

IMAGINE

CITIZENS Collaborating for Health

What We Heard: Talking Digital Health *Community Conversations* October 28th, 2020

I. Background

Community Conversations is a new series of informal, online conversations designed to bring Albertans together to discuss relevant health and healthcare topics and issues. On a regular basis, IMAGINE Citizens connects with citizens from across the province who share their experiences and ideas. Their input helps steer IMAGINE's work by shaping an understanding of what matters most to Albertans.

IMAGINE Citizens' second online *Community Conversation* held via Zoom™ in late October 2020 brought together 41 participants and members of IMAGINE Citizens. The conversation was open to all Albertans with a special focus on those with experience using, or interest in public digital health tools. This event was a collaborative effort undertaken by volunteers from two IMAGINE Citizens project teams, [iKNOW Health](#) and [Citizens for Digital Health](#).

The conversation explored specific, publicly funded digital tools available to Albertans and tapped into experiences, stories and ideas about accessing and using them. The discussion explored three open-ended questions:

1. How are you or how would you like to use your digital health tools and information?
2. Where do you get stuck using digital health tools and information?
3. What functions are important to you when using digital health tools and information?

The planning team designed the event to be interactive and engaging, and to provide foundational insight to inform future engagement. The event was also intended to spark participants' interest in future, more focused engagement opportunities related to digital health tools and information in Alberta.

This document provides insight into our discussion approach (Section II), general demographics of our participants (Section III), and a high-level overview of discussion themes (Section IV).

II. Our approach

The discussion was facilitated by members of the Citizens for Digital Health and iKnow Health teams who posed three main questions to the group and steered the discussion. People commented and provided input verbally or by using the Zoom chat function. Comments were immediately captured and displayed visually by a team member using virtual Mural "stickies". Mural is a digital workspace for visual collaboration (<https://www.mural.co/>). As would be expected in any conversation, it evolved

beyond the three main questions, sometimes staying on topic, sometimes flowing to the next or previous topics, and sometimes introducing new ideas less related to the specific questions. In addition to dialogue and text input, Zoom polls were conducted to better understand participant demographics as well as digital health use.

This was an active and engaged Community Conversation; there were very few moments where participants were not talking or using the chat function. Our facilitator and planning group were careful to remain in the background and not summarize or extend comments participants openly shared.

The objective of the conversation was to give people space to converse. Feedback received through the chat function and a post-event evaluation suggests people felt they were provided this opportunity.

“Enjoyed the real-time Q&A. ... Really enjoyed hearing the perspectives of different participants. I got a much better understanding of digital health and the issues at hand.” – from post-event evaluation

“Enjoyed the variety of people and perspectives. Good to have some very keen interest and knowledge coupled with others with less experience and lots of good questions and comments.” – from post-event evaluation

III. Event participants

Talking Digital Health brought together 44 participants from many locations in Alberta plus participants from outside Alberta and Canada. People learned about the event via invitations shared through IMAGINE Citizen’s social media channels and newsletter. As well, team members who steered the event were instrumental in recruiting participants through their many connections and ties to community partners.

Through online polls, people shared the following information about themselves (note: participation in polls was not mandatory so may not be fully representative):

Location	Age
Calgary region: 17 participants	18 - 24 years old: 0
Central region: 2 participants	25 - 34 years old: 5 participants
Edmonton region: 5 participants	35 - 44 years old: 9 participants
North region: 4 participants	45 - 54 years old: 8 participants
South region: 2 participants	55 - 64 years old: 4 participants
Outside Alberta: 2 participants	65 - 74 years old: 6 participants
Outside Canada: 1 participant	75+ years old: 1 participant

Involvement in the healthcare system (many in multiple capacities)
Involved in healthcare in a professional capacity: 7 participants
Formerly involved in healthcare in a professional capacity: 8 participants
A patient with long-term or complex health challenges: 6 participants
A patient who does not use the health system frequently: 7 participants
Support a family member or friend who is a patient in the health care system: 8 participants
An interested citizen: 11 participants

Reasons for participating in the event
Wanted to contribute to a discussion about digital health tools: 5 participants
The topic is related to the work I do: 8 participants
The topic was interesting to me: 7 participants
I wanted to learn more about IMAGINE: 3 participants
I wanted to learn more about digital health tools: 8 participants

Beyond demographics, polls helped provide base insight into participants' current use of digital tools. The polls suggested there was a balance between those who have and have not used virtual visits to meet with a health provider this year. More than half of the participants who responded to the poll indicated they has signed up for Alberta's MyHealth Record. Few people had signed up for MyAHSConnect. However, this may be indicative of limited implementation across Alberta at the time of the conversation.

Have you signed up for MyHealth Record?

Yes = 20

No = 15

Have you used virtual visits or some other 'digital/virtual' approach to meet with a health provider this year?

Yes = 20

No = 15

Have you signed up for MyAHS Connect (where appropriate)?

Yes = 5

No = 30

IV. Discussion Overview

During and after the event, a small group of planning team members ensured all verbal and chat comments were captured on the Mural document. They then categorized and themed the comments. The information below is an overview of what we heard, based on category, themes and sub-themes.

Category A. I would like a set of tools that allow me to be an active partner in my own healthcare, to interact with the system and health providers on my own behalf.

- I'd like to help create a fully personalized digital health record in partnership with my health providers.
- I'd like to access my complete digital health record in different ways.
- I want to be able to visualize data /patterns over time to help me interpret my information in my digital health record.
- I want to simplify communications (questions, scheduling, etc.) with my care providers.
 - Improve scheduling and coordination
- I want to use contemporary communication and scheduling tools.
 - Improve communications
 - Be more independent and have more options about how to engage with providers
- I'd like to be able to integrate information from different devices and platforms.
- Can we find ways to integrate information from different sources?

Category B. My education, communication, and access needs

- Raw data is not information. People will need training about understanding, and interpreting our health information - what does info mean?
 - Data literacy needs to help me interpret the information within my digital health record.
 - Suggestions to help me understand context when interpreting data – context matters.
- I need more information and communication about the roll-out of My Health Record and My AHS Connect.
 - Communication is needed to address questions about roll-out.
 - Confusion about MyHealth Record and MyAHS Connect.
- There are barriers to accessing the digital health records (My Health Record and MyAHS Connect) that seem not to have been considered.
 - Skill barriers
 - Access to technology barriers
 - Cultural barriers
 - Language barriers

Category C. I would like to be able to share my digital health record with different people to ensure continuity of care for my health and support secondary analysis. Data could be useful for people with conditions like mine, and to improve public services and supports.

- Who needs to be able to see my digital health record with me?
 - I want to be able to share my digital health record with my family and carers
 - I need to be able to securely share my digital health record across teams, transitions, and disconnected parts of the system.
- I need to be able to share my digital health record with my GP or NP in community settings.
- Sometimes my doctor and I are sharing information outside of public tools.
- I can see potential for different secondary uses of digital health information.

Category D. Privacy and legal issues, regulatory change

- Participants recognized that privacy from the citizen/person view might be different to privacy from the 'legal' view.
- Some participants talked about potentially being willing to trade privacy for solutions.
- Some participants talked about concerns about privacy and data ownership and breach.

Category E. System, policy, broader perspective changes needed

- System enablers
 - I recognize that using my complete health record will require a shift in
 - a) how we think about receiving and providing care and
 - b) my relationship with my health provider
 - c) roles for a health professional and for citizens/ people.
- People recognized that there are numerous barriers and challenges, such as cost, at the physician/Primary Care Network/ Community clinic level that need to be worked through.
- People acknowledged we have made progress.

V. Conclusion

Talking Digital Health was an engaging and active conversation capturing experiences, needs and hopes around digital health tools and information in Alberta. The discussion opened the door to perspectives from those with a high level of tech and digital health tool understanding to those without and wanting to learn more. Participants from all over Alberta and beyond provided their stories, insights and ideas around how they are or how they would like to use digital health information and tools, where they get stuck, and what functions are important to them.

All comments from the event were compiled and analyzed, falling within five main categories or topic areas:

- I would like a set of tools that allow me to be an active partner in my own healthcare, to interact with the system and health providers on my own behalf.
- My education, communication, and access needs
- I would like to be able to share my digital health record with different people to ensure continuity of care for my health and support secondary analysis. Data could be useful for people with conditions like mine, and to improve public services and supports.
- Privacy and legal issues, regulatory change.
- System, policy, broader perspective changes needed.

Multiple themes and sub-themes emerged in the above categories; wanting data visualization and information translation, exploring who can access personal data, and barriers to accessing tools and personal health data, to name just a few.

The information gained at the session will be used to build future engagement steps, including conversations and events that focus on individual categories or themes noted in this document.