

Alliance EQ-5D PROMs Pilot Project – Final Report



**Alliance for
Healthier Communities**

Alliance pour des
communautés en santé

Introduction

During the fall of 2022, the Alliance for Healthier Communities (Alliance) launched a research project to pilot the implementation and use of the EQ-5D patient reported outcomes measures (PROMs) tool within 6 Community Health Organizations (CHCs).

The aim of this project was to investigate:

- 1) If the integration of the EQ-5D tool helped to support collaborative care planning and program evaluation.
- 2) Identify the processes involved in the implementation for widespread adoption across the sector.

Why did we embark on this project?

Currently, the Alliance’s evaluation framework only captures patient experience measures via the client experience/satisfaction survey, as such the purpose of piloting the EQ-5D PROMs tool was to help to address this gap.

The Equity, Performance, Improvement and Change committee at the Alliance, specifically chose the EQ-5D PROMs tool over other PROMs tools due to its simplicity, validity, and worldwide use and availability in over 200 different languages. In addition, the collection of PROMs data is being used in Ontario Health Team evaluations as well as primary care throughout Canada.

This report will provide insight on provider and client experiences with the EQ-5D PROMs tool and overall lessons learned.

Summary of Key Findings



348 clients completed the tool in total from 6 organizations



84 (24%) of these clients completed the tool twice (baseline and follow-up)

- **Key finding #1** – Completion of tool generally took 5-10 minutes and was easily integrated into existing workflows.
- **Key finding #2** The tool supported collaborative care planning by providing an overall snapshot of their client’s health, helped to address unnoticed/forgotten

health concerns, and supported goal-centered care. Clients found the tool as a helpful exercising for reflecting on their health.

- **Key finding #3** – The tool supported monitoring changes in health and program evaluation for programs that were structured, had low drop-off rates, and were primarily focused on addressing physical/mental health concerns vs structural needs.

“I believe everyone should have an opportunity to look back medically, because most times, everybody's so busy. You don't have time to look back at your health records and see how far you've come. But that survey helps you to have a general understanding of your total wellbeing.” – Rexdale client #1

Methods

Patient Reported Outcome Measures (PROMs)

Patient-reported outcome measures (PROMs) are validated measurement instruments that clients complete to provide information on their health status relevant to their quality of life, including symptoms, functionality, physical, mental and social health. PROMs help to identify whether health care services make a difference to a person's health status and quality of life, and complement patient experience measures (Al Sayah et al, 2020). They also contribute to a learning health system that can better focus care and align resources with patient needs, coordinate services, enhance efficiency, and foster a culture of shared accountability (Clifton et al, 2017).

Why should we collect PROMs data?

The collection of PROMs and specifically the EQ-5D PROMs tool provides many benefits:

1. PROMs can be used for screening and making referrals. For example, since the EQ-5D is a generic PROMs tool, the tool assesses general areas of health to support identifying problems and needs.
2. PROMs can inform clinical practice by identifying health issues that may go unnoticed by providers and patients.
3. PROMs data can be used to monitor changes in symptoms and health concerns, and can help standardize symptom management.
4. PROMs support patient-oriented decision-making and self-management; a priority for our member organizations.

5. PROMs can be used to evaluate and improve program and/or service delivery.
6. PROMs are specifically designed to limit burden on client and providers. The EQ-5D tool takes approximately 5-10 minutes to complete and can be easily integrated into the EMR to support improvement of care.

EQ-5D PROMs Tool

The EQ-5D is a generic PROM tool designed to assess general aspects of health that are not necessarily disease specific. It is a simple and brief measure of health status that is comprised of two parts (see appendix 1 for sample tool):

Part 1 – The Five Dimensions

The first part is an assessment of five dimensions of health: Mobility, Self-Care, Usual Activities, Pain/Discomfort, and Anxiety/Depression. In this part of the tool, clients are asked to select a problem level for each of the five dimensions (see figure 1.). The levels have intrinsic ranking, meaning that level 1 is better than level 2; level 2 is better than level 3; and so on.

MOBILITY	
I have no problems in walking about	← Problem Level 1 <input type="checkbox"/>
I have slight problems in walking about	← Problem Level 2 <input type="checkbox"/>
I have moderate problems in walking about	← Problem Level 3 <input type="checkbox"/>
I have severe problems in walking about	← Problem Level 4 <input type="checkbox"/>
I am unable to walk about	← Problem Level 5 <input type="checkbox"/>

Figure 1: The five problem levels, shown with the Mobility dimension

Part 2 – Visual Analog Scale (VAS)

The second part of the questionnaire is a visual analog scale (VAS – see figure 2) which allows respondents to score their health from 0 to 100 (with 100 being the best health you can imagine) (Al Sayah et al, 2020). This is a direct measurement of how an individual feels about their own health and helps capture how respondents feel about aspects of their health that may not be captured in the first part of the questionnaire. The higher the value chosen for the VAS, the better the client feels about their overall health.

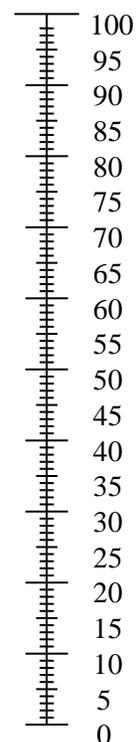


Figure 2: The VAS

Co-Designing the Pilot Project

This project was overseen by two separate advisory groups to ensure the implementation and evaluation of the tool was conducted in the most feasible and least burdensome manner. Our client advisory committee consisting of 5 CHC clients, reviewed the tool and provided input on how often the tool should be completed, any barriers clients may experience in completing the tool and the tool's overall utility.

The implementation and evaluation plan were reviewed by our research advisory committee, consisting of a subset of CHC researchers, healthcare providers as well as administrative staff. As per the advice given by this committee, participating organizations were given four implementation scenarios to guide implementation at their organization:

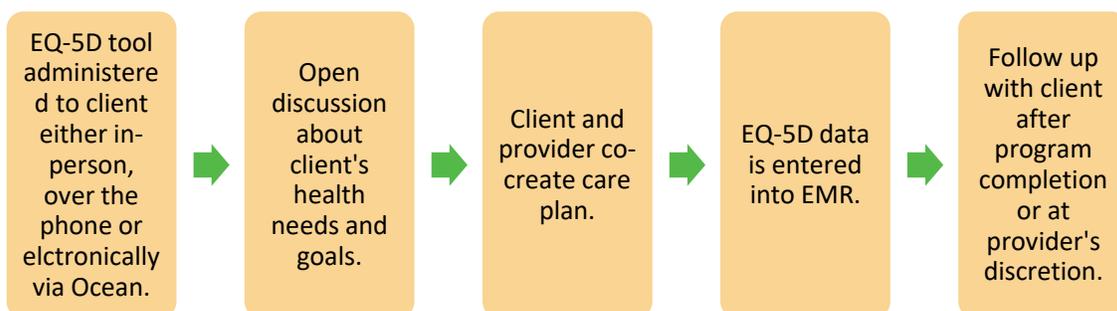
- 1) Embedding the tool within a clinical encounter
- 2) Embedding the tool within a new patient intake
- 3) Evaluating program/service delivery
- 4) CPIN (Canadian Primary Care Information Network) – a digital patient engagement tool to send short text or email messages to patients as well as the collection of PROMs data through linked surveys.

Organizations were provided the choice to administer the tool in-person, over the phone, electronically through the Ocean platform, or any combination of the three. Translated versions of the tool were also provided in ten different languages as well as the following resources to support implementation:

- Guide for using and interpreting results of EQ-5D tool
- Guide for EMR documentation
- Educational brochure for clients
- Telephone script version of the tool.

See figure 3. below for the general workflow implemented by pilot sites.

Figure 3: General outline of workflow implemented



Data Collection

This project used both qualitative and quantitative methods to answer our research questions.



Surveys were administered to organizations to identify the contextual characteristics of their organizations, previous experience with collecting PROMs data, their implementation approach as well as any facilitators/barriers that would influence implementation.



Interviews were conducted with 9 clients who had completed the tool twice and 12 providers across participating organizations. Interviews were conducted over zoom or phone depending on the interviewee’s preference.



EMR - As we wanted to keep the pilot low burden, organizations were asked to complete the tool for a minimum of 25 clients at baseline and follow-up. We collected both utilization data (i.e. how many clients completed the tool, mode of administration) and sociodemographic data.

Key Findings

Six Community Health Centres participated in this pilot project from October 2022-October 2023, with implementation varying in program/service and client populations served. Some sites focused on using the tool for collaborative care planning only while others also sought to use the tool for program evaluation purposes. This section covers the overall key findings from pilot sites we collected from surveys, interviews and EMR data.

Please refer to [appendix B](#) for a full description of how each organization implemented the tool and their specific lessons learned.

Implementation Experience

Utilization Data

- In total, **348** clients had completed the tool over the course of the pilot, with 85 (24%) of these clients completing the tool twice (i.e. baseline and follow-up).
- The majority of clients completed the tool in-person (77%), were between 61-80 years of age (57%), and identified as female (38%).

Completion

- Generally, clients were open to answering the questions listed in the tool and completed it within **5-10 minutes**.
- Providers found minimal differences between administering the tool over the phone vs in-person if the client's preferred language was English.
- Completion time was longer if interpretation services were required and for clients with cognitive impairments.

Integration

- Ease of integrating the tool within existing workflows was mixed.
- Some providers were easily able to integrate the tool within their existing workflows as they were often already discussing different aspects of health with their clients.
- Integration was more burdensome for programs with already lengthy intake processes and more challenging if clients were presenting with immediate needs.
- All providers found documentation within the EMR seamless.

For more detailed information regarding implementation of the EQ-5D tool, please refer to the how-to-guide.

Did the EQ-5D tool support collaborative care planning?

The tool provided an overall snapshot of health and helped to identify forgotten/unnoticed health concerns.

The majority of providers commented that the tool helped to identify and address aspects of their client's health they were not aware of. This was especially helpful for non-CHC clients who often did not get a chance to discuss more than one health concern with their provider.

The tool was less helpful for programs that involved already lengthy intake forms or home visits. Providers highlighted that the tool did not provide any new information when compared to their intake forms and home visits. The tool was also unhelpful for program in which clients primarily had structural needs.

Clients found completing the tool had given them an opportunity to reflect on how they felt about different aspects of their health as well as identify concerns they had forgotten about. A few clients expressed appreciation for their providers in wanting to know what other concerns they might have and their overall health.

"[...] a tool like this can be used to open up some other conversations and look at other issues that might be going on[...] And again, even if it's something that we can't address directly in our program, I think part of our role is getting people connected with other resource supports that can support their overall health." – Chatham-Kent provider

"[...] there was one client who said I don't have any problems [...]. But his health was like a 40 on the VAS. So, it was something health-related, but not captured. So, the follow-up referral I made was based on what I picked up on using the tool." Rexdale provider

"Yes, it drew my attention to some things that I wouldn't necessarily pay attention to like my mental health, my energy level, my mood and my activities. [...] after I completed the survey, I was referred to the mental health therapist in the hospital, in the community center, and they helped me out." – Rexdale client #1

Provided structure to conversations and supported goal-centered care.

Completing the tool provided structure to conversations if clients were all over the place when discussing their health concerns. Others described the usefulness of a tool as a conversation starter about how the client feels about their health concerns versus how the provider perceives the health concerns. This also helped to validate discussions between clients and providers. Overall, the tool helped to guide clients on setting health goals.

"And I think many times in terms of, let's say clients who are probably all over the place. You could actually maybe pick again, those two or three to say, out of this, I see that you're scoring, or saying that you are struggling in this area, would you want us to maybe talk a little bit about, what's ongoing for this, particular area? Or do you want to set some goals around this area?" – Access Alliance provider #1

"Yeah, actually I thought it was very helpful. The hardest question to answer is when you have to rate yourself. And I think it starts to get you going on not only what you currently, your situation is, but also as a preventative measure to say, what do you need to shore up on?" – Langs client #1

Facilitated discussions around depression and anxiety.

The depression and anxiety question, was cited as the most useful for providers in terms of care planning. It provided clients with an opportunity to bring up their mental health concerns through the tool versus on their own. Providers and clients alike cited that many clients would not readily open up about their mental health without directly being asked.

"And having, especially, that question about the anxiety and depression, a lot of people wouldn't, I think, readily open up about that unless they're asked directly about it. So if we can keep questions like that in to keep the conversation open and then help them get connected with the supports they need and also to validate that what they're feeling is normal. And yeah, I think that it's very helpful in that way. And we have a lot of people that come in and we have some emotional conversations when that question comes up." – Chatham-Kent provider #1

"Cause it's not probing, it's not asked me to, okay, say what specific conditions you're going through, but it gives room if you want to talk about it, you can bring it up naturally." – Langs client 1

Did the tool support monitoring changes in health outcomes and program evaluation?

Providers had varying experiences with using the tool to monitor changes in health outcomes and program evaluation.

Experiences were directly tied to the programs the tool was implemented in, given only 24% of clients had completed the tool twice.

Providers who used the tool during routine visits and for structured programs found it much easier to capture changes in outcomes. They also found that showing client's their improvements had helped to boost their confidence and morale. For such programs, the tool was helpful for program evaluation.

However, the tool was less successful in this regard for programs that were more loosely structured or primarily addressed immediate/structural needs. Regardless of the program/service, a few providers found that the point in time assessment (i.e. how you're feeling TODAY) prevented capturing health improvements that may have occurred between assessments.

"[...] because there is such a time gap between our intakes and discharges for this program they forget where they started out, so it's nice to bring that perspective back in. And especially because these changes that they make, things can happen so slowly and gradually that they don't notice.

– Chatham-Kent provider #1

"And I feel like a lot of what we actually do with our clients wouldn't be reflective in the survey. For example a client needs glasses and they're low income. Well, we get them involved with the city to pay for the glasses, we go to the optometrists, we get them the glasses. That was a goal of theirs, but is that reflective of the survey? Not at all."

– South-East Ottawa provider #1

Clients found completing the tool a helpful reflection of where they started and where they are at now (i.e. to keep track of changes in their health), which prompted them to think about their health in the long-term.

"I just enjoyed [...], both of us reflecting on where I am at at the end comparing to where we started." – Access Alliance client #1

"Start getting you to think about your health more than just the sort of the day-to-day kind of thing and what's the future gonna look like if I don't change my habits - Langs client #1"

Conclusion and Next Steps

From this pilot project we learned that the EQ-5D tool is quick to complete and is easily integrated into existing workflows. The tool is helpful for collaborative care planning and monitoring changes in health/program evaluation for structured programs that primarily address physical/mental health concerns.

The Alliance plans to support the collection of EQ-5D PROMs data across member organizations and has drafted a how-to-guide based on pilot learnings to support implementation. The Alliance is also exploring the use of this PROMs tool for evaluation of health promotion programming.

If you have any questions or comments regarding the pilot project, please do not hesitate to contact either Sara.bhatti@allianceon.org

Appendix 1 - EQ-5D Questionnaire

Part 1: 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

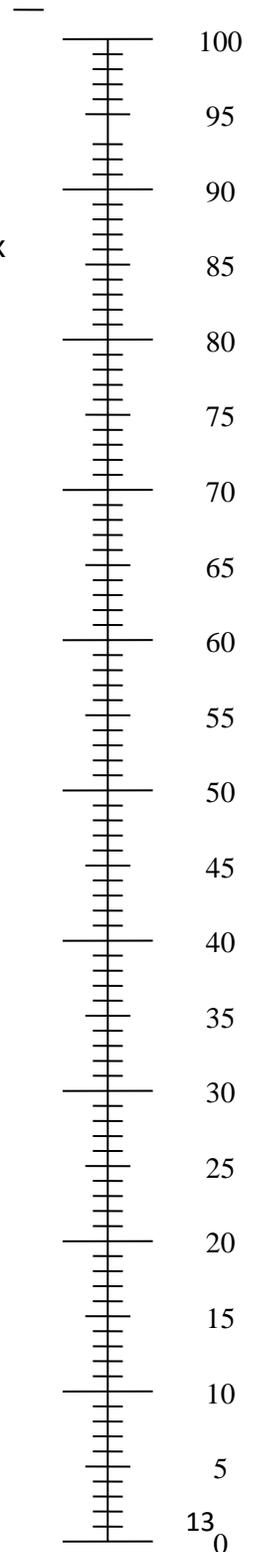
ANXIETY / DEPRESSION

- 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

Part 2: 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 =



Appendix 2 - Case Summary

Below is a case summary describing each centre's reason for piloting the tool, their implementation approach and post pilot learnings.

South-East Ottawa CHC – Primary Care Outreach to Senior's Program

Setting: This urban CHC aimed to use the EQ-5D tool to identify health concerns and co-create care plans for clients within their Primary Care Outreach to Senior's (PCO) program. The program involves supporting seniors to achieve their goals and their quality of life, timely access to care and empowering vulnerable seniors to live at home.

Approach: The PCO team consisting of registered nurses and community health workers had embedded the tool within their intake process and hoped the comparison of EQ-5D results before and after the program (3 months) would be helpful for program improvement.

Post-pilot learnings: Providers had mixed experiences - some mentioned that because they were primarily conducting home visits when administering the tool and that their intake process was detailed enough - the tool did not provide any additional information. Furthermore, some found it hard to implement with this client population given their cognitive impairments and the immediate needs they frequently presented with. However, they would recommend the tool for primary care.

Access Alliance – Health Coach Program

Setting: At this Toronto based CHC, the EQ-5D was used within their Health Coach program to measure client's perception of health and wellbeing to enable effective provider and client collaboration when co-creating care plans. Health coaching is the practice of guiding clients to actively engage in taking charge of their own health through health education, resource sharing, personalized plan of care, increased client independence, etc.

Approach: The coaches primarily administered the tool over the phone using the telephone script version during the client's second visit. The team intended to use the results to support client's achieving their self-identified health goals.

Post-pilot learnings: The tool was easy to administer and supported goal-centered care however, was not helpful for monitoring changes in outcomes/program evaluation due to clients presenting with immediate needs more often than not, high drop-off rates and point-in-time assessment did not allow for capturing changes made

between assessments. Suggested the tool would be better for more structured programs.

Chatham-Kent CHC – Cardiac Rehab Program

Setting: Located in the urban-rural community of Chatham-Kent, this CHC intended to use the tool to evaluate and improve their Cardiac Rehab program. By embedding the tool within the intake and discharge process (at 3-months), the team hoped to capture changes in client's health outcomes to improve service delivery.

Approach: The program team decided to have clients complete the tool after the full medical review as part of the intake. A laminated version of the tool was handed to clients when necessary.

Post-pilot learnings: Tool was easily integrated into existing workflow and helpful in monitoring changes in health and program evaluation.

Langs CHC – Outreach Team for those Experiencing Homelessness/Precariously Housed

Setting: This CHC located in the city of Cambridge viewed piloting this tool as an opportunity to evaluate and validate the work of their outreach team who work with those who are experiencing homelessness and/or are precariously housed.

Approach: The team consisting of a physician, nurse practitioners, registered practical nurse, outreach worker and a social worker, embedded the tool within their intake process in outreach settings. After establishing a relationship with the client, the results of the intake (done either on paper or Ocean), were used to provide and link clients to the appropriate services. The team planned to complete the follow-up tool within 2-3 weeks from intake.

Post-pilot learnings: For some clients, tool was useful as a point in time assessment and for understanding how they viewed their health, but providers generally found it difficult to administer with this client population and suggested it would be better for more structured programs, not outreach settings.

Rexdale CHC – Diabetes Education Team

Setting: Within this urban centre located in Etobicoke, the diabetes education team consisting of nurses and dietitians used the tool to identify health concerns that may be

missed during routine visits, support the creation of care plans for clients and collect client outcome measures.

Approach: The EQ-5D tool was administered both electronically (Ocean) and on paper to clients who had been seen within the past 12 months, with follow-up completion of the tool conducted at the 3-6 months mark. Depending on the usefulness of the tool, the centres plans to expand the use of the tool to all teams at the centre.

Post-pilot learnings: Tool supported goal-centered care, helped to address multiple aspects of health and was useful in capturing changes in health outcomes/program evaluation. Centre is in discussions regarding implementing the tool centre-wide.

Durham CHC – Diabetes Education Program

Setting: Located in Oshawa, this centre participated in the pilot to develop patient reported key performance indicators in order to measure the impact of their programs and services on clients.

Approach: The EQ-5D tool was administered by paper and given to clients participating in the diabetes education program. Providers coordinated follow-up completion of the tool at their discretion.

Post-pilot learnings: Tool was not suitable for the selected program as providers did not have enough time to administer the tool and clients seemed uninterested in completing the tool.