

What health outcomes matter to Albertans?

Report of a Workshop February 20th, 21st 2020 Calgary, Alberta

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Campus Alberta Health Outcomes Workshop Grant

Health Quality Council of Alberta

www.hqca.ca

IMAGINE Citizens Collaborating for Health

www.imaginecitizens.ca

Alberta SPOR Patient Engagement Platform
(Alberta Innovates and O'Brien Institute for Public Health)

What health outcomes matter to Albertans?

Report of a Workshop held in Calgary February 20th and 21st , 2020

This workshop evolved out of the overlapping interests of three partners¹. It was our belief that the health outcomes currently attended to, measured and reported are of relevance mainly to those that deliver health services and make policy, and not those of most importance to patients. An overarching aim of this workshop was to set the stage for ongoing collaboration among key partners to help achieve balance whereby outcomes that matter to everyday Albertans are attended to as well as outcomes of importance to service providers and policy makers. Participants in the workshop included Albertans with significant lived experience related to health and analysts/researchers involved in collecting, analyzing and reporting health data. The workshop involved frank and impassioned discussion and resulted in the identification of relevant next steps. There was strong support for processes that moved towards citizens defining what health means in our province, and how we might measure it.

Objectives of the Workshop:

1. To begin to understand what health means to Albertans, and how they think healthcare² contributes to our health
2. To initiate a mapping process to identify gaps between indicators currently measured (by the health sector) and citizen defined outcomes.
3. Identify some collaborative processes to develop and test citizen defined outcomes measures

Day One: Thursday, February 20th, 7-9 PM (Patient/citizen participants)

- To understand different ways of thinking about health and health care
- To create a framework for a larger discussion on Feb 21

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IMAGINE Citizens Collaborating for Health who had identified the topic of health results that matter to Albertans as one of their [initial areas for focus](#). The intent was to identify, assess and report back to Albertans on what matters most.

Health Quality Council of Alberta whose mandate includes measuring and monitoring patient safety and health service and surveying Albertans on their experiences.

SPOR Patient Engagement Platform provides support and resources to assist researchers and patient partners in meaningful engagement in the health research process.

² In this workshop, when we referred to healthcare we included all those entities that provide care when we need it – Alberta Health Services, physicians and other health professionals, allied health services (e.g. physiotherapy), primary care networks, etc.

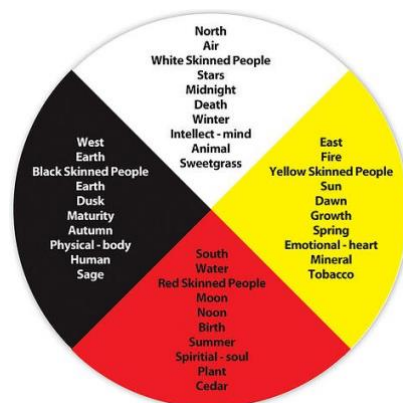
Gathering Initial Thoughts about Defining Health:

Participants engaged in a 'Tic Tac Toe' exercise in which they identified 9 words/phrases that answered the question: What does health mean to you³? Themes emerging from this exercise included the list below. In Attachment X the words and phrases that participants shared to support these themes are given.

- Able to do what I want to do physically
- Mentally/emotionally healthy
- Being seen as a whole person
- Able to work/contribute
- Absence of negative aspects
- Good quality of life
- Knowledge
- Healthcare
- Social life
- Caring for others

Setting the Stage: Two perspectives:

Medicine Wheel (Indigenous): Len Auger who is a member of the Big Stone Cree band north of Slave Lake gave an overview of the key points that are embedded in Indigenous traditional views of health. Although specifics vary depending where geographically the community is, the concept of the medicine wheel is ubiquitous in Indigenous cultures. Key attributes of the wheel are that it includes four quadrants that are four different colors (always the same) that represent four dimensions of key aspects of Indigenous cultures e.g. directions, nature, life cycle, dimensions of health. Humans and nature are closely interwoven and health involves four dimensions physical, mental, emotional and spiritual. Life is understood as passing through cycles/seasons. Teachings include topics such as use of plants, importance of animals. Although many Indigenous people have embraced Christian religion(s) they also believe that there is a power (spirit) greater than God. A typical example of a medicine wheel is below:

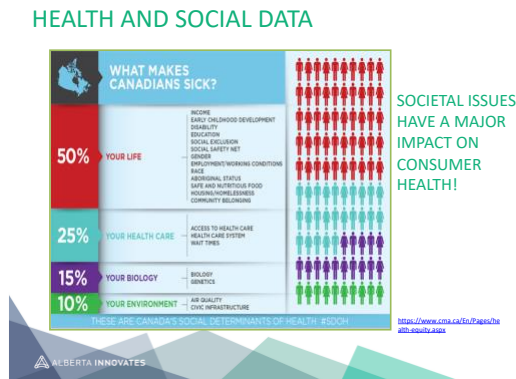


Source: <https://www.ictinc.ca/blog/what-is-an-aboriginal-medicine-wheel>

³ Raw data is included in Attachments

Determinants of Health (Western Science):

Judy Birdsell shared a slide that is often used to show different factors that contribute to the health of populations. In this type of analysis actions taken by the formal health system are estimated to account for about 25% of the health status of a population. The other influences for our health include our biology, the environment and activities we undertake and situations in our daily lives.



Reflections on Healthcare

As a transition to the conversation on Day Two participants were asked to think (and then share) their thoughts about healthcare and its role/contribution to one's health. While it was acknowledged that those entities that contribute to health by providing 'healthcare' are only part of the total experience, we focused in on this given the perspectives and roles of those analysts who would join the next day. Participants were asked to provide answers to four questions and these were summarized on Day Two to set the stage for the discussions. The four questions were:

1. How do people/Albertans currently experience their efforts to get and stay healthy in their everyday lives?
2. How is healthcare helpful in these efforts OR positively contribute?
3. How is healthcare not helpful, or get in the way of these efforts?
4. How do we begin to map what matters to Albertans, in terms of how healthcare makes (or could make) a difference to their health, wellbeing and everyday lives; as well as their families and communities?⁴

⁴ Raw data regarding healthcare is provided in Attachments

Day Two: Friday, February 21st, 8:00 AM-2:30 PM (Researchers/analysts joined)

Setting the Stage:

To set the stage for the day, the facilitator summarized the input that the citizen/patient participants had provided the previous day. Key themes from the Think-Pair-Share exercise follow⁵:

1. How do people/Albertans currently experience their efforts to get and stay healthy in their everyday lives? Main themes were:
 - Frustration/ with great difficulty – especially if faced with various health challenges
 - Health isn't actually important to many people until it becomes an issue
 - Personal resources affect ability to be healthy – money, physical ability.
 - Vastly different depending on one's specific situation.
2. How is healthcare helpful in these efforts OR positively contribute?
 - Providers who you trust, are compassionate, accessible and advocate for your needs.
 - When professional considers mental, emotional and spiritual dimension
 - Evidence based practices that lead to better quality of life
 - Education of public, supports in community.
3. How is healthcare not helpful, or get in the way of these efforts?
 - System designed around providers, not patients. Excessive burden for patients
 - Siloed services; poor communication, difficult to navigate.
 - Inadequate involvement of patient/family in decisions – 'we know best'
 - Lack of time and attention means focus on short term situation, not long term, or attributing mental/emotional issue to physical aspect.
 - Healthcare makes people do what healthcare wants – you are a 'typical' patient.
4. How do we begin to map what matters to Albertans, in terms of how healthcare makes (or could make) a difference to their health, wellbeing and everyday lives; as well as their families and communities?
 - Listen, include all stakeholders – open, honest dialogue, ask tough questions, drill down
 - What do we expect from healthcare system; what outcomes matter?
 - Short, creative, accessible ways for people to engage and participate
 - Address all aspects of health, not just acute physical needs; embrace wellness
 - Enable people power (communities, etc.) AHS is not the only player in the game.

⁵ Raw data regarding healthcare is provided in Attachments

Our hopes for the care that is delivered in the healthcare system.

All participants independently answered the question: What is your number 1 hope for the care that is delivered in the healthcare system? Participants then moved around the room comparing response and clustering into groups where the concepts described were similar. The respondents eventually clustered into three more or less overlapping themes:

- Quality, safe, effective care
- Personalized/individualized care that is compassionately delivered (this was the largest group on the far side of the room)
- Person-centred care

What outcomes matter to participants?

After considering the input to this point in the workshop and robust discussion, there was reasonable agreement on the outcomes that were important to this group. These include:

- A proactive system that helps people from needing care (e.g. prevention, wellness)
- Quality of life (defined by each individual as meaningful to him/her)
 - Involve me in scheduling of procedures, tests not 'Come for your surgery to X hospital at 9 am tomorrow'
 - Quality of life is defined individually by each person.
- Quality, safe, effective care that is individualized and delivered compassionately, person centred care
 - Having providers really listen is part of this.
 - Ability to have care providers deal with cumulative information so they see one's whole picture. 'Don't eat a sliver of the pie; eat the entire meal'.
 - Outcomes attended to now are very deficit focused;
- Equity⁶
 - Transitions between care sites very different urban versus rural
 - Transportation from rural home community sometimes not possible.
 - We are not measuring things that reflect equity – e.g. indigenous communities, low income, refugees, disabled persons
 - We often refer to deficit measures (negative lens) rather than equity
- Citizens increasingly involved in co-designing or shaping the health eco-system (A measure of change in the desired direction)
 - Companies ask for programs to reduce stroke risk, obesity, etc.
 - Are implementers of major expensive interventions (e.g. Connect Care) accountable for results?
 - Citizens are the payers
 - We have a lot of data; we aren't using it.

⁶ Defined as unwanted variation by one participant

Current Situation with Collection of Health Data Currently:

Those entities who are major players in the collection and use of health related data in Alberta were invited to give brief presentations about the data they collect. Each presenter was asked to describe how patients were involved in developing the measures and who is using the information and for what reason. A more detailed description of what each of the entities measure and report is included in the Addendum. These attachments are intended to serve as reference documents to support further discussions. As such, they sometimes include a bit more detail than was actually presented during the workshop. The following section gives a very brief summary.

Alberta Health (Shaun Malo)

Alberta Health collects a great deal of information. It maintains many ongoing data repositories that include such things as Inpatient data, communicable disease reporting, Vital statistics, Diagnostic imaging, Cancer Registry, Lab test results, fee-for service, etc. Many of these databases are shared with other entities and in particular there is much data flow back and forth between Alberta Health and Alberta Health Services. In addition to these ongoing databases derived from administrative data, there are occasionally surveys done. For example, the Alberta Community Health Survey has been done several times since 2006 and is done annually today. Alberta Health also uses data from other data sources such as the Alberta Congenital Anomalies Surveillance system. With all these sources of data, Alberta Health calculates health status (e.g. mortality, life expectancy), determinants of health (e.g. income and social status, health behaviours), and health system characteristics (e.g. accessibility, continuity of care, effectiveness, safety).

There is virtually no public/patient input into the data collected by Alberta Health. The data is used for administrative and planning purposes.

Alberta Health Services (Stafford Dean)

AHS collects a great deal of information derived from various activities that AHS is involved in. The most logical place to start to look at their publicly accessible information is at <https://www.albertahealthservices.ca/about/Page11908.aspx> Under the 'About Us' section is a folder called 'Reporting and Transparency' and then the 'Performance' tab provides links to relevant outcome data. They report on key measures aligned with their four goals:

- Improving Patients and Families' Experiences
- Improving Patient and Population Outcomes
- Improving the Experience and Safety of our People
- Improving Financial Health and Value for Money

There was very limited involvement of patients in developing any of these indicators. The customers for these analyses are governments, boards, executives, etc. There is an acknowledged need to provide useful data to direct care providers but this would require a rebuild of the measurement systems from the bottom up. There are many more pages/reports that provide measurements by AHS. A more complete report is found in the Attachments.

Health Quality Council of Alberta (Markus Lahtinen)

The HQCA does analysis and works with data provided by other agencies (primarily Alberta Health) and also does some primary data collection to fulfill its mandate. Many of the topics for focus for the HQCA come as a result of their collaborative relationships. The HQCA does considerable analysis of primary care data. Through discussion, the HQCA identifies system priorities and then does analysis and related work to add value to that area of work. They collaborate with Alberta Health Services, Alberta Health, professional colleges etc.

In addition, the HQCA is mandated to report on patient experience in the health system. Overall experience is the summary measure they use and surveys are currently done in various settings – primary care, continuing care, emergency departments. Patients are involved in the development of these measures, and the primary audience varies somewhat depending on the report. Primary care physicians are a major target audience and so is the general public. Uptake and use of the data reported is less than ideal.

Person-Centred Care Team & the SPOR Patient Engagement Platform (Maria Santana)

Maria Santana has led a group of researchers who have developed a comprehensive framework to guide the assessment of Person-centred care Quality Indicators. Aspects of the study have been published, and further work will be shared in the coming years.⁷

Patients were extensively involved in the development of that framework. The framework has been presented to various policy makers in Alberta, across Canada and the world, with use in Sweden. There has been some interest shown in Ontario, and the Health Quality Council of Alberta is using the framework to collect their patient experience data.

Airdrie Blue Zones Project (Kendra Chow)

The Blue Zones Project in Airdrie (Blue Zones are places with high concentration of centenarians enjoying a high quality of life) is in the process of defining their data collection targets and processes. The project in Airdrie is the first in Canada. Airdrie has a population of 70,000 and community leaders turned to a community-based focus on health promotion and healthy living. The Blue Zones Project has three main components – People, Places and Policy. The project is designed as a very data driven approach. They are collaborating with AHS and Alberta Blue Cross to incorporate data collected by others from Airdrie (this includes individual and community metrics) and also developing custom tools to augment that data and support community action. People data comes from AHS and survey tools; places involved are workplaces, schools, grocery stores, restaurants. Policy focus includes attention to the such things as the built environment, food and tobacco policy.

⁷ <https://bmjopen.bmj.com/content/9/1/e023596>
<https://bmjopen.bmj.com/content/8/7/e021525>

Both are Open Access publications.

The project will involve measuring many dimensions (personal and otherwise) as time goes by. The project has been shaped by the community – it is community led and incorporates best practices.

The project will launch in June and at that time their data collection and reporting processes will be made public. Having a community-based entity involved in these discussions is useful as the hope is that the Airdrie approach may have lessons for other communities.

Engagement Strategies to Increase Understanding of What Health Outcomes Matter to Albertans

To help focus our discussions the group provisionally agreed to a vision statement that we had a collective sense of where we were trying to get to. The group agreed (although not unanimously) that for our purposes a vision that would provide a common end point for this discussion was: *A healthcare system that offers person-centred care*⁸. Groups were tasked with identifying a target group with whom to engage and to recommend engagement strategies through which we could increase our understanding of what person-centred health care means to Albertans

Target Audience	Engagement Strategies
Seniors	In person conversations; Use existing settings: recreation centres, residences, disabled transport, home care, Diverse, random cross section of population (age, sex, etc.) Targeted marketing/communication (e.g. telephone for elderly) Use PR firm to brand, market, seek feedback
Rural communities without ready access to services	Involve prepared volunteers – PaCERs?, (e.g. polio vaccination campaigns in Afghanistan, Pakistan and Nigeria that use volunteer community mobilizers)
Rural communities	Community Ambassadors (Champions) – trusted community members – engage all ages and all people. Humanize healthcare and engage people in IMAGINE.
IMAGINE Citizens	Amplify need for point of care experience data

Next Steps

Participants working in four small groups recommended next steps and suggested the appropriate agency to take this forward if that was clear. The partners who sponsored this event will convene to assess the feasibility of suggested actions and advance specific actions as possible.

⁸ It was acknowledged that this was an often used phrase and that was not particularly unique from patient/citizen perspective, but it served the purpose. The concept of ‘person-centred’ includes many dimensions that the group endorsed – compassionate care, sensitive to context of family and community, social aspects

1. Introduce incentives to change practice and patient activation. (No actor identified)
2. Increase impact of Experience Surveys (HQCA)
 - Seek to understand both provider and patient points of view
 - Require increased number of patient experience surveys returned and show comparative stats to encourage improvement. (Friendly sense of improvement competition)
 - Find out how to get surveys to more people e.g. use motor vehicle registry emails
 - HQCA collect and evaluate outcomes at each point of care
 - Introduce collection of email addresses at point of care episode to enable follow-up efficiently.
3. Adopt and introduce Care Opinion ⁹to Alberta (No actor identified)\
 - It is a change mechanism
 - Platform exists and has a history of successful use in England, Scotland, Northern Ireland and Australia
 - Provides some information on various providers (consequences for poor care and/or kudos for good care)
 - It is somewhat analogous to 'Trip Advisor' for care
4. Measure and advocate for access (No actor identified)
 - equitable access to essential care and
 - to pro-active care
5. Enhance patient/citizen voice (No actor identified)
 - Put public in the drivers' seat
 - De-politicize the system
 - Organize patient advocates in the system
 - Position statement on what personal health data Albertans want access to. Tell government what we want; don't wait for them to tell us.
 - Health system has a public board determined by lottery¹⁰
6. Actions to incentivize policy with ideas coming from people (Start patient revolution)
7. Awareness and education
 - Continuing education for health care professionals on patient and family centred care
 - Positive targeted education to all elected officials – all levels of government
 - Raise public awareness of healthcare through social marketing
 - Look for 'bright spots', positive deviance, identify and share what is going well
 - Positive targeted education to citizens to raise awareness
8. Streamline care and adapt to context.

⁹ Care Opinion www.careopinion.org.uk is an independent online public platform in which citizens can share narratives about any care experience in a forum in which those agencies involved in providing the care may respond and interact if they choose to.

¹⁰ Or at least by some process that is apolitical in nature?

On Further Reflection OR Food for Further Thought

Participants were invited to offer reflections after reviewing this report. Their comments are below. They will be considered by the Planning Committee during deliberations of next steps.

Participant #1: (Citizen, Planning Committee) With a highly engaged group, the primary focus of the workshop evolved from that which was originally anticipated. We started asking the question about what health outcomes matter to Albertans. The group ended up with some pretty clear statements about what matters to Albertans when it comes to health, but the primary focus was not narrowly focused on outcomes. What follows are some themes that reoccurred during the workshop and which will shape our collective actions going forward. If the workshop participants agree with these further reflections, the priorities for collective action may need to be revisited. In the end, the original vision and the subsequent discussion which evolved were both focused on solving the same problem – which roughly speaking can be framed as: How can we support Albertans to claim or reclaim their rightful role in shaping the future of health and healthcare? Some key themes that emerged during the workshop.

- There is lots of relevant data already collected or envisioned that could provide intelligence to citizens/patients about how well our healthcare system is performing. A major issue is no one pays attention to it and entities are not held accountable through use of data. Part of the problem with no one paying attention is that the data is not shared in ways that are meaningful and readily available. We should not make this more difficult than it need be. Let's start by enhancing or making more useable data and processes that already exist, such as were described during the workshop – person-centred care measures; packaging and reporting of existing data to inform Albertans about aspects that care e.g. prevention and wellness.
- Albertans mainly care about how the system is working when it matters i.e. when they are ill and need help.
- We need to tell the story i.e. put data together in ways that make it relevant to the public. Perhaps consider some alternative framing
 - What is the Trip Advisor equivalent for healthcare? Airbnb?
 - Is health a Do-It-Yourself enterprise now, or should it be? Years ago we went to a lumber yard to buy nails and boards. Now we go to a home building store to get supplies and expert advice for a project that you define and design.
- Healthcare is a political entity. It should not be! The system is funded by citizens. It was said several times during the workshop that what is needed is a patient revolution.

Participant #2 (Analyst, Planning Committee): Some overall 'aha' moments for me:

- Equity lens means (looking for unwanted variations in outcomes that matter to Albertans)
- Outcome management (once we identify outcomes that matter to Albertans, how do we manage them?)
- Confidence in services (for me very much indicating a measure of safety)!

Participant #3: (Citizen)

- Notes are all good and cover what we discussed. FYI, this was the best meeting I've attended in the last five years. Well done.

Participant #4: (Analyst)

- Data and outcomes must be made meaningful to healthcare practitioners. They are Albertans too, and while there are undoubtedly negative experiences for patients, very often practitioners want positive outcomes for their patients too. We need to collaborate with allies on all sides to advance and enable this process.

Participant #5: (Citizen)

- Excellent synopsis of the think tank.
- My only add on comment, that I do not believe the group touched on in discussion of health and healthcare is the wait times –
- Wait times to be seen in an ER
- Wait times to be seen in a PCN
- Wait times to get in to a Medical Specialist,
- Wait times when surgery is required.
- Everywhere in the current system – we are expected to have a long wait. What is this attributed to - Is this reflective of the way the system works ? not enough health care personnel? Poor administrative management standards?
- Are patients giving up seeking medical help because of this?
- I think that this “wait time” makes a big impression on people’s general view of healthcare in Alberta.

Participant #6:(Citizen)

- This may well be a first step in a critical question. From the title of the event I thought the answer to the question was the goal, albeit a lofty one. I am a literal person and knowing the steps, process and timeline we were to undertake beforehand would have been helpful to me, especially with my decision to be a part of the committee. I am involved and committed now, but knowing what is expected of me is helpful in determining if I am a good ‘fit’ for the task.
- The awareness that Albertans do not know of the number of deaths due to medical error or the reality of our medical system cost to users beyond taxes was a shock for me.
- Additionally, the presentation of Care Option and the Airdrie Blue Zone Projecy were interesting but raised the question of the various health options available throughout the globe. Is it reasonable or fair to ask Albertans when they have neither a clue what they actually have nor what some options are available to them are?
- Once the event ended I felt perhaps the point was missed. I still do not know what health outcomes matter to Albertans or how we find out. I am unclear if this action will be going forward. The timeline for this considering the current political climate, seems urgent and daunting.

- I await more understanding and trust the insights of the agencies and persons involved. Thank you for the summary of the event.

Participant #7: (Citizen)

- Patient safety is paramount.
- Critical care is important.
- What health outcomes matter to Albertans is important. Everyone wants positive outcomes for any health care issue they encounter, either as a patient or family member.
- When I get assessments and treatment from my Doctore, I want to remain as healthy as I can – that is an outcome.
- Keep the outcomes simple – easy to relate to by the common person.

Participant #8: (Analyst)

- You captured it well.

Participant #9: (Analyst)

- I really like how you captured the conversations in the right context.
- It would be a stronger message if the reflections were distinct in terms of patient voices vs provider voices.

Follow up by Planning Committee

The planning committee that included representatives from the three sponsoring entities (IMAGINE Citizens, HQCA, SPOR Patient Engagement Platform) will convene shortly to review in depth this report and consider how best to move forward with the Next Steps suggested by participants, including feasibility and inviting others to collaborate as is desired or necessary. Participants in this workshop will be invited to be involved on a continuing basis as they are able.

Workshop Participants

Larry Albrecht	Alberta Health Services (AHS)
Len Auger	Health Quality Council of Alberta (HQCA)
Judy Birdsell*	IMAGINE Citizens Collaborating for Health (IMAGINE Citizens)
Luna Brunton	IMAGINE Citizens
Kendra Chow**	Blue Zones Project (ABRIO Health)
Mollie Cole**	HQCA
Teena Cormack	HQCA
Stafford Dean**	AHS
D'Arcy Duquette	HQCA
Paul Fairie*	SPOR Patient Engagement Platform (SPOR PEP)
Jo-Louise Huq	IMAGINE and AHS
Jeanette Jackson*	HQCA
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