

# IMAGINE

## CITIZENS Collaborating for Health

### What We Heard: COVID-19 & You *Community Conversations* September 30<sup>th</sup>, 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. Every month we connect with citizens from across the province who share their experiences and ideas and ultimately help IMAGINE better understand what matters most to Albertans.

IMAGINE hosted its first online *Community Conversation* via Zoom™ in late September 2020. The conversation was open to all Albertans and invitations were shared through IMAGINE's social media channels and newsletter.

COVID-19 & You brought together 22 Albertans of all ages and from many regions of Alberta and beyond. Guided by six IMAGINE members, interactive, group discussions delved into the impacts of COVID-19 on health, and the role of citizens in making healthcare and system decisions during a pandemic.

This document provides insight into our participants (Section II), an overview of discussion themes we heard (Section III) and a detailed view of discussion notes captured during the event (Section IV).

#### II. Event participants

Through online polls, participants shared the following information about themselves:

|                 |                                 |            |                                   |
|-----------------|---------------------------------|------------|-----------------------------------|
| <b>Location</b> | Calgary region: 13 participants | <b>Age</b> | 18 - 24 years old: 1 participant  |
|                 | Edmonton region: 3 participants |            | 25 - 34 years old: 1 participant  |
|                 | North region: 2 participants    |            | 35 - 44 years old: 3 participants |
|                 | South region: 1 participant     |            | 45 - 54 years old: 5 participants |
|                 | Ontario: 1 participant          |            | 55 - 64 years old: 4 participants |
|                 |                                 |            | 65 - 74 years old: 1 participant  |
|                 |                                 |            | 75+ years old: 1 participant      |

#### **Involvement in the healthcare system (many in multiple capacities)**

Involved in healthcare in a professional capacity: 8 participants  
Formerly involved in healthcare in a professional capacity: 3 participants  
A patient with long-term or complex health challenges: 2 participants  
A patient who does not use the health system frequently: 4 participants  
Support a family member or friend who is a patient in the health care system: 7 participants  
An interested citizen: 6 participants

#### **Reasons for participating in the event**

Had a COVID-19 experience they wanted to share: 1 participant  
Wanted to hear about others' experience: 11 participants  
The topic was interesting to them: 9 participants  
Wanted to learn more about Imagine: 5 participants  
They were curious: 2 participants

### III. Discussion Overview

Technology permitted the group of 22 to be divided into five small groups for break-out sessions twice during the event. These sessions were facilitated by IMAGINE members. After both break-out sessions, a representative from each small group shared the main points and themes with the large group. These main points and themes are summarized below.

#### **A. Themes from first break-out session: personal experiences**

The first half of the event explored personal experiences during COVID. Participants were asked to share a story of how COVID affected their health or wellbeing or that of someone they support. The conversations focused on experiences, challenges, barriers and opportunities related to health and well-being during the pandemic.

*Unintended consequences - an overarching theme.* Many of the policy or health related decisions surrounding COVID-19 resulted in a cascade of unintended consequences affecting health and well-being. While most acknowledged the decisions were necessary, made quickly, and with the best intentions, participants felt their experiences pointed to a need for review and adaptation.

Unintended consequences and their impacts were revealed within the following themes:

*A1. Lack of access to health or social services.* The primary focus on COVID-19 prevention and treatment came at a cost to other health and mental needs.

- Health and mental health concerns were compounded or caused by lack of access, limitations or changes to health and social services, personnel, and facilities.
- An overwhelmed long-term care system meant reduced care and services for all patients.
- Confusion and ever-changing communications around policies and rules increased the challenges to access health or social services.

*A2. Mental health.* Making difficult personal or family health-related decisions, alarming media and data reporting, testing delays, and isolation resulted in a range of mental health concerns. Discussion groups most commonly cited:

- *Quarantine anxiety and fears:* from missing human interaction, to fears of lack of support if quarantined, and to the many “What ifs?” if tested positive,
- *Long-term care and dementia patient impacts:* loneliness, lack of human interaction, family stress, confusion and limitations around visitation, unable to recognize people in masks.
- *Children’s isolation impacts:* stress on family, increased workload, concern over social development, stressed children wanting to see friends.
- *General impact on wellbeing:* anxiety, lack of focus and motivation, and feeling of helplessness.
- *Support:* Need support groups and access to affordable mental health services, including virtual. Need to help those helping others.

*A3. School re-opening concerns.* All discussion groups brought up challenges and difficult decisions for families and teachers related to the re-opening of schools. Many brought up the need for reconsideration of the limited symptoms required for a student’s quarantine.

*A4. Resilience and adaptability.* Resiliency and capacity for adaptation was spotlighted via personal stories. Personal and organizational examples ranged from taking advantage of learning opportunities such as podcasts and webinars, to connecting virtually with family and friends, adjusting work practices, to simply buying a pretty mask. In addition:

- *Virtual care* was noted as a key action for individual and health system adaptation.
- *Equity* was a topic of concern. It was acknowledged that some people are far more affected by COVID-19, and the public health measures put in place, than others. Some people may be missed in terms of support. The capacity and opportunity for resilience and adaptation is also inequitable; adjustments and changes to policies, services (including virtual care), and communication are required to address unique needs.

## B. Themes from second break-out session: our role in decisions related to the pandemic

The second conversation of the evening was prefaced by a brief presentation of IMAGINE survey findings related to citizen involvement in COVID-related policy decisions. Survey results indicated that the highest-priority policy issues for citizens were:

1. How to re-open schools, businesses and events (52% ranked this #1)
2. How to access virtual care (25% ranked this #1)
3. How to manage restrictions on family caregiver access to patients (in hospital) or residents (in long term care or congregate care facilities) (28% ranked this #1)

Break-out groups were asked to select one of the three issues above to discuss in more depth. Groups talked about actual experiences they had in contributing to policy decisions, how they would like to contribute to policy discussion, and how we could make it happen.

Overall, participants agreed they want to be more involved in COVID-related policy discussions, had limited examples of how they already were involved, and felt that the “how we could make it happen” was a challenge. Key discussion points from the second conversation include:

*B1. Personal, family and work responses to COVID policies.* People described being involved in decisions that did not specifically contribute to policy. Instead, people shared the personal, family, or work decisions they made *in response* to COVID policies and public health measures. These opportunities often demonstrated a measure of personal control through choices. Examples included options for sending children back to school or not, and preferences related to virtual care. Being an activist was also cited as an opportunity to attempt to influence policy.

*B2. Communication: key to being involved.* We cannot make a difference and be involved in COVID policy development unless we are aware of and understand the opportunities to do so. To support entry into the conversation, information provided must be appealing, visual, clear and accessible. Information should also provide long-term goals and projections rather than focusing primarily on day-to-day data, allowing us to see ourselves in the information.

*B3. Access to virtual care must be equitable.* Virtual care is an opportunity for involvement. But, for many it is fraught with challenges such as lack of access or comfort with technology, lack of support of friends or family, and language and cultural barriers. This illustrates the need to invite citizen and patient involvement in this aspect of COVID health policy development.

*B4. Improving the structures and processes that support citizen involvement in pandemic policy development.* A proactive approach based on continuous improvement is required. Examples of system changes suggested included:

- Recognizing the untapped skills of immigrant doctors,
- Utilizing comparative research across all regions and countries, and

- Working directly with families and patients to determine how to access facilities and accommodate visits.

## IV. Detailed Discussion Notes

Notes captured from the event are provided below based on relevant key themes and examples.

### A. Break-out session one: personal experiences

#### 1 Unintended consequences

##### 1.1 Lack of access to health or social services

- Challenge to find appropriate balance between caring for patients and fear of virus.
- In long-term care the system was overwhelmed with the demands of COVID to the detriment of other resident or patient health or wellbeing needs.
- Cancellation of services including surgery, diagnostic imaging causing increased health and mental issues.
- More pharmacy visits needed as a result of prescription restrictions at a time when trying to limit exposure.
- Home care services reduced to “essential only.” However, there was no clear definition of essential to address individual patient’s needs.
- Unable to visit patients or residents in care. “There are no hugs.”
- Essential services reduced including social aspects such as respite care and day centres.
- Confusion in primary care offices around on-site appointments and coordinating virtual care.

##### 1.2 Mental Health

- General impact on wellbeing including anxiety, lack of focus and motivation, feeling of helplessness, and “being starved for human interaction.”
- Need to support people who are supporting people.
- Important for people to have access to affordable mental health services, including virtually.
- Development of support groups for people and families would be beneficial.
- Impact of media and reporting approach. Anxiety and confusion induced by alarming reporting based on daily numbers without goals and long-term outlooks.
- Challenging dealing with people who don’t believe the pandemic is an issue. “Being called a sheeple.”

### 1.2a Quarantine and isolation anxiety and fears

- “What if I am positive?” - anticipating the possibility of self-isolation. E.g. – if self-isolation is required, how do I get food, how is the dog walked?
- For those with mobility issues answering the door for a delivery is an issue.
- Testing delays lengthen quarantine time unnecessarily and add to anxiety related to other illnesses. E.g. – an elderly mother with pneumonia waits seven days for test results.

### 1.2b Long-term care and dementia impacts

- Loneliness with few to no visitors.
- Stress on families who could not visit.
- Essential services reduced.
- Unable to recognize people in masks.
- No physical contact such as hugs.

### 1.2c Children’s isolation impacts

- Concern about educational impact.
- Increased family workload and stress.
- Social development concerns.
- Confused and stressed children leading to stressed families.

## 1.3 School re-opening concerns

- Ensuring children’s social and educational development.
- Balance return with teacher’s fears and concerns.
- Confident in child safety and health.
- Concern for flu season.
- Symptoms for quarantines are too strict. Children home for common cold and long wait for test and test results.
- Other provinces/territories are more flexible in terms of symptoms.

## 1.4 Resilience & adaptability

### 1.4a Personal & organizational examples

- Learning new skills to adapt by taking advantage of things like books, podcasts, online programs offered by various organizations.
- Support services and third-party brokers constantly having to adapt and change with new and ever-changing rules.
- Regular Zoom meetings with friends or organizations.
- Drive-thru prescription pick-ups and ordering online in general.
- Buying a pretty mask.
- Taking advantage of early morning shopping hours.

#### 1.4b Health system and patients adapting through virtual care

- Minimizing physical interaction with system is a positive in pandemic for many.
- Learned new skill of self-monitoring and reporting on health from home.
- Able to care for mother at home with virtual support.

#### 1.4c Equity: capacity & opportunity for resilience & adaptability is not equal for all

- Programs, information, messages need to be accessible to all and translated for all:
  - 811 information was not available or limited in other languages.
  - Many initial and large outbreaks affected workers whose 1<sup>st</sup> language, was not English. Making accessible communication of accurate information critical.
- Things like deliveries from online ordering can be a challenge for those with mobility issues. How do you get to the door?
- What if no computer?
- What if an individual doesn't have family or other supports to help whether it be with childcare or personal needs?
- With support services limited or eliminated, how do some connect with others or get the help they need?
- Those that are isolated may be completely missed.

### B. Break-out session two: our role in decisions related to the pandemic

#### 1. Examples and experiences of contributing to decisions

Many could not think of ways in which they were able to contribute. However, some examples of contribution opportunities included:

- Made choices about their approach to virtual care
- Able to choose from three options for their children to return to school
- Attended a school orientation: was like a test to help us see school precautions and decide which option was best for family
- Through work there was opportunity to be involved in Dementia strategy
- Promoted town halls with Dr. Hinshaw
- Participated in protest regarding back-to-school policies.

#### 2. Communication: key to being involved

- People need to know what the opportunities are to be able make a difference
- People need to know where there are important conversations happening
- Help people learn how they can be involved
- Communications has to support the conversation with more appealing and visual information
- Information has to go beyond daily updates by providing a more long-term view that people can see themselves as part of.

### 3. Virtual care

- Must be equitable
  - Not everyone has a computer, platforms must be available on mobile apps for phones, iPad.
  - Not everyone speaks English
  - What if you are not comfortable with technology?
  - What if you are concerned about your data and security?
  - Language is only one dimension of diverse culture.
  - Not everyone has private location to feel comfortable discussing health virtually
  - Working with Alberta International Medical Graduates could help ensure the experience of some 'underserved' groups
  - Virtual care may require care by family and friends, not just healthcare.

### 4. Improving the system and processes to support citizen involvement

- Be proactive instead of reactive
- Need for continuous review and improvement. Collect and use data for elsewhere and adjust accordingly
- Compare research across all regions and countries
- Take advantage of existing and available skills. Decrease barriers for immigrant physicians to help lighten the load. Tried to be involved and wanted to be involved but to many barriers.
- Work with families and patients to determine how access to facilities and patients can work.
- Establish working task force, standardize and distribute work.
- Mental health supports increased especially for those working on the front lines.
- Need to explore ways for all to enter the system.