



## Background

IMAGINE Citizens' vision is: *"To enable and mobilize citizens' ability to influence, and become valued partners in improving health care experiences and outcomes for all"*. Policy is an important lever for improving health and health care. An important role for IMAGINE then is helping to create space for the public, citizens, patients and families/caregivers to influence policy development and change.

IMAGINE Citizens is committed to increasing the citizen, patient and family/caregiver voice in pandemic discourse and policy development. After some discussion internally about what we felt were some key COVID 19 policy issues, we decided to test our initial thinking with our broader community.

## What we did

IMAGINE's newly formed Policy Working Group, through our discussions, had identified nine pandemic policy areas that we believed could benefit from having more citizen and patient involvement. (See Box 1). We wanted to reach out to our broader community to test these. Which of these nine areas were of highest priority to others in our community? Were there other areas that were important?

### Box 1: Nine pandemic policy areas

1. How to decide how to distribute/use resources, such as ICU beds, ventilators, or PPE
2. How to manage quarantine restrictions
3. How to use tracking devices or apps to facilitate contact tracing
4. How to manage restrictions on family caregiver access to patients (in hospital) or residents (in long term care or congregate care facilities)
5. How to access virtual care (medical advice or services without an in-person appointment, such as by phone call, video call, email or secure messaging)
6. How to access our personal health information/what information we access to help us manage our health during a pandemic
7. How to design long term care facilities
8. How to re-open schools, businesses, events, etc.
9. How to manage non-emergency health procedures and surgeries

From late August to mid-September 2020, IMAGINE Citizens Collaborating for Health conducted a short survey of people connected with IMAGINE, in order to better understand which COVID policy areas people feel are most important for citizens and patients to have a voice. A link to this survey was sent out to the more than 800 individuals who regularly receive IMAGINE's newsletter, and was also shared via our social media channels to our broader network.

## Who completed the survey

The 226 Albertans who completed the survey can be described as:

- Predominantly female (83%)
- Highly educated - 64% university graduates
- Primarily from the Calgary Zone (60%) and the Edmonton Zone (17%)
- Generally located in large cities (64%) or suburbs (11%)

The demographic description of the survey respondents reflects what we know to be the current membership of the IMAGINE Citizens community and our respective networks. These are people living in Alberta who are actively interested in health and healthcare, and so likely not 'representative' of the population of Alberta.

## What we learned

### Priority rankings

Of the nine specific pandemic policy areas we asked about (see Box 1), the four areas ranked most frequently by respondents as their number one policy priority were:

1. How to re-open schools, businesses and events - 52 (29%) ranked this #1
2. How to manage restrictions on family caregiver access to patients (in hospital) or (residents (in long term care or congregate care facilities) - 28 (15%) ranked this #1
3. How to access virtual care - 25 (14%) ranked this #1
4. How to design long term care facilities - 22 (12%) ranked this #1

### Other important pandemic issues

Respondents were also asked if there were other issues related to the pandemic, not included in our list of nine, that were important to them. Many respondents (n=99) had something to add, and provided a wealth of information in response to this question. NVivo was used to support the analysis of these responses. Four key themes emerged: clear communication; protecting those potentially at higher risk; addressing mental health issues; and, access to essential services. These themes are briefly described in Table 1 below.

**Table 1: Other important pandemic issues identified**

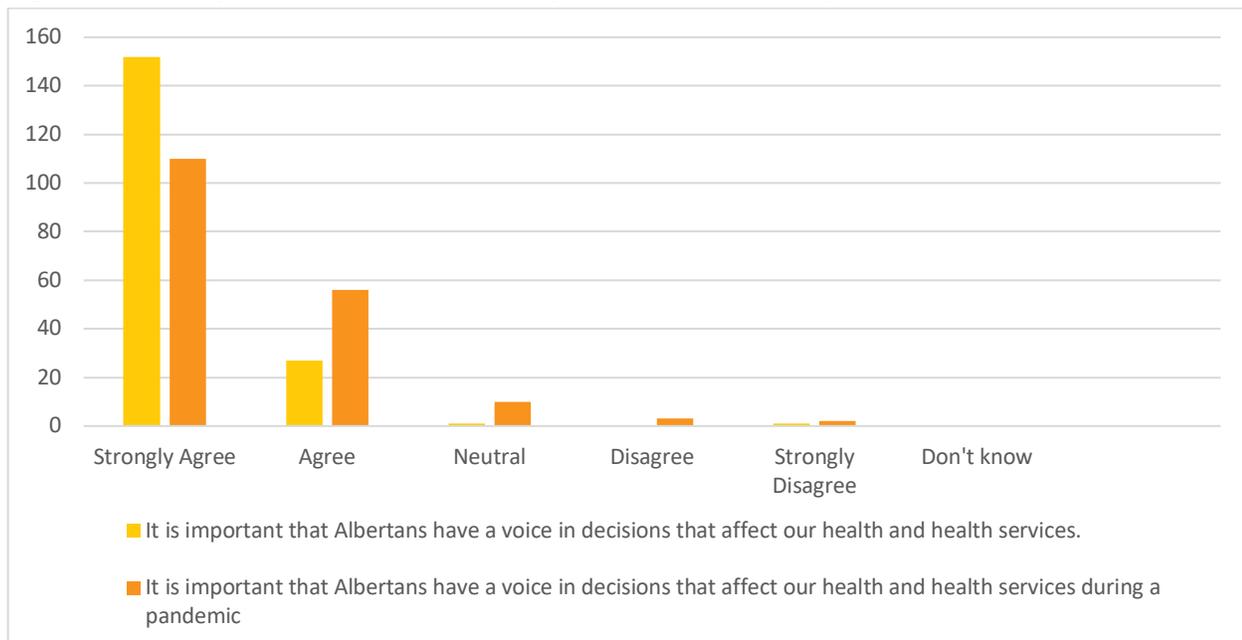
<i>Theme</i>	<i>Description</i>
Clear communication	<ul style="list-style-type: none"> <li>- Managing COVID-19 messaging</li> <li>- Accurate, transparent, and science/evidence-based public health messaging</li> <li>- Framing of issues during the pandemic</li> <li>- Consistent messaging on rules for mask wearing</li> <li>- Information on the quality of different masks and hand sanitizers</li> <li>- Having an informed citizenry</li> <li>- Addressing how media report on public health information</li> </ul>
Protecting those at potentially higher risk	<ul style="list-style-type: none"> <li>- Protecting homeless, families and children, people with disabilities, seniors, people with chronic health issues, and others who are being more negatively impacted</li> <li>- Responding to acts of discrimination during the pandemic</li> <li>- Addressing loneliness that affects the most under-served or vulnerable population groups</li> </ul>
Addressing mental health issues	<ul style="list-style-type: none"> <li>- COVID has compounded mental health issues</li> <li>- Access to mental health services is a challenge during the pandemic</li> <li>- Focusing on the mental health of individuals, families, health staff, and people with chronic conditions is important - with a particular emphasis on children and youth - is important</li> </ul>
Access to essential services, including healthcare	<ul style="list-style-type: none"> <li>- Access to food, shelter, medicine, household supplies (including hand sanitizers) is a challenge</li> <li>- There is concern about the quality of health care during the pandemic, and access to a variety of services including:               <ul style="list-style-type: none"> <li>o Specialists</li> <li>o Support services and care for people living with disabilities and/or complex health issues</li> <li>o Physical therapies</li> <li>o Other non-essential appointments</li> </ul> </li> <li>- Ensuring stability of services such as food banks, drop in centers, and supports for seniors is important</li> </ul>
Other concerns	<ul style="list-style-type: none"> <li>- Concern about the politicization of some public health communication</li> <li>- Concern about how the tension between the government and physicians here in Alberta is impacting health care during COVID</li> </ul>

## Citizen participation in health policy development

Finally we asked respondents their views on whether ‘people living in Alberta’ should have a voice in health policy decisions. Over 90% of respondents either strongly agreed or agreed that it’s important for Albertans to have a voice in decisions that affect our health and health services, both overall (99%) and during a pandemic specifically (92%).

They felt more strongly about citizen involvement in health policy overall, in comparison with health policy during a pandemic; that is, 84% strongly agreed that Albertans have a voice in these decisions overall, and 72% strongly agreed that Albertans should having a voice about these decisions during a pandemic.

Figure 1: The Importance of Citizen Participation in Health Policy



## Concluding remarks

IMAGINE Citizens extends a sincere thank you to everyone who took time to complete this survey. What we have learned from you about what’s important with respect to COVID 19 policy issues will be used by our newly created Policy Working Group to help us prioritize what to focus on going forward. We also plan to share these findings widely with our health system and patient and citizen organization partners, in an effort to amplify COVID related policy initiatives they are involved in. The complete survey findings are available from IMAGINE Citizens.