, right across Alberta's healthcare system.

That's why the HQCA is so pleased to collaborate with APERSU, Alberta Health, Alberta Health Services, and other partners, to advance Patient Reported Outcome Measures (PROMs).

The PROMs initiative is more than a data capture exercise. It has the ability to improve screening and monitoring for certain symptoms at the patient level while equipping senior health system decision-makers with the information they need to evaluate the impact of programs, services, and even the performance of healthcare providers.

Best of all, we believe it can contribute to a patient-centred, value-based model of healthcare delivery that supports better communication between physicians and their patients. And while the potential for PROMs are great, there remains a great deal of work to transition PROMs use from clinical effectiveness research to a more mainstream deployment across Alberta's healthcare landscape.

Currently, there are no guidelines or formal requirements for the use of PROMs – even as adoption of the EQ-5D health status measures increases in primary care clinics across Alberta. We suspect many of you may have valid questions about PROMs including when to measure, how often to measure, what tools to use, and how best to use the data available to make meaningful improvements in healthcare delivery.

As you'll learn in this white paper from the experts at APERSU, there are key strategies to consider as you move forward with your PROMs implementation. We encourage you to give this white paper a close read and check out the many additional resources available from APERSU's website at apersu.ca.

The HQCA is an organization that sees enormous value in increasing adoption and enhancing the use of PROMs data across Alberta to improve patient care. We hope you do too.

Markus Lahtinen
Director, Health Systems Analytics

4. An Overview of Patient-reported Outcome Measures (PROMs)

Health outcomes are broadly defined as changes in health status that occur as a result of a health-related event or illness, or a healthcare intervention. Patient-reported outcome measures (PROMs) are measurement instruments designed to assess health outcomes as directly reported by patients [6]. PROMs could take on many forms, assessing general health or specific symptoms, functional ability, general well being, health-related quality of life, or global quality in life. Some measures are generic, and others are disease or condition specific.

Generic PROMs are designed to assess general aspects of health that are not specific to a particular disease (e.g., EQ-5D, SF-12/36, HUI2/3, WHOQOL, ESAS, QWB, and PROMIS), while disease-specific PROMs assess aspects of health that are specific to a given disease (e.g., WOMAC, AQLQ, EORTC-QLQ-C30, PHQ-9, PAID-5) [7]. Generic and disease-specific PROMs each have their own advantages and disadvantages. For instance, generic PROMs are useful when comparing different groups of patients across different health conditions; however, they may be less sensitive to pick up important changes in specific aspects of health. On the other hand, disease-specific PROMs are not useful in comparing different groups of patients with different diseases; however, they are more likely to be sensitive to specific changes in health. Given these advantages and disadvantages, it is often recommended that a generic and a disease-specific PROM should be used together.

PROMs reflect a balance between length (shorter=better) and information (more=better), as the burden to the patient and the administrative system matters. Length is determined by number of items and complexity. Short classification measures like EQ-5D have an advantage over lengthy systems like WHOQOL, or measures that depend on electronic devices (adaptive questionnaires).

4.1 The EQ-5D

While all PROMs provide an assessment about certain aspect or overall health, some PROMs are also designed to describe a health state and generate a value for that health state that could be applied in the calculation of quality-adjusted life years (QALYs) in economic evaluations [8]. These latter measures are called preference-based or utility measures. The EQ-5D is the most commonly used generic preference-based PROM in the world, and has been recommended as the generic PROM of choice for various applications in Alberta, having already been adopted by Alberta Health, Alberta Health Services, and the Health Quality Council of Alberta.

The EQ-5D is a simple and brief measure of health status. It includes five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. In its older 3-level version (EQ-5D-3L), each dimension has three levels of problems: 1 "none", 2 "some", and 3 "extreme or unable to perform the task". With 5 dimensions, and 3 levels per dimension, the EQ-5D-3L can describe 243 distinct health states. In the newer 5-level version (EQ-5D-5L), each dimension has five levels of problems: 1 "none", 2 "mild", 3 "moderate", 4 "severe", and 5 "extreme". The EQ-5D-5L can describe 3125 distinct health states. Each health state can be assigned a value that represents the general population preferences for that state relative to other states, and the combined values – also called "value set" – reflects how a given population values health [9]. These values are derived using methods adopted from the economics field. Emerging research has demonstrated that the 5L version provides better measurement of health status than the older 3L version, which in particular situations still a good choice. In addition to its descriptive system, the EQ-5D also includes a visual analogue scale (VAS), which asks respondents to indicate how they feel about their own health on a scale from 0 (worst health you can imagine) to 100 (best health you can imagine). The VAS is a direct assessment of how an individual values his or her own health.

The EQ-5D has multiple versions, to accommodate needs of different users. Both an adult and youth version exists for both the 3-level and 5-levels versions, and the EQ-5D is available in many languages and administration formats (including telephone and face-to-face interview). Value sets to calculate index scores are available for many countries around the world including Canada. More details about the EQ-5D are available at www.euroqol.org and www.apersu.ca.

EQ-5D-3L Descriptive System	EQ-5D-5L Descriptive System
MOBILITY I have no problems in walking about I have some problems in walking about I am confined to bed	**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 with self-care I have some problems in washing or dressing myself I am unable to wash or dress myself	**SELF-CARE** I have no problems in washing or dressing myself I have slight problems in washing or dressing myself I have moderate problems in washing or dressing myself I have severe problems in washing or dressing myself I am unable to wash or dress myself
USUAL ACTIVITIES I have no problems with performing my usual activities I have some problems with performing my usual activities I am unable to to perform my usual activities	**USUAL 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 to do my usual activities
PAIN/DISCOMFORT I have no pain or discomfort I have moderate pain or discomfort I have extreme pain or discomfort	**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 moderately anxious or depressed I am extremely anxious or depressed	**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

5. Landscape of PROMs in Alberta

In Alberta, the EQ-5D is the recommended generic preference-based PROM for use within the healthcare system. As noted above, AH, AHS and the HQCA have all committed to using the EQ-5D as a generic measure of health, and have invested resources into collection of EQ-5D data in many different applications. For example, AHS has incorporated the EQ-5D into the PROMs module of *Connect Care*, the system wide electronic medical record in being implemented across the healthcare system. Additionally, the EQ-5D was recommended as an outcome indicator in evaluating primary health care in Alberta, and is being gradually implemented throughout the primary care system.

In many clinical settings, however, other PROMs, especially disease-specific ones, are used alongside the EQ-5D. Since 2015, APERSU has worked with 228 PROMs end-users in Alberta, and registered 137 projects utilizing the EQ-5D. To date, 215,315 administrations of EQ-5D have been completed by different types of patients in various clinical settings in Alberta, including primary care (e.g., Primary Care Networks "PCNs"), specialty care (e.g., epilepsy, hip/knee arthroplasty), and tertiary care centers (e.g., Cancer Control Alberta).

> Currently, there are no guidelines or formal requirements for the use of PROMs in the province. Use is often driven by the interest to incorporate patients' perspectives into the care model, and/or by reporting requirements. Despite the lack of guidelines and the various challenges in PROMs data collection, clinical settings in Alberta have accelerated the use of these measures within the system, with a noteworthy adoption of the EQ-5D. This increased use of the PROMs (primarily EQ-5D) highlighted the crucial need for guidance on how best to use PROMs data within the healthcare system.

The status of using other PROMs (generic or disease-specific) in Alberta is not documented, and therefore, we are not aware of the extent of use of other PROMs. From our experience at APERSU, we observed that the most commonly used disease-specific PROMs in Alberta are: Edmonton Symptom Assessment System "ESAS" (symptom specific scale, disease-specific versions available), Western Ontario and McMaster Universities Osteoarthritis Index "WOMAC" (hip and knee arthroplasty), Patient Health Questionnaire 9-items "PHQ-9" (depressive symptoms), Generalized Anxiety Disorder "GAD-2" (anxiety symptoms), and pain rating scales. The use of SF-12/36 has also been recorded in some instances.

6. Implementation of PROMs

PROMs were originally developed for use in clinical effectiveness research, as a means to incorporate the patient's voice in the assessment of clinical interventions [10]. Gradually, their use became more apparent in population health assessments, then in clinical practice, and eventually into the healthcare system more broadly.

In this transition from research to real world healthcare settings, several practical and methodological challenges in the use of PROMs became evident [11-13]. For instance, in research studies, there are defined time points for data collection and a specified mode of administering PROMs that is often managed by research assistants; however, in healthcare settings, patients and clinicians are not accustomed to the approach or PROMs data collection and use, which may disrupt the clinical workflow and the way care providers are accustomed to delivering care. Further, in research applications, PROMs data are often used at the aggregate level for the whole sample participating in a study; however, in clinical settings, there may be interest in using PROMs data at the individual patient level.

Research into the use and proper implementation of PROMs within the healthcare system has escalated over the last two decades. Currently, we have evidence that provides some guidance on ways to ensure successful implementation of PROMs [11-15].

In the table below, we offer a list of suggestions to help users in planning a strategy for PROMs implementation. Note that this is an iterative process that will vary depending on the context and purpose of using PROMs.

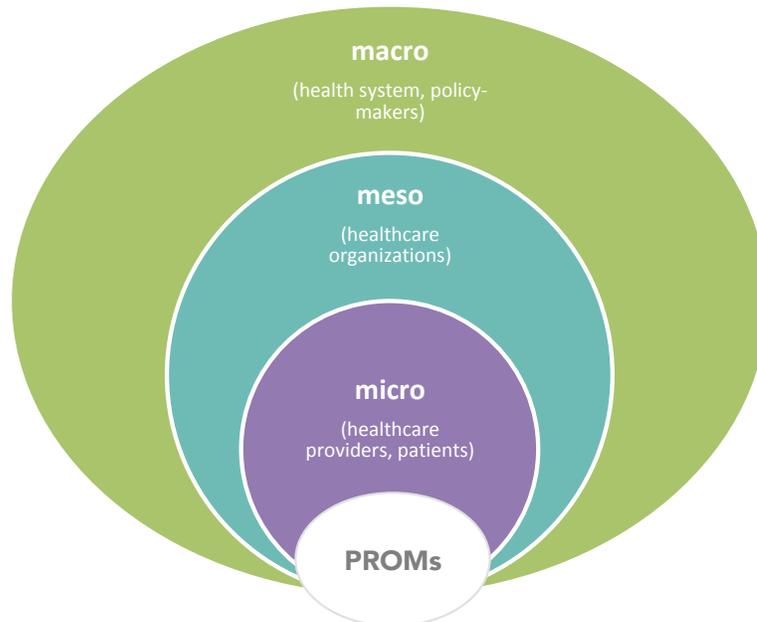|	
PROMs Committee	Establishing a team that plans and conducts PROMs implementation within a given setting is a key step towards success. It is advisable to have at least one clinician and one patient representative on the team. The committee composition will vary according to the setting.
Purpose(s) of Using PROMs	A significant task for the team is to clearly identify the purpose(s) of using PROMs including, for example: enhancing clinical practice (e.g., screening for certain symptoms, monitoring symptoms or outcomes at the individual patient level), evaluating the impact of a healthcare program or services, evaluating the performance of healthcare providers, or a combination of one or more of these purposes. Please note that the most effective use of PROMs involves all of these purposes. However, for successful implementation, it is advisable to start with few focused objectives, and then scale-up as the implementation progresses. There is a significant cultural change

	and learning curve in the implementation of PROMs, and staggered implementation would help identify and address factors that may impact the implementation along the way.
Target population	Identify and describe the target group(s) of patients that will complete the measure(s) based on their clinical condition(s), age group(s), language, ability to self-report vs. proxy, and feasibility of various administration modes (in person, via phone, web-based). These factors should all be considered when selecting a PROM.
Evaluation Plan	Users should set goals for PROMs implementation including timelines, uptake, and use, and conduct an evaluation to assess the success of implementation including the end-user experience in using these measures. This would help users in identifying successes and challenges, and revising implementation plans accordingly.
Selecting a PROM(s)	The choice of a PROM is primarily based on the purpose of the measurement. It is also important to specify what type of outcome (e.g., symptom, functioning, or health-related quality of life) is intended in the measurement; this would help identify the type of instruments to use. In Alberta, the EQ-5D is the recommended generic preference-based PROM; however, users could choose other PROMs if preferred. In addition to generic measures, you can use a disease-specific measure. In choosing a PROM, the user needs to ensure that the selected measure(s) serves the identified purposes, and that there is sufficient evidence on the measurement properties of the selected PROM(s) to support its use in a given population. Additionally, users need to take into account several practical considerations that would impact the choice of a PROM, these include: length of the measure, ease of administration, administration modes available (phone, paper, digital –portal), reference period of the measure, languages available, and licensing fees. These all need to be aligned with the purpose of measurement and discussed as part of the logistics of implementation. Choosing a PROM(s) is a challenging task and experts in the field of PROMs could assist users particularly in this step. Further details are offered below.
Education and Training	Perhaps, the most critical step in ensuring proper implementation of PROMs is educating and training the potential users, including front-line health-care providers, who may be tasked with collecting data, and patients, who will be tasked with completing the measures. Education and training should emphasize the purpose of using

13

	PROMs, provide a detailed description of the selected PROM and how it should be used, the interpretation and use of PROMs data to inform clinical practice (e.g., if the PROM assesses symptoms, there should be guidance for healthcare providers on how to address symptoms based on clinical guidelines), the logistics of implementing the PROM in the clinical setting, the roles and responsibilities of the various team members, and a plan for monitoring and evaluating PROMs use [16]. Local support for education and training is available at APERSU.
Collecting PROMs data	Determining the following details of collecting PROMs data will primarily depend on the purpose of measurement, the clinical context, and some of the practical considerations discussed above.

One-time measurement vs. repeated measurements: A one-time measurement is often simple to implement, and could be done as a first step towards introducing PROMs in the pilot phase. Repeated measurements are more commonly used in healthcare settings as changes in health outcomes are more useful than one-time measurement for various type of applications.

Implementing repeated measurements requires a system of tracking patients over time and ensuring that PROMs are completed at the specified frequency and time points. Implementing PROMs in a web-based environment may facilitate this approach.

Frequency of measurements: The frequency of PROM measurements depends on the clinical context and the nature of changes in a given health condition. For example, patients with chronic pain actively receiving treatment could complete the PROM on a weekly or bi-weekly basis as their clinical status may change more rapidly; however, patients with chronic conditions like type 2 diabetes could complete a PROM every 6 months or once every year.

Timing of measurements: The timing of measurement primarily depends on the purpose of PROM use. If the PROM is used to inform clinical patient management (screening for or monitoring certain symptoms or outcomes), the patient could complete the PROM at each clinic visit. If the purpose is evaluating the effectiveness of a healthcare program or intervention, the patient would complete the PROM prior and after the program or intervention. If the purpose is assessing the performance of the healthcare system, one or two measurements annually could be sufficient.

Mode of administration: PROMs could be administered on-paper or web-based platforms. The choice of mode depends on the type of patients and some practical considerations previously discussed.

Place of administration: PROMs could be completed in-person at the healthcare setting, or remotely via phone or web. The choice of |

14

	place of administration depends on the purpose of measurement, the mode used, and other practical considerations previously discussed.
Using PROMs Data	In planning the implementation of PROMs, users need to identify the potential usages of PROMs data. A detailed description of PROMs data use is available in the next section.
Pilot	It is advisable that users consider conducting a pilot of PROMs implementation in a small sample of patients, or in one site or clinic, before scaling it up to the whole setting. A pilot would enable users to identify and address potential issues in implementation, and to improve the implementation plan if need be. In some instances, a pilot is advised when resources are limited, and when buy-in from healthcare providers is not optimal; a pilot could serve as an introductory step to PROMs implementation and showcase the advantages of PROMs use in these settings.
Electronic Tools	It is highly advisable to use electronic tools when possible, particularly for PROMs data capture and reporting. Many users have developed their own data capture and reporting platforms, which facilitates the implementation and buy-in from care providers. In Alberta, users have the option of using REDCap, which is a free tool. Additionally, Alberta Health Services have incorporated the EQ-5D instrument, a generic preference-based PROM, into *Connect Care*. This development provides an outstanding opportunity to capture PROMs for every patient utilizing healthcare services in Alberta.
Consult with Experts	In Alberta, PROMs end-users could benefit from APERSU's end-user support staff, who specialize in PROMs and could assist in various steps of the implementation process. To learn more about services provided by APERSU, visit the website www.apersu.ca
Reporting and Feedback	Users should include in their plan the timelines and methods by which PROMs data will be reported, and how that data will be shared with interested parties including patients, healthcare providers, and managers/ administrators.

7. Use of PROMs Data – a Multi-Level Approach

Identifying approaches to using PROMs data is becoming increasingly important with the volume of PROMs data capture in Alberta. We recommend thinking of 3 different levels for the use of PROMs data and provide suggestions for each:

macro
(health system, policy-makers)

meso
(healthcare organizations)

micro
(healthcare providers, patients)

PROMs

Micro Level

At this level, PROMs data are often used at the individual patient or at the patient-panel levels. PROMs offer an opportunity for patients to provide input and perspective into their own care, and enhances communication with their healthcare providers [15, 17, 18].

At the individual patient level, PROMs data can inform clinical practice, and enhance patient management. Data could be used by healthcare providers to screen for certain health issues or symptoms, and assess and monitor patients' symptoms or outcomes including health-related quality of life.

For example, a patient with type 2 diabetes presenting to a primary care clinic completes the EQ-5D-5L instrument (generic PROM), and indicates that she has moderate levels of pain/discomfort. This response would in turn prompt the healthcare provider to ask the patient about pain/discomfort, and try to uncover the potential causes for it and subsequently provide the necessary clinical management (e.g., requesting tests, making referrals, prescribing medications). These types of alerts that PROMs assist healthcare providers may uncover health problems often missed in clinical encounters, particularly when a patient presents for a different health issues. For instance, the use of

PROMs is widely used in screening for mental health problems, particularly anxiety and depression, especially in high-risk patients.

When this type 2 diabetes patient completes the PROM repeatedly at each follow-up visit, their care provider could monitor the change in health based on PROMs data and evaluate the impact of healthcare on this particular patient from their own perspective.

Meso Level

At this level, healthcare providers could use aggregate PROMs data to identify certain outcomes or symptoms in a panel of patients or at a given clinic or treatment site, and compare such data across providers, clinics or sites. For example, a PROM assessing anxiety and depression in cancer patients could inform providers about the prevalence of these symptoms in different groups of patients at different sites, and accordingly, review existing care options (e.g., availability of mental health specialists) and propose solutions to provide mental health care for these patients.

PROMs data could be used to monitor and compare patient outcomes across healthcare providers and organizations, which helps identifying those who require further support and healthcare services programming. For example, PROMs data from patients undergoing a hip replacement surgery could inform care providers and organizations about the effectiveness of surgery across different providers and surgical sites. Alternatively, PROMs data may inform the case-mix of patients receiving care in different clinics, and inform guidelines for the appropriateness of certain treatments or procedures.

PROMs data could also be used to redesign healthcare services delivery. For example, a PROM that assesses symptom burden in patients with cancer could assist in prioritizing care delivery (in terms of timing and frequency) to patients according to their needs. Having information about the symptom burden of patients can also help in planning the appropriate staffing to support those patients at upcoming clinical visits.

Additionally, PROMs could be used to evaluate the effectiveness of new or existing healthcare services, programs or interventions from a patients' perspective.

Macro Level

At this level, PROMs data are primarily used for benchmarking and for evaluating the performance of the healthcare system by incorporating a patient perspective, to compare outcomes across different jurisdictions and health zones, or over time [4, 19]. This high-level PROMs data could support health policy-makers in health service allocation decisions that take into

account patients' perspective and priorities.

For example, PROMs data from patients receiving rehabilitation services across Alberta could inform about the performance of different service providers in different health zones, and identify sites/regions that require professional development activities and other types of resources. Along with cost data, PROMs data could also be used in examining value for money spent on rehabilitations services, and support policy makers in allocation of existing or additional resources accordingly to patients' needs.

There are several practical and resource-related factors that impact the use of PROMs data within the healthcare system [11, 18, 20]. To date, what we learned from the Alberta experience is that once proper training of healthcare providers is done, the use of PROMs data at the micro level is often straightforward. Further, if PROMs data are collected and reported/presented electronically, the use of PROMs data can be maximized, and more easily applied at multiple levels.

What has been most challenging for PROMs users within the healthcare system is the use of the data at the aggregate level (at both the meso and macro levels). Based on a recent assessment we conducted with PROMs end-users in Alberta, we learned that this challenge is often due to lack of expertise in analyzing PROMs data, and of staff and resources dedicated to PROMs work. Further, users often report that there is lack of clarity or guidance for using PROMs data, especially at the meso and macro levels. We hope this white paper provides some direction to users.

In analyzing routinely collected PROMs data, users need to consider some methodological challenges, particularly when repeated measurements are conducted, and when comparisons between sites or providers are made. These methodological issues include attrition and missing data, lack of a control arm in comparative effectiveness analysis, large data pitfalls, representativeness of the sample, statistical significance vs. clinical importance, response shift, and case-mix adjustment, among others. Users should be aware of the potential impact of these factors on PROMs data analysis, and consult with experts for guidance on how best to address them.

Other issues that impact PROMs data analysis and use are related to data access and the ability to link PROMs data with other data sources, especially administrative health data, that would allow for more comprehensive analysis. For users interested in economic evaluation of programs and services, for example, considerable attention needs to be made to collection of data on the cost of those services, not just on the PROMs data. These issues require a wider discussion among PROMs stakeholders in the province, and subsequent guidance to users. This also involves developing relationships between PROMs stakeholders at various levels within the system.

8. PROMs Stories from Alberta

There are many stories of successful PROMs implementation in Alberta. Here we share some of these stories, which provide insights on how to implement and use these measures in different clinical settings. In these stories, you will see examples of using PROMs data at micro and meso levels for various purposes including informing clinical practice, health services programming, comparative effectiveness analysis, and quality improvement initiatives. The use of PROMs data at the macro level remains in its infancy, and more work is needed by key stakeholders to promote and advance the use of PROMs at this level.

Alberta Health Services
Community Rehabilitation Program

PROMs use at Micro, Meso, and Macro Levels

The implementation of the EQ-5D-5L in Alberta Health Services' (AHS) adult community, outpatient and specialized rehabilitation began in 2017 as part of patient reported outcome measurement collection within the new Rehabilitation Model of Care. The pilot phase involved 17 early adopter teams, and has since spread to include over 140 urban and rural teams in single and multi-provider programs across the province. Patients complete the EQ-5D-5L on paper, or electronically via REDCap, at the beginning and end of an episode of care. Patient reported outcome and experience data is aggregated and fed into Tableau Dashboards for analysis at the micro site/service level, the meso zone level, and macro provincial level. Patient's responses to the EQ-5D-5L are reviewed by rehabilitation providers at the point of care and serve as an opportunity to discuss current health state and rehabilitation goals. The systematic collection of patient reported data is informing provincial strategic priorities, service planning and evaluation. The data enhances clinical quality improvement initiatives and facilitates accountability throughout the community rehabilitation system.

The implementation of the Rehabilitation Model of Care, and the use of the EQ-5D-5L and other patient reported metrics, has had a positive impact beyond the collection of data. It has created a learning community within the rehabilitation setting as care providers have an increased awareness and appreciation for the value of the patient's voice throughout the health journey. It has also led to skill development in quality improvement, analytics, and promoted a culture of inquiry at point of care. Access to Tableau Dashboards, which wraparound the Health Quality Council of Alberta's quality dimensions, promote data informed decision making for clinicians, teams and service areas. Since the start of implementation of the EQ-5D-5L in adult community rehabilitation programs, over 3500 patients have completed the EQ-5D-5L and the volume of data is increasing with spread and scale. For the first time in Alberta, community and outpatient specialized rehabilitation patient outcome data will provincial standardization, establish common expectations, and underscore the commitment to delivering effective, high quality, patient-focused care.

By: Lisa Warner and Katie Churchill

Alberta Bone and Joint Health Data Repository

PROMs use at Meso and Macro Levels

Implementation of patient-reported outcome measures (PROMs) has become part of the routine care for hip and knee arthroplasty in Alberta. The following story briefly introduces how the PROMs are implemented in the routine care, how the PROMs services the routine care, and how we use the PROMs data beyond the routine care.

In 2004, an evidence-based novel clinical pathway for total hip and knee arthroplasty was developed under the collaboration between Alberta Orthopaedic Society, Alberta's Ministry of Health and Wellness, Alberta Bone and Joint Health Institute, and orthopedic surgeons, general practitioners, and other clinicians in the province . This new clinical pathway was evaluated in an RCT against the standard of care between 2005 and 2006 and assessed using the Alberta Quality Matrix for Health (AQMH) which includes six dimensions of quality of care: acceptability, accessibility, appropriateness, effectiveness, efficiency, and safety. Effectiveness was assessed using the PROMs including Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC) and 36-Item Short Form Survey in this RCT . Since 2010, most of the surgeons who preform joint replacement in Alberta had adopted the new clinical pathway in their practice.

The Alberta Bone and Joint Health Institute (ABJHI) launched the Alberta Bone and Joint Health Data Repository (ABJHDR) in 2010. Using a measurement framework and key performance indicators (KPIs) to measure, monitor and manage the performance of total hip and knee arthroplasty, continuous quality improvement (CQI) reports are provided routinely to individual health care providers, large public health agencies, individual hospitals and clinics . These CQI reports track and measure the quality of hip and knee surgery care for adult patients at 13 hospitals across Alberta following key performance indicators (KPIs): waiting time, surgery length, post-surgery length of hospital stay, serious surgery complications rates, readmissions, patient-reported outcomes, and patient satisfaction.

The EQ-5D and WOMAC are routinely administered PROMs at the baseline (pre-surgery), 3 months, and 12 months after surgery. The administration mode and the schedule of measurements varies across different clinics. Typically, patients complete the measures ahead of clinic visits (first clinical assessment for baseline measurement, and post-surgery follow-up visits for post-surgery measurements) through a hyperlink (to the survey page on ABJHI's website) included in the appointment confirmation email or after the visit through a link included in the follow-up email. Otherwise, measurement is done using a hard copy or electronic tablet during the clinical visit. The clinics shifted from using the EQ-5D-3L to using the 5L version over a period of seven years and since 2017 all clinics now use the EQ-5D-5L. As from 2010 to March 2019, the ABJHDR had cumulatively collected information from 92,595 hip and knee arthroplasty surgeries (among which, 53% had pre-surgery PROMs records).

(continued on next page)

By: Deborah Marshall and Xuejing Jin

Alberta Bone and Joint Health Data Repository

(continued)

PROMs use at Meso and Macro Levels

ABJHI tracks the PROMs information along with other indicators and compares results in each of these indicators to benchmarks and provides semiannually confidential CQI reports. Currently, 83% of surgeons (representing 95% of the total volume of hip and knee arthroplasty) who do hip and knee arthroplasty in Alberta receive CQI reports from ABJHI. This semiannual feedback can help to improve care process, infrastructure planning, and patient outcomes. Through a CIHR funded research grant, the "Best Evidence for Surgical Treatment in Knee Osteoarthritis (BEST-Knee) Study", PROMs reflecting knee symptoms together with other appropriateness indicators (non-surgical management, patient readiness and expectations of joint replacement, and net patients benefit) are being examined as an approach to inform the selection of appropriate patients for surgery based on their post-surgery outcomes at the two largest joint arthroplasty centres in Alberta.

Currently, the EuroQol Group and researchers from Alberta are examining the effectiveness of decision aid that provides individualized patient-reported outcomes (using routinely collected pre- and post-surgery PROMs data in terms of the EQ-5D, and clinical and demographic characteristics) to help the individual patient make surgical decisions in consultation with their orthopedic surgeon.

The implementation of the new mode of care for hip and knee arthroplasty and the intensive knowledge transition activities that developed from this new mode had made significant changes in policies and practices. This new mode also improved patients' accesses to care in Alberta. As one of the essential components of the new mode of care, Alberta's RPOMs implementation in hip and knee arthroplasty has been taking a lead and pioneering role at the national level and international stage.

Currently, Canadian Institute for Health Information is making efforts to promoting national wide PROMs implementation in hip and knee arthroplasty. Alberta's initiatives also contributed to the analysis of PROMs for hip and knee arthroplasty at the OECD wide alongside other jurisdictions' initiatives.

By: Deborah Marshall and Xuejing Jin

Cancer Control Alberta (CCA)

PROMs use at Micro and Meso Levels

Cancer Control Alberta (CCA) has started the integration of patient-reported outcome measures (PROMs) in 2013. The Edmonton Symptom Assessment System - revised (ESASr) was chosen to assess symptom burden, and the EQ-5D-5L to assess health-related quality of life. As part of program wide implementation, clinicians were trained through small group training sessions or online training as well as in clinic practice support when the PROM was first integrated into clinical practice.

PROMs are administered to all cancer patients attending a clinical appointment at any of our 17 ambulatory cancer care facilities in the province. We developed a standard operating procedure that outlined when the PROM should be administered which included multiple time points across their care trajectory. Patients complete the ESASr at each clinic visit, and the EQ-5D-5L is completed adhoc, but the goal is to have it completed every 6 months.   Due to technology limitations patients complete the PROM on paper, and then the data is entered into our provincial cancer EMR along with documentation regarding PROM review and clinical response. Entry into the EMR began in 2018. Once PROMs data are in the EMR the data flows into a data warehouse where Microstrategies, a data viewing platform has been used to produce several PRO visualization dashboards and reports. PROMs data are used at the individual patient level, whereby patient's scores are displayed on the dashboard trended over time, and the clinician can review and monitor patient's progress and discuss changes in symptoms or overall health with the patient during the clinical encounter. Further PROMs data are used at the aggregate level. For example, we used aggregate ESASr data to categorize patients according to their symptom burden as low, moderate, and high. We are exploring if patients in the low symptom burden group, who have good blood work could have a virtual clinic appointment, while those with moderate and high symptom burden groups would be seen in the clinic thus allowing for a redistribution of care resources based on symptom burden. In this context, PROMs data are used to stratify patients according to their symptoms and thereby their healthcare needs, which then allows for redesign of the delivery of services to them accordingly. These changes would in turn lead to shorter wait times for patients with high levels of symptom burden, better use of clinic time according to patients' needs, and better use of specialist's time. Currently, we are exploring approaches to using PROMs data to evaluate the effectiveness and cost-effectiveness of changing to this tailored model of care to provide targeted symptom management services to our patients. To date, 45,000 unique patients have completed at least one ESASr, ~157,000 unique ESASr measures are in our database and 4,500 patients have completed the EQ-5D-5L at least once.

The routine use of PROMs data in our provincial ambulatory oncology clinical practice has demonstrated many benefits, which include enhancing patient-provider communication, increased detection of escalating symptoms and concerns, and improved symptom management opportunities. Further work is required to ensure clinicians and patients can interpret and act on the scores.

By: Linda Watson

Calgary Comprehensive Epilepsy Program

PROMs use at Micro and Meso Levels

The Calgary Comprehensive Epilepsy Program (CEP) began the routine collection of EQ-5D-5L in 2016 for clinical and research purposes. This information is meant to supplement additional patient reported outcomes on depression (NDDI-E), quality of life (QOLIE-10), epilepsy severity and disability (GASE and GAD instruments), and treatment satisfaction. Patients are responsible for completing each instrument and are provided options to do this online in advance of clinic (via email) or at the clinic using a tablet application or through conventional 'pen and paper' Clinicians and administrative assistants are available in clinic to answer questions that patients may have when completing the forms.

With respect to the EQ-5D-5L at the first and each subsequent follow-up visit. These data are uploaded to the Calgary Comprehensive Epilepsy Program (CEP) Registry that is stored on a REDCap database on a secure University of Calgary server. The EQ-5D-5L data is being used at the individual patient level, whereby patient's responses at each visit are displayed, and clinician could assess and monitor changes in these scores alongside all other measurements on a 'one pager' that is appended to the patient's chart at each clinic visit. Currently, through the University of Calgary's Clinical Research Unit, data visualization platforms are being developed that will permit comparisons of metrics, such as the EQ-5D-5L, between the patient and their peers of a similar age, sex, epilepsy and seizure types.

Data is also being used at the aggregate level to inform practice and health services programming. For example, an exploratory analysis of a cross-sectional segment of the data showed that a large proportion of patient report mild-severe pain/discomfort and anxiety/depression. Although it is unsurprising to encounter high response rates for depression and anxiety, two common comorbidities of epilepsy, it was not anticipated that pain and discomfort would be commonly reported. Epilepsy is not conventionally thought of as a 'painful' condition and this warrants more research to elucidate any underlying cause that is either directly or indirectly related to seizures. Additionally, current work is being performed using unsupervised machine learning algorithms to determine if there are discrete clusters of patients that score similarly on patient reported outcome measures including the EQ-5D-5L.

To date, almost 800 patients have completed the EQ-5D-5L at a baseline clinic visit. Our current care delivery model will continue to assess and monitor the EQ-5D-5L and its subcomponents on an ongoing basis. For us, this is an incredibly powerful means of gauging overall patient health. Often, even on direct questioning, patients may not be entirely forthright or aware of how their epilepsy in impacting their quality of life or health valuation. By showing them their responses, how they have changed over time, and correlations with seizure frequency and medication changes, we are able to engage meaningfully in developing robust individualized treatment plans to treat the disease beyond just seizures themselves.

By: Colin Josephson

Red Deer Primary Care Network

PROMs use at Micro and Meso Levels

The Red Deer PCN started using the generic PROM SF-12v2 in 2010 as part of the Evidence Synthesis Support Opportunity through the Rural Health Chair at Red Deer College. To date, 3308 SF-12v2 surveys have been administered in our group programs, including Health Basics, Anxiety to Calm, and Happiness Basics, both at baseline and at the end of the 7 or 8 week program. Currently, the SF-12v2 continues to be used in our Recreation Therapy program both clinically and for evaluation. A baseline is collected at the first appointment, and follow up surveys are mailed to participants at 3 or 6 months. The EQ-5D-5L has been in use in RDPCN since 2017 in the Moving on with Persistent Pain program, and more recently in the Health Basics and Strong and Steady programs. Surveys are administered at the beginning and end of programs. A total of 354 EQ-5D-5Ls have been completed.

All PROMs are administered through paper surveys, and data is compiled and used for evaluation purposes. These aggregated results are reported to the RDPCN Board, management, Alberta Health, and are included in the Community Impact Report.

SF-12v2 and EQ-5D-5L have been valuable in assessing change in patient mental and physical health in our group programs. Year by year evaluation results have been useful in determining the impact of changes to the program. For instance, the Happiness Basics program is 7 weeks and was redesigned for a 4 week format as well. SF12-v2 results had been collected for the 7 week program for many years. This consistency allowed us to feel confident in their use in comparing the new 4 week format. Clinically the EQ-5D-5L has been useful in that the pharmacists, who often see our Moving on with Persistent Pain patients, have used the baseline survey from the program to determine a patient's functioning levels prior to seeing them for individual care.

The collection and use of the PROMS in RDPCN has been successful due a number of factors. First, staff are interested in evaluation. Our surveys are embedded in our printed participant journals for each of the group programs, which makes it easy for staff to use. Second, administrative support for implementation is deemed necessary. Dedicated evaluation staff is also important for analysis and reporting of the data. The templates and information provided by APERSU for the EQ-5D-5L have been useful in analysis and in presenting the results in effective ways. Finally, the results are used by the RDPCN Board and management as information for decisions on programs.

Our groups programs are now offered through other PCNs, academic institutions, or health/social service organizations, some of which use the EQ-5D-5L. These organizations submit information on their programs to RDPCN at the end of the year so that it can be compiled into an annual report. This allows for comparison of EQ-5D-5L results across different locations and types of programs. However, not all submit information to RDPCN, and smaller PCNs may require evaluation assistance. As this program grows, there may be ways that the data can be collected in other ways, such as electronically. This could potentially be done on a zone basis in order to support smaller PCNs. RDPCN will be exploring ways to work with others in the Central Zone.

By: Margo Schmitt Boshnick

9. Summary

The transition of PROMs use from clinical effectiveness research in primarily teaching hospital environments, into the real world healthcare setting with all its variants, imposes various practical and methodological challenges on users. Nonetheless, this trend is continuing, in Alberta, and around the world which can afford these information systems. Experience from Alberta provides several examples of successful implementation and use of PROMs in various clinical settings, which can be shared with other users to help support the next wave of successful implementation, and the realization of the overall aim of PROMs programs. The successful PROMs programs in Alberta set an example of PROMs use within the healthcare system for Canada and the rest of the world.

APERSU has been supporting PROMs end-users within the province since 2015, and has conducted several activities (seminars, webinars, workshops, end-user meetings, monthly educational communications) that aim at end-user education, training, and capacity building in using PROMs within the healthcare system. In the coming years, APERSU will continue to support end-users in planning successful PROMs implementation, and in analyzing and using PROMs data for the aforementioned purposes. Additionally, APERSU will continue to work with various stakeholders to provide further guidance and direction to PROMs users on ways to enhance PROMs use within the healthcare system.

We call on PROMs stakeholders within the province to continue their support to PROMs end-users, and to join us in enhancing the use of PROMs within the healthcare system. We believe that Alberta could provide an outstanding example to the rest of the world on proper implementation and use of PROMs.

10. Abbreviations

EQ-5D	EuroQol 5 Dimensions Questionnaire
SF-12/36	Medical Outcomes Study Shot-Form survey
HUI2/3	Health Utilities Index
WHOQOL	World Health Organization Quality of Life Questionnaire
ESAS	Edmonton Symptom Assessment Scale
QWB	Quality of Well Being
PROMIS	Patient-Reported Outcomes Measurement Information System
WOMAC	Western Ontario and McMaster Universities Osteoarthritis Index
AQLQ	Asthma Quality of Life Questionnaire
EORTC-QLQ-C30	European Organization for Research and Treatment of Cancer – Quality of life Questionnaire – Cancer 30 items
PHQ-9	Patient Health Questionnaire 9 items
GAD-2	Generalized Anxiety Disorder 2 items
PAID-5	Problem Areas in Diabetes 5 items
QALY	Quality adjusted life year

11. References

1. OECD, *Recommendations to OECD Ministers of Health from the high level reflection group on the future of health statistics: Strengthening the international comparison of health system performance through patient-reported indicators* 2017, OECD.

2. Black N, *Patient reported outcome measures could help transform healthcare.* BMJ, 2013. 346.

3. National Quality Forum, *Patient Reported Outcomes (PROs) in Performance Measurement*. 2013, National Quality Forum: Washington DC.

4. Greenhalgh J, et al., *How do aggregated patient-reported outcome measures data stimulate health care improvement? A realist synthesis.* J Health Serv Res Policy, 2018. 23(1): p. 57-65.

5. Squitieri L, Bozic KJ, and Pusic AL, *The Role of Patient-Reported Outcome Measures in Value-Based Payment Reform.* Value Health, 2017. 20(6): p. 834-836.

6. Canadian Institute for Health Information, *Patient Reported Outcome Measures.* 2015, Canadian Institute for Health Information (CIHI).

7. Patrick DL and Deyo RA, *Generic and disease-specific measures in assessing health status and quality of life.* Med Care, 1989. 27(3 Suppl): p. S217-32.

8. Whitehead SJ and Ali S, *Health outcomes in economic evaluation: the QALY and utilities.* Br Med Bull., 2010. 96: p. 5-21.

9. Herdman M, et al., *Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L).* Qual Life Res., 2011. 20(10): p. 1727-36

10. Valderas JM, Alonso J, and Guyatt GH, *Measuring patient-reported outcomes: moving from clinical trials into clinical practice.* Med J Aust, 2008. 189(2): p. 93-4.

11. Foster A, et al., *The facilitators and barriers to implementing patient reported outcome measures in organisations delivering health related services: a systematic review of reviews.* J Patient Rep Outcomes, 2018. 2(46).

12. Greenhalgh J, *The applications of PROs in clinical practice: what are they, do they work, and why?* Qual Life Res., 2009. 18(1): p. 115-23.

13. Sloan JA, et al., *Lessons From Large-Scale Collection of Patient-Reported Outcomes: Implications for Big Data Aggregation and Analytics.* Int J Radiat Oncol Biol Phys, 2016. 95(3): p. 922-929.

14. Ishaque S, et al., *A systematic review of randomised controlled trials evaluating the use of patient-reported outcome measures (PROMs).* Qual Life Res, 2019. 28(3): p. 567-592.

15. Valderas JM, et al., *The impact of measuring patient-reported outcomes in clinical practice: a systematic review of the literature.* Qual Life Res., 2008. 17(2): p. 179-93.

16. Santana MJ, et al., *Training clinicians in how to use patient-reported outcome measures in routine clinical practice.* Qual Life Res, 2015. 24(7): p. 1707-18.

17. Boyce MB and Browne JP, *Does providing feedback on patient-reported outcomes to healthcare professionals result in better outcomes for patients? A systematic review.* Qual Life Res, 2013. 22(9): p. 2265-78.

18. Chen J, Ou L, and Hollis SJ, *A systematic review of the impact of routine collection of patient reported outcome measures on patients, providers and health organisations in an oncologic setting.* BMC Health Serv Res, 2013. 13.

19. Devlin N and Appleby J, *Getting the most out of PROMs: putting health outcomes at the heart of NHS decision-making*. 2010, The King's Fund and The Office Health Economics: London.

20. Boyce MB, Browne JP, and Greenhalgh J, *The experiences of professionals with using information from patient-reported outcome measures to improve the quality of healthcare: a systematic review of qualitative research.* BMJ Qual Saf, 2014. 23(6): p. 508-18.