

IMAGINE

CITIZENS Collaborating for Health

Community Conversations

What We Heard: Talking Digital Health Mapping with Rural Albertans & Youth

Talking Digital Health Mapping with Rural Albertans: April 6th, 2021

Talking Digital Health Mapping with Youth: April 10th, 2021

VI. Background

On a regular basis, IMAGINE Citizens connects virtually with citizens from across the province who share their experiences and ideas on a range of health and healthcare topics. These conversations allow participants to help shape future engagement approaches and important health initiatives that matter to Albertans. Using a collaborative and participatory approach, IMAGINE Citizens has hosted three Community Conversations with people to explore digital health literacy needs, aspirations and engagement tools and opportunities.

Exploring a digital health map with two audiences: rural Albertans and youth

IMAGINE Citizens hosted two *Talking Digital Health Mapping* Community Conversations. The first brought together ten Albertans from various rural communities across Alberta. The second conversation was with four youth (under 25 years old) and one youth leader. These conversations followed an event hosted in October 2020 that captured experiences, needs, and hopes around digital health tools and information in Alberta. [Input](#) from this initial *Talking Digital Health* session was foundational in guiding the development of a digital health information map. The map is currently a draft of a tool aimed at engaging and supporting Albertans in navigating and understanding Alberta's public digital health landscape (see the Appendix for a snapshot of this map). The subsequent conversations with rural Albertans and youth were an opportunity to present the map concept and gain feedback on the map approach and on how the map might be used.

Talking Digital Health Mapping Community Conversations were hosted via Zoom™ on April 6 (rural Albertans) and April 10th (youth), 2021. These engagement sessions were supported by [Alberta Innovates](#) and were a collaborative effort undertaken by representatives from two IMAGINE Citizens project teams, [iKNOW Health](#) and [Citizens for Digital Health](#).

Both sessions were casual conversations steered by questions examining what participants thought about the map's quality and clarity of information, ease of use, and design. Participants were also asked how they saw themselves using the map (if at all) and how the map could be shared with others.

This document provides insight into our discussion method and approach (Section 2), general demographics of our participants (Section 3), and an overview of what we heard during both sessions (Section 4).

2. Our method and approach

The discussions were facilitated by a representative from IMAGINE Citizens' iKNOW Health team with support from two other IMAGINE Citizens' members. Both conversations explored the digital health map displayed via an online, interactive MURAL™ platform. This visual facilitation platform enabled participants to access and place virtual "stickies" on the map. The comments provided on stickies are in addition to verbal comments and those provided through the Zoom™ chat. Depending on the technology some participants were using (e.g., iPad or smartphone), participants experienced problems accessing the MURAL™ map during the first session. Learning from that, IMAGINE adjusted the access steps for the second session to avoid similar issues. In addition to dialogue and text input, Zoom™ polls were used to understand digital health use better.

This engagement uses a co-design approach that evolves and builds from one Community Conversation onto the next. This approach provides ways for people to engage and communicate with each other, to be creative and to share insights and test ideas. In this case, a map and ways for it to be used are being co-designed to help citizens understand why digital health tools should matter to them, where to start and how to find their way in Alberta's landscape of digital health. This engagement approach is reciprocal - a back and forth process of learning from each other as we collectively advance our digital health literacy.

3. Event participants

Talking Digital Health Mapping conversations brought together 15 participants combined. The session with rural Albertans saw ten participants from locations such as Blackfalds, Canmore, Cremona, Fort McMurray, Okotoks, Peace River, and Sundre. Some participants worked for organizations supporting clients all over Alberta. The youth session attracted five participants from Calgary and the surrounding region. Some are active in the Southern Alberta Child and Youth Advisory Council.

Promotional opportunities for the events were very limited due to tight timelines. People learned about them via invitations shared through IMAGINE Citizen's social media channels and internally within the organization. IMAGINE team members were also instrumental in recruiting participants through their many connections and ties to community partners.

At the beginning of each session polls were used to look at the adoption of Alberta's public health tools by participants. Of all participants, less than half are currently using digital health tools profiled in the map including MyHealth Alberta functions, My AHS Connect or virtual connection with their family doctor or specialist. The top reasons for not using these tools are; participants have no health issues and/or never thought about it.

Rural Alberta conversation

Do you currently use digital health tools?

Yes = 50% No= 50%

If you are not currently using any digital health tools, why not?

- Never thought about it
- Have no health issues
- Worried about privacy
- Not certain about the advantages



Youth conversation

Do you currently use digital health tools?

Yes = 40% No= 60%

If you are not currently using any digital health tools, why not?

- Have no health issues



4. What we heard

The conversations were active and engaging with moments of silence where participants were referring to the map to respond to questions or simply taking time to reflect on the question. In both sessions the conversation flowed back and forth between digital health literacy and tools, and then the digital health map itself. This dialogue stream aligns with the map's intention to engage people in digital health literacy discussions and opportunities to adopt digital health tools.

a. Digital health literacy issues and concerns

Participants in the rural Alberta session brought up concerns they felt needed to be acknowledged and addressed for our province to embrace and access digital health tools and information successfully. Concerns about digital health tools and literacy were not a prominent topic of the youth session.

Participants in the rural session noted a number of barriers to accessing digital health tools and information including:

- Lack of access to reliable internet or none at all in rural and remote areas.
- Cost of technology such as computers as well as reliable internet.
- Keeping technology such as a computers or phones adequately up to date for advancing digital health tools.
- Cognitive challenges and/or limited technological literacy.

- The need or desire for face-to-face interactions rather than options like telehealth.

One participant who supports clients with long-term and complicated illness in Alberta wondered how her clients perceive digital health tools and information. “Does it overwhelm or help clear it up? There is a lot of information with complicated health conditions. How does this help me other than it is another thing to take care of?” she asked.

Others expressed a lack of confidence in the overall system and the implications of that when thinking about adding another layer of services to the system. “I fail to understand AH and their failure to understand the simple things in life never mind knitting together a whole integrated digital health system,” said one participant. Building on that idea, they noted that COVID-19 showed us how unprepared we are in embracing digital technology. One participant pointed to her experience supporting many senior members in her community to register for COVID-19 vaccinations. “It was not fun, easy or simple... It was an acute lesson on how NOT to get people involved in digital interaction.”

b. Why it matters: the value of digital health tools and digital health literacy

In both sessions, a prominent line of discussion was the value and importance of digital health and digital health literacy. Participants in each event felt that the map’s use was limited unless people understood “the why” behind digital tools and information and the importance of learning to use them now rather than trying to catch up later. They felt people need to understand the value of digital health before they will navigate through it via a map or in their own health journey.

Rural Alberta conversation highlights: why it matters

Rural participants noted the importance of keeping in step with digital health tools, considering the movement towards digitization is well on its way across many levels. One participant pointed to the federal government’s mandate to get every service we rely on to be digitized by 2025. “Somehow, citizens have to keep up with all this,” said a participant. By not using digital health tools now, a wide gap develops between a person’s capacity to use digital health tools and technology advancement.

Participants discussed ways that digital tools can help us as patients or potential patients, such as:

- Providing continuity of care if you do not have a regular primary care physician and instead, visit different doctors.
- Helping you be more prepared for doctor’s appointments by giving you the knowledge to ask the right questions and better use limited appointment time.
- With shared access, helping family members better support aging parents or family members with illness.

- Helping monitor and track your health and your health journey steps and manage what can be overwhelming amounts of data and information.

“I’ve had more tests in the last 14 months. I am overwhelmed that I haven’t kept the right paper, or I don’t remember when I went for a test. On bad days it is my kids that are helping me to navigate my records. When I think about people when they are the middle of not feeling well, the last thing they are thinking about is grabbing that x-ray or the notes that they had with the MRI, because I know I am just so overwhelmed.” – A comment from a participant from the rural Alberta session

Youth conversation highlights: why it matters

The youth session featured a discussion about how participants would convince their friends to sign up for digital health tools such as MyHealth Record. Youth would persuade their peers using advantages connected to their values such as environmental benefits from limiting paper usage, convenience, accessing information from anywhere in the world, and being proactive.

“Would you rather have all this in a big folder at home and add to it yourself or would you rather be able to hop on your phone or hop on your computer and be able to check it anytime from anywhere in the world and not have to manage the paper?” – A youth participant comment

“Something that has helped me explain this to friends is, ‘Isn’t it inconvenient to you to have to call your clinic for information? Wouldn’t you want to have that information for yourself and feel empowered enough to ask questions about your health?’” – A comment from a youth participant who has convinced friends to sign up to get their digital health ID.

“You might not need it right now and you might not see the point of it, but if something happens and you do end up in the doctor’s office or the hospital, you get sick, it would be good to have it already set-up, so you don’t have to scramble around and figure it out then. You’ll already have a plan in place and be able to find what you might have missed.” – A youth participant comment

c. The potential & value of a digital health map

As discussed above, both sessions noted that the map should help guide the discussion around the reasons to access and use digital health tools and information. The map can provide a starting point to explore the importance of digital health and progress further into understanding and adoption.

Rural conversation highlights: the value of a digital health map

Participants commented that digital health literacy is a lifelong learning process, and tools to help navigate that learning are beneficial. One participant noted that seniors are excited to learn and to harness that. She described her efforts to coordinate a group of seniors for regular Zoom™ meetings and how they embraced and enjoyed the opportunity.

Participants said the growing gap between knowledge and adoption and digital technology emphasizes the need to find ways to encourage and support people to get on board now, so we are not continually trying to catch up.

Using the map

Participants saw the map as a tool they might share with friends and family to guide a discussion about digital health information. They saw themselves as potential connectors - someone trusted who could support others like family and friends by walking through the map together.

“I’d like to be able to go through it with people and point out what currently exists and what will exist so they can become adroit in the use of that technology, because it’s going to be with us before we know it.” – A comment from a participant from the rural Alberta session

“I would use this as a slide deck with my own household members that ask me ‘why would I need this?’” – A comment from a participant from the rural Alberta session

However, participants also noted that a technology-based tool to help navigate digital health information could only go as far as the technology you have at hand – so, not valid for those with technology access barriers. Others acknowledged that without health literacy, digital health tools and any navigation supports could be too overwhelming. How can it help someone understand their health information, someone asked? “If I just feel overwhelmed with all this information, I am less likely to use it,” said one participant.

They also wondered how youth would be engaged to design and use this considering that “the younger generation are driving this,” as a participant noted.

Youth conversation highlights: the value of a digital health map

The youth discussion featured the importance of taking health information seriously and supporting youth to do that. “I think it’s really important to empower teenagers and help them to start to take part in your own health because you are so used to being under your family’s care that you need to learn to take care of yourself,” said one participant.

d. Designing the map

Participants noted in both events that the map was too busy but had good information on it. The two different conversations with unique demographics underscored the importance of addressing multiple learning and communication needs. The same information needs to be shared in different ways, and the map needs to be designed to acknowledge that. Participants shared their insights into how the map could best be organized and designed.

Rural conversation highlights: designing the map

Many felt the map's information could be separated and absorbed better by something more categorized, such as a PowerPoint. Rural participants acknowledged that this visual and learning preference is likely generational and that youth would be more inclined to work with a storyboard approach similar to the map discussed.

Youth conversation highlights: designing the map

Participants in the youth session liked the compass visual and seeing information easily in four quadrants. They had the following suggestions to improve or use the map.

- The map visual is well-suited for a vertical format to maximize its use on mobile phones, the technology most of us have in our hands.
- The compass could potentially be a web landing page with it acting as a navigation bar to other information.
- Break the information down into chapters that flow with links to more information.
- Provide tangible and actionable information in the map such as what to look for in a digitally forward-thinking doctor. “If you are looking around for doctors, here’s what you want to ask them to figure out if they are doing their part to centralize your information,” suggested a participant.
- Tie the information back to why you would want your health information centrally stored. “You need to explain and convince someone why they would want to use digital health tools, what their health information is and why having their health information centralized matters,” said one participant.

5. Session feedback

At the end of each event participants were polled, asking what they hoped to gain by attending the meeting. For the meeting with rural Albertans, most hoped to expand their knowledge and find solutions to problems. Some also wanted to network, present their ideas and opinions to others, and/or learn beyond their field of interest. In their meeting, youth and a youth leader primarily hoped to expand their knowledge and find solutions to problems. Participants were then asked if they felt the meeting met these expectations. All participants agreed it had. Some participants added to that with comments such as:

“It’s great to see what organizations like you are doing because it’s coming, and we have to be there to greet it.” – A comment from a participant from the rural Alberta session

“We might think we have the best solution because we are experts but that does not always translate to be true. So, there is a lot of learning and listening that people in my position have to do and get involved in meetings like this. ... We typically make decisions and push it down to people. This initiative is bottom up and top-down meeting in the middle.” – A comment from a participant from the rural Alberta session

6. Conclusion

Exploring a digital health map as a group opened the door to a range of digital healthcare topics. Two different groups shared their unique insight regarding barriers and challenges to accessing digital health tools, the value of digital health information, and the value and potential opportunities of a map to engage people in navigating this overwhelming and growing frontier that is uncharted from a citizen perspective.

The discussions pointed out that a “build it and they will come” approach to digital health will not help close the gap between digital advancements and our adoption and knowledge rate. Barriers to access need to be fully understood and addressed, and people need to see the personal benefits of digital health tools and information before they adopt them. If designed and provided to address multiple audiences with multiple needs, a map is an entry point into the discussion of digital health information and tools, why it matters, and how it can help us manage our health.