OSSU-BeACCoN Workshop: Principles for Selection of Patient-Reported Measures to Support the Transformation of the Ontario Health System

October 3rd, 2019

Notes and Next Steps

On October 3rd, 2019, the Ontario SPOR Support Unit (OSSU) and the Better Access and Care for Complex Needs (BeACCoN) Network co-hosted a workshop on patient-oriented measurement in the Ontario Health System. Both OSSU and BeACCoN are Ontario's components of the Strategy for Patient Oriented Research (SPOR). The OSSU engages researchers, patients and other partners in patient-oriented research to improve the health of Ontarians and the health care system. They provide supports such as expertise, infrastructure, training and resources to people conducting patient-oriented research to help implement Canada's Strategy for Patient-Oriented Research in Ontario. OSSU also funds projects that demonstrate the value of patient-oriented research and how it can leverage OSSU supports to achieve greater impacts. BeACCoN is Ontario's SPOR network for Primary and Integrated Health Care Innovations (PIHCI). It is a network based on partnerships between research, policy and practice. Its intent is to create a learning network. This network encourages the development, evaluation and scale up of new approaches to the delivery of integrated and cost-effective primary care services. The integration is vertical through the health care system and horizontal across multiple sectors.

OSSU and BeACCoN held a previous workshop that led to a set of principles on the use and collection of PGHD developed by Ontario patients and caregivers. The purpose of this workshop is to build on that work by bringing together patients, researchers, decision makers, clinicians and other interested stakeholders to discuss the principles that can be used to select standardized metrics that can support the Ministry of Health, the Ontario Health Teams (OHTs), and patient care. The discussion also centered on collaborating together over both the short and longer term to join together the numerous different efforts in the province on this issue, and how to reliably test, implement and scale any desired measures for the benefit of patients, Ontario Health Teams, and the Ministry of Health.

Objectives for the day

This workshop was intended to fulfil two major objectives:

1. Identify core principles for the selection and use of PROMs, PREMs and PRISMs in Ontario.
2. Outline an ongoing process that would be required to systematically select, evaluate and scale up the use of measures in a timely fashion for multiple different stakeholders in OHTs.

Context

The collection and use of person-generated health data (PGHD) is recognized as an essential component of modern healthcare systems. Work from the OECD, the Commonwealth Fund, ICHOM, IHI and others internationally and HQO provincially has been crucial in supporting health systems to understand and incorporate these patient-centric measures. As Ontario transitions to a newly designed health system featuring OHTs and Ontario Health, there is an opportunity to ensure that the new system can make of use of sound and collectively agreed upon measures of three key forms of PGHD – patient-reported outcome measures (PROMs), patient-reported experience measures (PREMs) and patient-reported or inferred social measures (PRISMs).

The development, support, implementation and evaluation of OHTs will transform health care in Ontario. This transformation provides an opportunity for patient-oriented researchers and patient partners to work with the Ministry of Health and leaders of the developing OHTs to ensure that Ontario makes effective use of sound PROMS, PREMs and PRISMs.

Welcomes

Dr. Vasanthi Srinivasan, the Executive Director of the OSSU, welcomed all participants and acknowledged there was a good representation of patients, caregivers, researchers, and policymakers at the workshop. Participants, both in-person and on the phone introduced themselves.

Dr. Geoff Anderson provided a brief overview of the SPOR Enterprise in Canada, which is made up of the 11 SPOR Support units, the SPOR Network in Youth and Adolescent Mental Health, the 11 Pan-Canadian SPOR Networks in Primary and Integrated Health Care Innovations (PIHCI), and the 5 Chronic Disease Networks. SPOR is a national initiative that is funded by the federal government and other partners. The Ministry of Health is actively involved in SPOR in Ontario. Both BeACCoN and the OSSU work with Anne Hayes, the Director of Research, Analysis and Evaluation at the Ministry of Health, to support SPOR activities.

Person-Generated Health Data (PGHD) Principles

Dr. Geoff Anderson provided an overview of the PGHD Principles that were created by Alies Maybee and Samira Chandani from the Patient Advisors Network (PAN). Having a set of common principles is essential for everyone to move forward.

BeACCoN engaged in a yearlong process with PAN to create the principles for PGHD. PAN and BeACCoN co-hosted two stakeholder workshops on PGHD: Sep 10, 2018 and Apr 15, 2019. Following the workshops, PAN surveyed its community and had in depth discussions on its member forum as well as at meetings to gather insights from experienced patient and family advisors from across Canada. They also underwent two rounds of consultations with stakeholders present at the workshops, where feedback was provided at in-person meetings or via email exchanges. The final document for principles for PGHD was completed on September 30, 2019.

The audience for the document are researcher, policymakers, and individuals responsible for delivering care. The purpose is to get the patients vision in front of them. These are going to be used both in clinical care to help with the care of individual patients and in the public interest (e.g. policy, planning and research). PREMs and PROMs are there – but this is the tip of the iceberg. The types of data generated data will be vast (e.g. from cell phones, surveys, wearables).

The following is a brief overview of the principles:

- **Patient/Caregiver as Partners** – Essentially, “nothing about them, without them”
- **Purpose** – We must be able to articulate why we are collecting the data from patients and caregivers. Each purpose would have a different set of ethics.
- **Access** – Patients cannot live in a world anymore where data is given, and then it disappears, without knowing who used it how it is used. We need to provide access to the data patients already gave.

- **Consent** – You are going to have lawyers at the room at some point. There needs to be legislation about this.
- **Transparency** – We need to explain exactly how the patient's data will be used. There also needs to be an ability for patients to comprehend the information.
- **Harm Prevention and Trust** – This is the flip side of consent. If patients provide data, you need to tell them what the benefits are for them. They are willing to agree to some harm, but there needs to be a balance. Again, the information needs to also be comprehensible.
- **Utility** – You need to tell patients why it is useful and you need standards to ensure it is useful. There needs to be high standards of data collection and you need to be 100% clear on why you're collecting data.

The report on PGHD principles will be made available on the PAN, BeACCoN, and OSSU websites.

<u>Context for collection and use</u>

Dr. Andrew Pinto provided some context about PREMs, PROMs, PRISMs and the Ontario Health Teams. There is a current movement that is happening and this is overlapping with the need to identify value, particularly for patients and caregivers. There is a larger recognition on the upstream social determinants of health. Integrated health and social care are necessary to reduce unnecessary health care use. There is a long-term trend around quality improvement that are converging to create more patient centred care:

- Patient reported experience measures (PREMs) – Gauging peoples' experience of health care and the system
- Patient-reported outcome measures (PROMs) – Discerning which outcomes are important to patients and whether we are gauging them
- Patient reported or inferred social measures (PRISMs) – This is a new term that captures the third leg of the stool: social measures. An example of the inferred aspect includes the work in this area that uses people's postal codes to figure out what neighbourhood they are in, linking that with their health record and pulling their data.

Some core components of OHTs include improved performance across outcomes that are linked to the quadruple aim. There are certain measures that teams need to be reporting on, such as PREMs and PROMs. There are several existing measures in Ontario and we should consider the utility of existing measures.

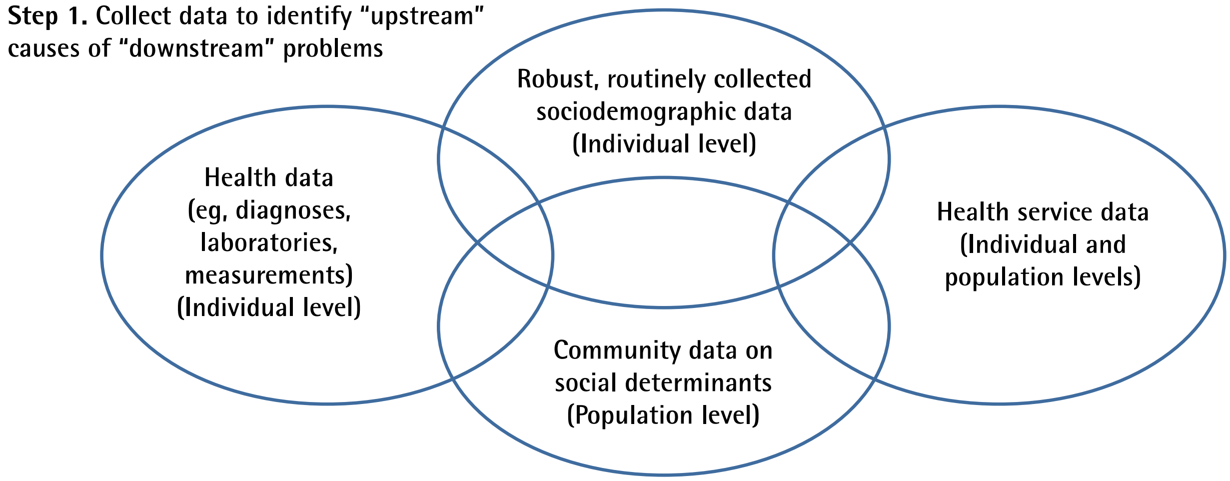
There are several existing measures for PREMs, including:

- Commonwealth Fund survey items (strong focus on primary care)
- OECD Health Quality Indicator Group
- CIHI: Canadian Patient Experience Survey
- Ontario's Health Care Experience Survey
- HQO and others: extensive work on PREMs related to transitions in care

For PROMs, there is a challenge to identify a single measure across all health conditions:

- CIHI: EQ-5D-5L & specific work on hip/knee replacement
- International Consortium for Health Outcome Measures (ICHOM) standard sets for a variety of conditions
- Ontario: pilot work with CCO on hip/knee replacement, renal care

For PRISMs, Dr. Pinto provided a framework of how data can come together to support integrated and social care:



We need to think about which communities the OHTs are embedded in and what resources are available. We need to consider how we can quickly gather the data that informs patient care. At the practice level, we need to look at roster of patients and identify where the gaps and inequities are and what needs to change. We can use these to measure performance and when you look across teams, it can inform systems change.

Dr. Pinto received a large grant form CIHR for the screening for poverty and related social determinants and intervening to improve knowledge of and links to resources (SPARK) study. The study involves 5 provinces and the goal is to develop a standard data tool for socio-demographic data collection. The SPARK pilot had very high response rates for both sociodemographic questions (e.g. race, health, sex, gender) and social needs questions (e.g. housing, employment).

To summarize, OHTs are evolving because of a need for patient centred care. Routine collection of standard PREMs, PROMs, and PRISMs will allow for comparison amongst teams. One important thing to note is that patient-oriented measures will need to be collected for Individual patient care, practice level improvement, and provincial level assessment. However, we must think about the respondent burden. The intersection of all this work is in the research world. People could debate for days about which survey is best. There is a lot of work about what has been done and there are people still developing measures. We must deal the pipeline – we have to land somewhere.

Neil McMullin is part of the newly minted Integrated Care Branch for the Ontario Health Teams at the Ministry of Health. There are currently two steams of applications for OHTs – full application (31 teams) and in development (43 teams). Despite the level of interest in PREMs, PROMs, and surveys, there has been confusion about the scope of OHTs. There will continue to be pockets of OHTs and pockets of normal operations. They are trying to create a performance measurement framework for OHTs that matches the quadruple aim. They are also trying to ensure that surveys are applicable to OHTs and non-OHTs. He reiterates that there have been lots of incredible work done in terms of PREMs and PROMs and they want to leverage that work in the near term. Consent is at the forefront of their mind. They wish to understand how they can make sure patients feel comfortable giving their data, and too what extent will patients know that they are in an OHT.

Discussion

There was a facilitated group discussion of principles for selection of measures. The discussion began with the idea that we need to work with what we have now. However, we must ensure that what we are doing now will not stop us from doing better in the future. We need to get this done quickly, and cost-effectively.

Alies Maybee, co-author of PAN's PGHD principles, started the conversation by reminding the audience that the first key principle is that patients and caregivers are involved in the conversation. More and more patients want to have a say in this and they should be involved in developing the purpose. Patients are looking at safety and confidentiality. We need to strive for something simple that patients could understand, which comes back to the transparency piece. For example, getting simple information out about OHTs, such as why they are collecting the data. The harm prevention piece is also very important and we need to look at it in balance with the benefits. Furthermore, the need for digital health literacy is huge – and she believes the Ministry could help with that. Overall, participants agreed that it is going to be important to think about how to educate patients. We need to show the value of what the information that is being collected could be used for so they are comfortable.

Another participant, currently in the process of completing the full OHT application remarked that patients are asking what it means for them to be in an OHT. It would be great if there was a way to consent patients/community members into an OHT, and then consent them into everything. Patients are generally agreeable to this idea, and already thought we were doing it anyway. Ideally, this is something we could adapt into the OHTs. A patient remarked that is so much data out there – and wondered whether everything could be combined into one system. Patients do not want to be consenting left and right to navigate the health system. They do not want to use multiple apps either – just one or two that will help them navigate the system.

Another participant mentioned that the most important principle is to start listening to patients. They are becoming more involved in their care. It is also about building that trust and ensuring that we are not only listening to patients but that we are also committed to using their information. The same goes for research. Not all patients want to give their email to hospitals, which makes it hard to get surveys to them. Yet, people provides all kinds of information to banks. People and banks have built trust – it is possible to build that trust. It takes a lot of work and there cannot be a breach.

Dr. Anderson agreed that a little piece of this around digital. Eventually, these two worlds are going to have to connect. When people download an app, there is often a confidentiality agreement where an individual can "agree" to certain terms. No one ever reads these. We are looking for something better than that, but acknowledge that formatting it in the right way will be a challenge.

Participants were mindful that there is an equity piece where only people with smartphones will be included. We must all remember that this doesn't work for everyone. There are going to be people who don't want to consent into using data from their phone – we need to acknowledge that piece and have other options available.

Some participants believe the challenge is not about identifying the principles. The importance is in connecting why we are doing something, how we going to collect the data, and what we are collecting. In their own work, one participant remarked that when they were able to identify what was most meaningful for patients and providers, there was huge engagement and great impact on people's health.

Participants agreed that we need to consider the language and ensure that it is informed by patient and caregiver values and preferences. For example, at HQO, some work has been done to understand what matters most to patients/caregivers in their transition from hospital to home. Many things are not routinely asked in surveys, or are not asked in the right way. Participants further pointed out that many of the concepts patients find important are not captured or if they are, it is not captured in a way that uses the patient's phrasing. For example, when using metrics to capture timely access to homecare, the phrasing in our metrics may not be aligned with theirs. We may asked whether a patient is able to get homecare within 5 days, when in reality, the patient perspective is 0 days. We need to ensure the measurement we are collecting is informed by the patient. Survey questions need to matter to the individual today. It is good to have benchmarks across the country and internationally, but you also need to sit down with the patients and see if the questions are important to them.

The Health Care Experience Survey (HCES), is a telephone dial survey, and is an example of a provincial survey that collects patient experience measures that is linkable at ICES. Participants pointed out that once a survey is implemented, its weak points becomes evident but there is a hesitation to change the questions. The expansion of HCES is being considered right now. It is an incredibly long phone survey and the cost is a big factor. If we are asking providers to collect information, they often do not have the expertise and there's also an opportunity cost to that. A lot of people still use the HCES. If you are adding questions to it, then you are also removing others, and need to be mindful of that. Long surveys equals less response rates.

At CIHI, they have started in this space and are waiting to see what the priorities are. They are engaging patients and working with them. For example, they wish to understand what successful navigation of mental health care looks like. They are thinking about how to leverage existing data and how to align across the country. There was an emphasis on the large burden that comes with collecting patient experience measures and a need to land on a set of questions. There is no need to re-invent the wheel. Yet, it is important to keep in mind that that patients only have so much time to fill out surveys and it will burn a lot of trust if we collect data but don't use it. We are asking patients these questions but need to make sure its clear who is responding to the questions. What if someone responds to say that they are suicidal, who follows up? Responses need to be addressed—you cannot ask and not act. Saying you are suicidal and having no one respond to it would be demoralizing. We need a core set of questions that everyone answers and then others that are used in certain circumstances (e.g. specific modules can be opted into).

Again, participants reiterate that it is vital to emphasis the benefit to patients. Dr. Pinto's work embeds this into the episode of care. Furthermore, not all measurements need to necessarily need to be linked directly to patient care. Integrated care is not the sum of all your individual encounters, there is another layer on top that encompasses all your encounters. You are not seeing the benefit of getting a call from an organization. This can be embedded into the actual episodic care – like having patients fill out a survey in the waiting room, since they are already filling out information about their allergies and medications. If you think you can develop a limited set of core measure for Ontario, it probably would not be that difficult to have that available at the point of care.

We need to make a decision about what is being done in the short term. One participant remarked that if we want a way to collect data from patients, it needs to go towards their care. However, another one disagreed and does not believe all information to should be directly linked to their care. For example, patients do not want their physician to be aware when they say that they do not feel their physician involves them enough in their care. We can de-identify the data and provide that information to the physician in a aggregate form. Dr. Pinto believes we need to engage clinicians in the discussion. We need to talk to them about how this data can be used to change their practice and how it can be used to shape care.

Participants pointed out the need to balance the measures across the continuum. If information is only being collected during the point of care, it is going to miss out on the on what happens upon discharge. Patients may not wish to share things when they in the hospital. There is a need to capture that balance. Dr. Anderson pointed out that patients are the only ones going through the continuum. The integrated care experience is not the same as the experience in each specific scenario.

To summarize, whatever work that is going to be done needs to work for patients and caregivers. Since we are collecting the data from them, they need to understand the purpose and there is an added advantage if they could see immediate benefit. We need to start thinking about how this will affect their care directly and how they can access their information. There needs to be something done in the short term. Eddy Nason wants participants to consider how we align the concepts of the PGHD principles with the fact that there are some things we want to get done. We need to remember that there will be a burden on the providers as well. It would be beneficial to give providers the necessary tools and the support to act on the data from a legislative point of view. We must also focus on the enabling patient self-management and not forget that both patients and caregivers are members of their care team. Whatever we decide on, we are going to have to evaluate it with the idea that we are going to do something better in the future.

A participant remarked that the data that is being collected needs to be suitable to the population (e.g. putting an aging lens on the PREMs and PROMs). Older adults who have technology are systematically different than older adults who do not. Additionally, older adults with multimorbidity are vulnerable and asking them questions at the point of care may not be an appropriate time. Dr. Anderson pointed out that if we really want to improve care, we need to do it for the most vulnerable, who tend to be individuals with low SES. We do not want to get down the rabbit whole where everything is digital However, we should not let perfection be the enemy of starting something. There will be blind spots, and recognizing those is more important than convincing certain groups they need to fill something out. Ultimately, unless we have a set of principles and a framework, we will not be able to identify the blind spots.

<u>Second Facilitated Discussion</u>

After a short break, there was a second facilitated discussion about stakeholder timelines, potential next steps in testing, and evaluating and scale up. There are two timelines that need to be considered for accountability on the OHT side. We wish to consider how the PGHD can be enacted with this current work. We need to consider a timeline of what can be collected and how that aligns with the principles that we want to use across the system. Essentially, we wish to create a matrix that will include the principles and provide examples of how we can do this. Dr. Pinto announced that at their national team meeting for the SPARK study, he will be sharing the PGHD principles and thinking about how the team can adopt them with the work they are doing. This would demonstrate a way to meet these principles and how to integrate it into care. There is a further opportunity for a short term (6-12 months) project. A subset of the OHTs in full application are connected to UofT Medicine's practice based research network, UTOPIAN. The principles could tested there and it would be an early way to test the roster of the OHTs.

Dr. Anderson provided an overview about the OECD's interest in PREMs and PROMs and how they have made it a priority over the years. They are currently developing and field testing tools on PREMs and PROMs for integrated care. The hope is to get on board with the field test. They will be testing it in various countries and BeACCoN/OSSU would like this to be a priority project for Ontario. The OECD have picked core questions and countries interested in participating would have to try them. Both BeACCoN and the OSSU would like to get this on the radar of the Ministry and believe SPOR can be part of this project. The hope is to get Health Canada and the other provinces on board. There are a variety of levels for PREMs and PROMs. There will be international items we will not have a lot of control over, then there things at the national level, and provincial level – we think to think about all of this and what we need to collect.

The matrix that is going to be used to think through the measurement will include sections on validity, acceptability, feasibility, and consistency. The PGHD principles created by PAN will be listed in additional columns.

It would be beneficial if the Ministry was willing to look at the differences/similarities of indicators listed on the OHT applications and organize it onto a chart. This would helps us understand what OHTs are looking at and it will be a way to propel them forward. Participants were in agreement that they would like to know more about what OHTs have in place moving forward. This includes information on what they are looking at and what areas they are covering that they could provide information on. We also need to understand that there are people who will be a part of the OHTs and those who will not. A provincial survey would capture the latter. OHTs are mandated to collect this data, but they are not going to articulate what they are going to do with it in their applications.

Dr. Pinto Andrew proposed doing a pilot in a limited number of OHTs. The way that data is collected is essential and is important to building trust and relationships. For many individuals, using tablets are okay, but you will always have some people who will need staff to explain things to them. The work we do needs to meet PAN's PGHD principles. There can be standardised data collection across 7-8 sites, and we would feed the data back to the teams.

Dr. Pinto pointed out that it is easiest to see how PRISMs affect care – we notice a patient has a social need and we can do something to help. For PREMs, there is an aspect within the care team. Concerning PROMs, there was some confusion to whether they can be acted upon in the primary care setting. Should PROMs only be for certain conditions? Is there any value for generic PROMs? Another participant remarked that PROMs could include information looking at why hospital use or certain events are higher in certain demographics. The same participant mentioned there are examples across Canada that can be looked at for data collection. A standardized approach to collecting data is needed and Alberta is an excellent example and is much superior to Ontario. The participant further mentioned that PROMs are not actionable at the practice level. Dr. Anderson disagreed and remarked that PROMs are inextricably linked to PRISMs. The people who report their health status as poor are the people who require the most help. It may not be help that a family doctor can provide, but there are other people who can provide that help. This PROMs piece will help in terms with equity. That is where it is actionable and this needs to be done beyond family practice. Another participant mentioned that goal attainment is an example of a generic, person-centred, and actionable outcome. It makes sense to the patient and provider and allows them to discuss what is working and what is not.

Some participants believe that providers should not be administering the surveys. It should be a third party to ensure that patients are providing unbiased and honest feedback and that it would remove the fear of retaliation that their services will be rescinded. It should made explicit that the questions will be improved over time. If we are going to be parsimonious about which indicators to have, we should prioritize areas we are not doing well in or where there is a lot of variation.

Participants pointed out that we should also consider how much quantitative data is needed. Many believe we are lacking the qualitative data. The most meaningful data we can collect may be the two questions: What do you like about your care? How can we serve you better? These are actionable actions in the patient's voice.

Participants also pointed out that PREM and PROMs are both patient reported but they are two very different buckets. Just because they are patient reported, they are bundled together. Patient centred is not the same thing as patient reported. When we think of how these things should be reported, we should not ask patients questions that could already be measured. An example would be asking patients how long they have been waiting – that is something that can be measured without asking them. When there is a good standardized survey in place, there can also be supplemental questions that hospitals can opt into.

Next Steps

The next steps would be to send out the matrix, which will include PAN's PGHD principles. It would be great if participants are able to come back and list what they have in terms of PREMs and PROMs. We are hoping to fill in the matrix with work that others are doing, and then have it filled out by the Ministry about the OHTs. There are many things we could have for the inventory, but the idea would be to narrow it down to the key domains used by the OHTs and narrow it down to the key measures that many are using.

Further steps include considering the ways to keep all participants engaged, such as bringing the group back together by teleconference on a fortnightly basis. Another step is to arrange a meeting with Neil Neil McMullin, Phil Graham, and Michael Hillmer to discuss how we can work together in the short term and what plans we might have in the longer term just to keep things in sync. Vasanthi will arrange this meeting.