POLICY *Brief*

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▶▶ Part of the solution to managing pandemics is in our pockets

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When our society has faced existential crises in the past, we have banded together to overcome the challenge. The COVID-19 pandemic is one such threat that requires not only a cohesive effort, but also enormous trust, to follow public health guidelines, maintain social distance, and share basic necessities[1]. Are democratic societies with civil liberties capable of doing this?

The answer to this question is perhaps right in our pockets. The Internet connects us all, and with more than three billion devices currently in circulation globally[2], if there is one ubiquitous tool that leverages the power of the Internet like no other, it is the smartphone. The idea of smartphones being one of the primary solutions to this global problem might seem far-fetched, until we unpack its potential.

Smartphones provide us with the ability to directly reach and engage with a significant proportion of the world's population in near real-time—which has immense potential for addressing COVID-19 outbreaks via rapid detection. Moreover, smartphones have the capacity to provide big data via sensors, such as global positioning systems[3]. Smartphones can provide data about population movement patterns[4], which are extremely pertinent to not only understand and implement social distancing and isolation measures, but also to develop predictive epidemiological modeling of virus spread. Finally, smartphones can facilitate real-time interventions to modify behaviour and link people with healthcare services, factors that can be used to manage both the physical and mental health effects of COVID-19. However, for such intensive and intrusive data collection measures to succeed, we need buy-in from citizens.

COVID-19 SERIES: FROM CRISIS TO RECOVERY

This issue of *JSGS Policy Brief* is part of a series dedicated to exploring and providing evidence-based analysis, policy ideas, recommendations and research conclusions on the various dimensions of the pandemic, as it relates here in Canada and internationally.
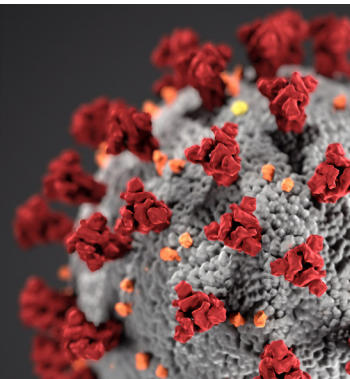
The policies and responses of governments around the globe have varied in speed and intensity[5], but what unites them is the evidence that COVID-19 is highly contagious. The reality is that success of government policies to detect, contain, and minimize the spread of COVID-19 lies beyond healthcare systems that are currently barely coping with the ever-increasing growth of COVID-19 positive cases[6]. The success of government policies ultimately depends on the willingness of citizens to follow public health guidelines and abide by laws restricting free movement, which is a challenge in free societies. Thus, whether it is the ability to leverage ubiquitous digital tools such as smartphones. or whether it is the success of government policies to manage and minimize the COVID-19 outbreaks, implementation of these strategies ultimately depends on citizen engagement. The key to building public trust is to link citizen science to citizen engagement.

▶▶ The mHealth and Citizen Science Policy Solution

Citizen science is a participatory approach that can range from contributory and collaborative methods (data collection and analysis) to co-creation of knowledge (conceptualization and knowledge translation). It can pave the way for increased citizen engagement during this crisis.

Citizen science offers an opportunity to transform population health science by engaging a larger proportion of the population in data collection to bring citizen perspectives closer to traditional decision-making processes[7]. However, there is currently no coherent citizen science policy to tackle the COVID-19 pandemic. The success of citizen science depends on innovative mobile health (mHealth) applications. The ultimate purpose of mHealth and citizen science, particularly from a disease risk management point of view, is to enable digital epidemiological modeling to prevent, detect, and manage the current wave of the COVID-19 pandemic, as well to predict and prepare for subsequent waves.

Digital Epidemiology is a novel field of science that has been growing rapidly in the past few years, fueled by the increasing availability of data and computing power, as well as by breakthroughs in data analytics[8]. The digital health revolution has transformed the collection and analysis of electronic health records, as well as physiological and behavioural measurements at the individual level. But our healthcare systems are primed for disease management rather than promoting upstream policies to prevent disease development. Another concern is the lack of ethical engagement in digital health, where the power resides predominantly with researchers and providers.

These challenges point towards the need for policy that enable ethical surveillance, integrated knowledge translation, and real-time interventions[9]. This combination is critical to address population health crises such as the COVID-19 pandemic.

The creation of mHealth and citizen science platforms can enable:

1. Implementation of ethical real-time surveillance to assess COVID-19 community risk.

2. Implementation of near real-time integrated knowledge based on the data provided by crowd-sourced participants.

3. Implementation of evidence-based real-time communication that links citizens to healthcare services and ensures safe social distancing and psychological support.

4. Development of decision-making dashboards, which enhances real-time information sharing and data analytics that would inform community decision-making.

5. Addressing future pandemics by developing models of risk mitigation, which prepare communities and enhances health system capacity for future communicable diseases.

The development of such platforms requires robust theoretical underpinnings that provide a clear pathway to decision-making. One such pathway is the SMART Framework[10]. It integrates citizen science, community-based participatory research and systems science through ubiquitous tools to conduct population health research in the digital age. A key component of this framework is the necessity to repurpose citizen-owned ubiquitous communication devices (ie, smartphones) that have revolutionized the ability to sense, share, and link big data. This potential for re-purposing smartphones is magnified in the current COVID-19 crises because smartphones have the reach to source big data to inform policies through the voice of the citizens.

▶▶ Operationalizing mHealth and Citizen Science Policy

The flexibility of mHealth and citizen science platforms to scale-up as necessary opens up enormous opportunities to operationalize policy across jurisdictions, whether within a single country or across a cohort of nations. From a Canadian perspective, healthcare implementation is the mandate of provinces and territories, thus natural authorities to introduce mHealth and citizen science policies would be the provinces and territories. The federal government can play a larger role in mandating such policies through the Canada Health Transfer program.

However, mHealth and citizen science policy can exist outside traditional healthcare systems. This approach takes a population health lens in all policies. By so doing it has its own advantages of systems integration, a natural fit for usage of big data that is not traditionally part of healthcare systems.

In fact, mHealth and citizen science platforms have traditionally been used for non-communicable disease monitoring and interventions, which are implemented outside healthcare systems by academic research units[9]. There are opportunities to commercialize mHealth and citizen science platforms that will break the silos of jurisdictional authorities. One scenario is that big technology companies, which already own most big data collected passively from smartphones across the world, will become major players in disease management. The pros and cons of such a scenario need to be debated and are beyond the scope of this policy brief. However, the opportunity to commercialize and introduce mHealth and citizen science platforms allows groups

at risk, such as Indigenous communities, to take control and tackle the risk of pandemics such as COVID-19. Thus, although the operationalization of mHealth and citizen science policies can take many shapes and forms, it is apparent that government agencies will lose their grip on digital health if they do not act now.

▶▶ Benefits of Citizen-Focused Digital Health

Apart from the obvious benefits to health of populations by reducing the risk of communicable diseases like COVID-19, when digital health takes a citizen science approach, it can enable community empowerment. There are multiple benefits that would result from linking citizen science and citizen engagement.

Social and Societal Benefits

1. *Community Empowerment*: Citizen science connects citizens with one another, facilitating engagement, knowledge sharing, and problem solving, especially during existential crises.

2. *Decision-Making*: Citizen science can bring citizens closer to traditional decision-making processes by contributing to the dialogue around issues of highest concern to society.

3. *Misinformation Management*: Citizen science can play an important role in countering digital misinformation that is currently highly prevalent.

Population Health Benefits

1. *Prevention, Early Detection and Policy Interventions*: This approach would engage citizens in real-time to predict and address global population health risks such as the COVID-19 outbreak, as well as link these risks with upstream policy and downstream healthcare utilization data to develop preventive public health policies.

2. *Evaluating Population Health Interventions*: A digital citizen science approach provides the ability to evaluate population health interventions in different jurisdictions. This is especially pertinent when different and incohesive municipal, provincial, and federal policies to counter a pandemic such as COVID-19 are being implemented globally.

3. *Real-Time Interventions*: Engage citizens in real-time to deploy behavioural interventions that can help manage population health crises such COVID-19 by implementing measures such as social distancing and mental health supports for self-isolating populations across the globe.

Benefits to decision-makers

1. *Development of Decision-Making Dashboards*: Real-time big data can be used to develop decision-making dashboards that incorporate advanced data analytics to inform global policies during pandemics.

2. *Assessing Environmental Effects*: Utilizing citizen science, we can understand the effects of physical, social, and cultural environment on health behaviours such as social distancing and abiding by public health guidelines.

3. *Identifying and Addressing Environmental Risks*: The trajectory of pandemics such as COVID-19 needs to be addressed by taking into consideration varied environmental risks in different geographic regions of the world, and citizen scientists could play an important role in enabling global risk management of pandemics.

Economic Benefits

1. *Licensing User Access*: mHealth and citizen science platforms can be licensed to external users at large scale to enable commercially viable digital epidemiological studies globally.

2. *Developing mHealth Apps*: mHealth and citizen science platforms can be the source of commercially viable frontend mHealth apps that can be developed rapidly to tackle population health crises such as pandemics.

3. *Commercialization of Dashboards*: Potential to commercialize decision-making dashboards for different jurisdictions from mHealth and citizen science platforms to facilitate real-time information sharing globally.

▶▶ Anticipating and Addressing Challenges

Data Privacy and Security

Clearly, one of the biggest challenges to deploying citizen science at any scale is individuals' right to privacy. As smartphone-based citizen scientist data are detailed owing to sensors such a global positioning systems[11], protecting privacy and anonymity of citizens through strong encryption processes must be the highest priority[12]. Moreover, before any citizen scientist engagement, obtaining informed consent has to be mandatory. Apart from obtaining informed consent, citizen scientists should be provided an option to dropout and delete their own data i.e., embedding of open source features as much as possible. However, to truly conduct ethical surveillance, data co-ownership is essential.

Data Validity and Linkages

Data validity eventually depends on successful and consistent citizen science engagement with digital tools that facilitate secure data collection, synthesis, analyses, and dissemination[13]. A significant factor in citizen scientist engagement would be intuitive front-end human-computer interfaces such as easy to use smartphone applications. However, big data obtained from mHealth and citizen science approaches will not realize their actual potential if they are not linked with administrative, policy, and health care access and utilization data to address population health risks.

Internet Inequity

The most systemic barrier to mHealth and citizen science is Internet inequity. Internet inequity is defined as differential Internet access based on wealth, location (urban, rural, or remote), gender, age, or ethnicity[10]. Thus, a risk of mHealth and citizen science approach is the potential to widen existing health disparities by excluding vulnerable populations who do have access to the Internet[14]. With respect to smartphone dependence, evidence indicates that

POLICY *Brief*

minority groups and younger, lower income, and less educated users are more likely to be dependent on smartphones to access Internet[15].

The digital divide is a complex phenomenon, with varying Internet bandwidth across different low-, middle-, and high-income countries. Ultimately, as United Nations has declared that access to the internet is a human right[16], policy makers have a moral responsibility to address internet inequity, and crises such as the COVID-19 pandemic should provide the impetus for Internet equity.

Legitimization and Citizen Scientist Compliance

As the COVID-19 experience has demonstrated, pandemics present public health, economic and social challenges on a global scale unlike anything else we have witnessed. Thus, tackling pandemics will require transformational change with significant support in terms of personnel training, funding, time, and increase of transparency to balance of power between decision-makers, researchers, and citizens.

However, the ultimate success of citizen science is dependent on effective engagement. The challenges of citizen scientist recruitment, retention, and compliance need to be addressed by a combination of logistical, technological, and methodological solutions before, during, and after data collection. The integration of citizen science with community-based participatory research can aid citizen engagement and empowerment[17]. Another important factor is developing strategies that are specific to different cohorts, demographic groups, and jurisdictions, by taking into consideration historical, cultural, and socio-political contexts of populations.

Nevertheless, the big question is, regardless of the need for a cohesive societal effort to overcome pandemics, why will citizens ultimately comply? Transformational change requires radical ideas and if we want citizens to trust institutions, perhaps there is need to incentivize ethical surveillance. In other words, pay people for sharing data that will enable us to understand the progression of pandemics, and enforce the stringent public health measures necessary to flatten their curve. We cannot surreptitiously monitor citizens. But at the same time we are in uncharted waters when it comes to health and economic consequences of this pandemic. So why not kill two birds with one stone? Let's pay people to share their smartphone data in return of basic income.

▶▶ Conclusion

The COVID-19 pandemic is an complex existential threat that requires cohesive societal effort to address health system inefficiencies and to overcome gaps in real-time data analytics. When our society has faced existential crises in the past, we have come together by using the technology at hand to overcome the challenge. Pandemics such as COVID-19, although extremely challenging, offer us an opportunity to innovate and consider options that would normally be ignored due to lack of vision, resources, and co-ordination. The answer to the current crisis could be right in our pockets. With more than three billion smartphones currently in circulation globally, they provide us with the ability to directly reach and engage with a significant proportion of the world's population in near real-time. However, for such intensive and potentially intrusive data collection measures to succeed, we need a cohesive effort with significant buy-in from citizens. A global policy for mHealth and citizen science that facilitates citizen engagement across the world via sophisticated digital epidemiological platforms is a viable solution to not only overcome the COVID-19 outbreak, but also better anticipate, prepare, and tackle future pandemics with the rapid response that is necessary in our globalized world.

▶▶ References

View the online version of the Policy Brief for a complete list of references (www.schoolofpublicpolicy.sk.ca).

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