Public Input into Pandemic Planning

Deliberating trade-offs in COVID-19 policy making

Background Information Booklet

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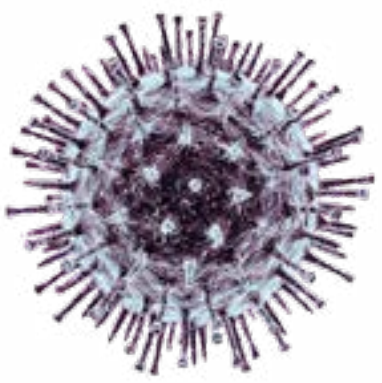

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1. What is the purpose of this booklet?

The information in this booklet comes from academic literature, consultations with experts and stakeholders, and media such as newspapers and radio.

The intent of this booklet is to inform you about some of the decisions public officials are considering at this point in responding to and managing the COVID-19 pandemic. It will explain how technology is one option that may allow some relaxation of current measures of physical distancing and business closures. It will outline both potential benefits and potential risks of these developments.

The information in this booklet is intended to support you and your fellow participants in your deliberations. We hope it will also be useful for ongoing discussion and reflection on these and related topics. You are not expected to be experts on this topic, and we encourage anyone with any interest to engage in conversations.

2. What is a public deliberation?

A public deliberation is a community discussion on issues that affect members of the public such as yourself. A public deliberation is a democratic process that supports people to understand issues and different perspectives about those issues. It encourages people with many different perspectives to share their views and together develop advice that is sensitive to the range of perspectives. The desired outcomes include recommendations and/or identification of areas of disagreement among participants.

3. What is the importance of this public deliberation?

Public deliberations are discussions about important societal issues that involve values or trade-offs. Instead of *telling* the public how such issues will be resolved, deliberations invite the public into *active participation about the issue*. Members of the public have an opportunity to identify what is important to them about a societal

issue and provide advice, in the form of recommendations, to decision-makers. In this deliberation, the trade-offs involve balancing the potential benefits and risks of using technology to help remove some of the current rules around staying at home and business closures.

A public deliberation is about respecting the diversity of perspectives amongst us and finding ways we can live together. The information you read and hear may inform your opinions, and your opinion might (or might not) change. The intent is to inform and engage people as they discuss issues and make recommendations.

4. What *usually* happens during a public deliberation?

Public deliberations can be organized in different ways. One well-established approach brings 25-30 people together over two different weekends, for a total of four days. On the morning of the first day, participants hear speakers who are experts on different aspects of the deliberation topic. The speakers are chosen to provide a wide range of perspectives and will not necessarily agree with each other.

The remainder of the four days is then spent working with trained facilitators in both small groups of 6-8 participants and the full group of 25-30 participants. The time is used to discuss a series of questions specifically prepared for the event. Small groups first discuss their different perspectives and the reasons behind them, with the intent of bringing out the broad range of participants' opinions. The large group then considers the different viewpoints raised in the small groups, with the intent of creating policy recommendations that can accommodate this diversity.

The group creates its own policy recommendations and then vote to support, oppose or abstain. The recommendations, the vote, and the reasoning behind the votes are all important information for decision-makers. The deliberation then ends with the participants sharing their recommendations, votes, and reasons with a panel of decision-makers.

5. How will we organize *this* deliberation?

There are two reasons that it is not possible to hold a deliberation in its usual format. The first and obvious reason is that under current guidance from public health officials, we cannot meet in a large group. The second is that decision-makers need input from the public very quickly. They want to move both quickly and safely to make decisions that will protect people who live in BC, our families and communities, our businesses and economy, and our health care system. These are not easy decisions, and there are many trade-offs involved.

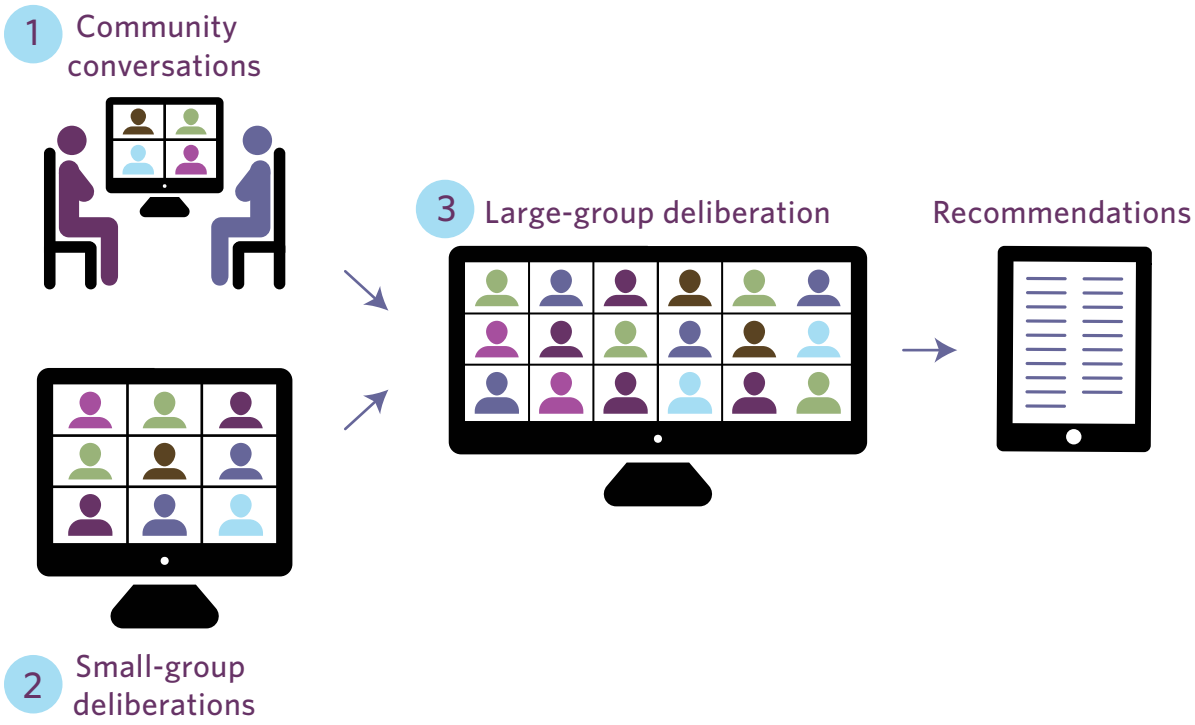
For these reasons, we have changed our approach to deliberation. We have tried to create a process that keeps key pieces of our usual deliberations, like emphasizing diversity, inclusiveness of perspectives, finding ways to live together, and providing reasons for positions. We have embraced technology to enable face-to-face conversations among people in different locations. And we have expanded our mission to encourage anyone who wants to deliberate to do so.

This deliberation includes three different layers or inputs.

First, we are encouraging *community conversations* about the technology options that decision-makers are considering now to ease social restrictions imposed by COVID-19. This booklet will provide you with background information, and a separate **Community Conversation Guide** will offer suggestions for how to organize and conduct your own conversations. The conversation alone may be all that is of interest, but we encourage groups that are willing to use the Community Conversation Guide and provide us with a summary of those conversations.

Second, we are organizing one-time, 90 minute deliberations with small, diverse groups of people who do not know each other and who come from all parts of our province. These groups will be selected from volunteers who sign up here. Groups will be scheduled and organized by a facilitator and reporter, who will guide the discussion, ensure that all perspectives are heard, and prepare a summary of the conversations.

Third, we are organizing a larger group that will meet over four days, for 90 minutes each time, first to deliberate themselves, and then to hear the results of the *community conversations* and the small-group deliberations. They will listen to all of that and, based on this, create a final set of recommendations, and reasons behind those recommendations, that will be given to decision-makers.



6. The pandemic

The COVID-19 pandemic has led to many unprecedented public health measures, including business restrictions and closures and physical distancing requirements. The success of these measures in managing the population spread of the virus means there are now ongoing conversations about how those restrictions might be relaxed. Contemplating changes in policy requires first understanding the full scope of their effects, which can extend from public health to social and economic effects, and then contemplate the trade-offs that need to be considered for the next phase of policy.

Choices revolve around finding a path that will protect both public health and the economy, as well as the health and broader social well-being of individuals, families and communities. These choices all involve trade-offs, not all of which are immediately self-evident or easy to quantify.

Very simply, the choices made, for example to put significant weight on public health (e.g. minimizing cases COVID-19), can create greater risk in another area that also has public value (e.g. impact on income because of loss of employment). The challenge for policy is finding the right balance in these trade-offs. They are informed by predictive models and other inputs, but at some point, the decisions made will be based on a combination of values and best guesses based on high-quality but inevitably imperfect information.

7. Policy context

7a. The public health perspective

Many countries are reaching a stage in the current pandemic of relaxing social control measures. This is a sign of optimism, if not complete success, indicating that while the current threat is still significant, there is a slow movement from "crisis" to "maintenance". There will, however, remain a constant risk of a potential return to "crisis" at least until there are ways to prevent, treat and/or manage the virus.

Scientists believe that relaxing current measures will be more successful if it is possible to identify all cases of COVID-19 and keep the reproduction rate to less than one—meaning that each case will infect and ultimately cause on average less than one further case. The requirements for this level of reproduction are widespread testing for the virus (both across populations and over time, as testing will need to be repeated), aggressive contact tracing for any new cases identified, and strict quarantines for cases and their contacts.

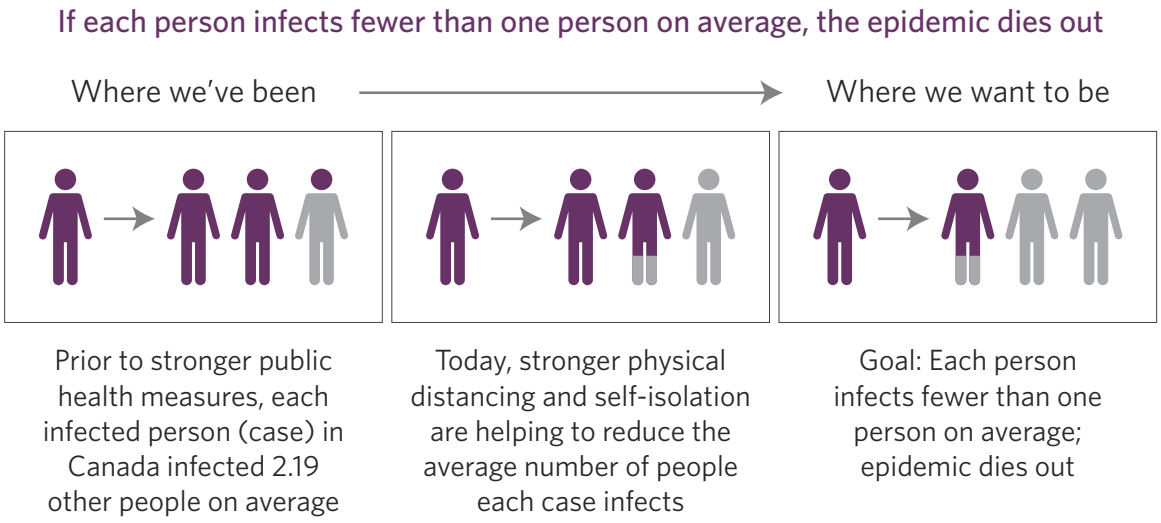


Figure redrawn from Public Health Agency of Canada. COVID-19 in Canada: Using data and modelling to inform public health action. Technical Briefing for Canadians. April 9, 2020.

While it is relatively simple to show what is needed, it is far more difficult to contemplate how to put those systems in place. We do not yet have capacity for widespread and repeated testing. Contact tracing is effective but very labor-intensive so is not easy to scale to large outbreaks. Quarantines can be mandated but are difficult to enforce. There may be technologies that would enable or at least support contact tracing and enforcement of quarantine, but it is less clear whether the public would accept them and their impact on individuals' privacy. Perhaps more fundamentally, there are decisions to be made about what technology could be used, how it would be deployed, who would oversee that deployment, and the acceptable time frames for these arrangements. These decisions will affect the speed or extent of us "returning to normal", how that return will be monitored, and the sharing of burden and responsibility of the remaining controls.

7b. Relaxing measures of physical distancing and business shutdowns

The desire to "return to normal" is obvious, but the path to that is less so. Leaders, both from public health and broader government, have cautioned that "normal" activity will not be possible until a good treatment is available, a vaccine is in place, and/or most of the population is immune to COVID-19, but that we could relax the current stringent methods with some guard rails. For example, certain sectors of the economy may be

easier to open depending on the type of work force (younger people are less prone to serious illness), continued physical distancing (and specifically distancing at the workplace) and proper protective equipment.

In effect, these considerations revolve around finding a road that will protect both public health and the economy, as well as the social life of families and communities. While these conversations are starting, they all involve trade-offs, not all of which are immediately self-evident or easy to quantify. For example, the implications of just letting the virus run its course (which some countries thought was a good approach early on) have proven dangerous. The human cost would be very high, and would very likely overrun health-care systems.

At the same time, there are implications of physical distancing measures too, including loneliness and isolation, which are known to cause harm, loss of income which will create enormous hardship and has the potential to increase inequality, online learning and isolation from peers and their unknown effects on a whole generation of children and youth, and reports of increased domestic violence, with one in 10 Canadian women reporting being fearful of others in their household.

WHO guidelines outline six questions for countries to consider:

1. Is transmission of the virus under control?
2. Is the health care system equipped to detect, test, isolate and treat every case, and trace every person who came into contact with a positive case?
3. Are outbreaks minimized in special settings like health facilities and nursing homes?
4. Are there measures in workplaces and schools to prevent the spread of the virus?
5. Are the risks of importing more cases from outside the country being managed?
6. Are local communities educated, engaged and empowered to adjust to the "new norm"?

Source: The Star. WHO issues guidelines for lifting COVID-19 restrictions. Is Canada ready? April 14, 2020.

It is also worth stating explicitly that these effects are not felt equally by all. Some individuals and groups may be at greater risk of COVID-19, such as health care workers, workers in essential services such as food supplies, rural communities, Indigenous communities, and of course older adults, anyone with underlying chronic conditions, and others who live in communal housing. Other individuals and groups may be at greater risk of the second order effects of the pandemic, such as women at risk of domestic violence, people whose elective surgeries have been cancelled, those awaiting diagnoses or needing care for non-COVID-related reasons (e.g., cancer, cardiac issues or kidney disease), workers in unstable or unpredictable employment, and people with family caring responsibilities.

7c. The questions in front of us

There are many questions that decision-makers, including public health officials, will contemplate when considering the right approach for the next stage of pandemic management. For example:

- What parts of the economy can open first, and how can safety be measured and maintained? Will this be different for urban and rural areas?
- How will new cases of COVID-19 be detected? Where cases are detected, how will they be traced and potential contacts notified?
- What kind of risk of a potential resurgence will be tolerated?
- Will we consider "immunity passports"? What are the social implications of this kind of system, which in some places and for some populations is likely to raise images of the 1930s and totalitarian requirements for physical identification?
- What can we learn from other areas that are slightly ahead of the curve, compared to where we are?
- How can we enforce local decisions if or where other jurisdictions take a different approach?

The implication is a need for high-level information from other places as a way to understand what seems to be working and what is less effective. This kind of information will need to be complemented with very detailed data from the local jurisdiction, about individuals as related to public health and about broader social

contexts. Real-time information on a range of things like travel patterns, social gatherings and social practices (handshakes, etc.), use of business and services that are allowed to open, and tracking of individuals and their contacts would all be useful inputs to managing the next phase of the epidemic.

A two hour online town hall related to COVID-19 in the US collected feedback from 7,000 participants, of whom about 1,000 stayed for the full two hours. There were three areas of interest or concern identified through this town hall:

1. Civil rights implications of long term mitigation strategies;
2. Economic matters broadly understood (public health and feeding a family are starting to feel mutually exclusive—need guidance on doing both; people want to comply); and
3. Understanding the complicated benefits programs that different levels of government are putting in place.

8. Why public engagement and deliberation?

Public input into pandemic policy is critical. Policy decisions will be based on a combination of values and best guesses drawing on high-quality but inevitably imperfect information. There is significant uncertainty among experts on the ramifications of this broad, global "social experiment" and expertise alone does not offer clarity about how to navigate ethical and other trade-offs. There are many trade-offs to consider, and complex relationships among them. Public trust in, and acceptance of whatever policies are put in place, will be key if they are going to have their intended impact, as people are more likely to participate in measures that they trust, understand, and support.

In general, public input is most valuable in situations that are values-based in nature, where there are trade-offs, where there may be controversy over a chosen path, and where the public will be expected to modify behaviour. Managing the next phase of response to COVID-19 clearly meets all of these criteria.

Put another way, decision-makers have a choice of either making decisions for the next phase and hoping for cooperation from the population, or engaging with the public and through that developing trust, both in government (including public health) and in one another. The latter path will put a strong emphasis on collective impact and collective good, and will require ongoing transparency and public input.

Public engagement and involvement of relevant stakeholders should be part of all aspects of planning

Policy decisions and their justifications should be publicized and open to public scrutiny. This will help to:

- Increase public awareness about the disease-related risks and enable people to take steps at individual, family, workplace and community level to prepare for and respond to an influenza pandemic.
- Contribute to the development of adequate and effective plans and increase public confidence that policies are reasonable, responsive, non-discriminatory, and in line with local circumstances and values.
- Secure the agreement of the public and civil society on the use of therapeutic and prophylactic measures and their distribution.
- Provide useful feedback to planners regarding both information that they may lack (such as on local conditions) and the acceptability of their plans to the general public.
- Maintain public trust, add to the legitimacy of plans, and ensure the accountability of decision-makers both in the planning stage and during a plan's implementation.
- Promote public compliance and mitigate fears of the unknown and the possibility of social disruption or panic that can result, particularly in circumstances where the public is expected to make sacrifices and possibly incur financial loss or infringements of their personal autonomy.

Source: World Health Organization. Ethical considerations in developing a public health response to pandemic influenza. 2007.

9. Issues, policy options and trade-offs

There are a number of implications of current and potential future policies related to the pandemic. We outline a few of these below, and then identify the policy options that are now being considered, or are likely to be soon.

We then focus further on one policy option around the use of technology to support pandemic management which is being used or considered in many jurisdictions. We provide some background information on these technologies, and then discuss the types of trade-offs that have to be considered by decision-makers when deciding both *whether* to use such technology, and perhaps more importantly, if used, *how* it should be implemented.

9a. Issues

Harms across the population

Focus on specific effects on individuals or populations, and to community functions and institutions, for example:

- Harms from the pandemic itself
  - Suffering, sickness, and death from COVID-19, including avoidable spread of the virus, in the community and to health professionals, reducing ability to care for others.
  - Potential for virus to reach population levels that threaten the ability of health care systems to respond.
- Harms from the response to the pandemic
  - Social isolation, loss of income, civic unrest.
  - Effects on community organizations and services, volunteer groups, sports clubs and other aspects of community life.
  - Displaced or delayed health care services, particularly "elective" surgeries and interventions.
  - Disproportionate distribution of harms to some marginalized populations.

Harms to business, employment and the economy

Through restrictions on business operations, including:

- Economic harms affect income, education and the health of the population, with potential long-term consequences.
- Effects that increase class, group, or occupational inequalities.
- Effects on particular industries.
- Effects on small businesses, and by extension their owners and employees.

Limitations on movement and association

Affecting individual rights such as:

- Freedom of movement and to gather together, which is fundamental to human rights, democracy and economic exchange.
- Despite online options, restriction of freedom of movement threatens commerce, education, religious and cultural practices, mental health/well-being.

Privacy and control of personal information

Through new data collection, surveillance and other efforts that are aimed at managing the pandemic, such as:

- Collection and use of personal information, including movement and medical diagnoses, control of which is fundamental to human rights, democracy and economic exchange.
- The intentional collection of personal information by governments to characterize and control the population, which is a significant loss of privacy.
- Surveillance that could potentially include both observed and invasive measures, e.g. monitoring using GPS tracking, but also measures such as temperature and testing results.

9b. Policy options

These are some of the tools that governments may have at their disposal as ways to manage the next phase of the pandemic.

Population testing

To identify those who have the virus, including the outwardly asymptomatic. This includes temperature tests and/or up-the-nose swab tests, either of everyone or of people entering certain locations like airports, train stations or supermarkets.

Contact tracing

A basic tool of public health practitioners for any infectious disease, contact tracing is the tracking, identification and notification of past contacts once an individual tests positive for the virus. Contact tracing is typically and currently being done by public health professionals interviewing COVID-19 positive patients and asking them to list everyone they have been in close contact with over the prior 14 days. Contact tracing is a tool that can be combined with other methods, such as increased testing, to keep people safer, open up an economy sooner and move closer to normalcy.

Immunity certification

Could be granted if tests show immunity, and would enable freedom of movement. These tests are currently unreliable and there is scientific uncertainty about both the level and extent of immunity in the case of COVID-19.

Quarantine powers

Would include orders to quarantine but also decisions about extensive the quarantine period would be, how it would be monitored, and how refusing the order would be punished.

Travel restrictions

What modes of transport are open, any limitations on non-essential travel, and international border controls.

9c. A specific and emerging policy option—the use of smart phone technology

The Ada Lovelace Institute identifies three general categories of app technologies that are being discussed related to COVID-19: symptom tracking (for monitoring disease and spread); contact tracing (for identification and management of cases and exposures); and immunity certificates (to enable free movement of those who have immunity).

These technologies offer the possibility of assistance with understanding the virus, identifying new outbreaks, and then managing the response to new cases. But they introduce risks as well, both from the perspective of understanding the reliability and validity of the technologies themselves, and in new and not well-explored ethical, legal and social implications of their use. The consequences of decisions made about technology and surveillance during the pandemic are likely to live with us into the future, so it is important to make those decisions carefully.

Yuval Noah Harari refers to the importance of understanding some of these technologies as making a transition from "over the skin" to "under the skin" surveillance. That is, there is tracking that could monitor movement and contacts, but also tracking of physical measures such as temperature, COVID-19 status and immunity status. (Harari goes on to say that "Biometric monitoring would make Cambridge Analytica's data hacking tactics look like something from the Stone Age.")

The Medium publication OneZero, which is focused on technology and science, is compiling an international inventory of techniques governments are using for surveillance related to COVID-19. These range from GPS-tracking bracelets for people entering Hong Kong and thus expected to quarantine, to cell phone providers turning over metadata to the Austrian government for purposes of understanding population movement, to the all-in approach used in China including phones, drones, and facial recognition applied to images from publicly located cameras. One article described use of contact tracing and immunity passport technology in China this way:

"When boarding Shanghai's metro system today, each passenger must scan a QR code of an application, so that in the case that any person on that train should test positive for COVID-19, everybody will be notified and quarantined. The application itself has been deployed to track everybody's exposure to the virus, and only those who have not had close contact with positive cases will get a green QR code, allowing them to move freely in the city."

A specific focus on contact tracing apps—how they work

All apps make use of smart phone technology. We focus on contact tracing apps to help illustrate how these technologies work.

Contact tracing can be done as described above, with interviews. It can also be done using technology, or by combining technology with traditional interview methods. Many jurisdictions are considering and/or introducing mobile apps with the intent of reducing the manual nature of contact tracing or at least augmenting the interview process with insight into a person's recent location or contact history. An example of combining these methods would be to use a contact tracing app and geo-location information from it to help remind people where they have been over the preceding days.

In very simple terms, these apps use GPS or Bluetooth and other technical features of smartphones either to keep track of the specific locations of phones (GPS) or to identify other phones in their proximity (Bluetooth). In the case of Bluetooth, after a certain threshold of proximity-time is reached, the nearby phones trade information and store it. Then, when a case is identified, this history can be used to notify other people who may have been exposed.

A high-profile example of this sort of app or service is the partnership recently announced between Google and Apple, but this is just one of several options.

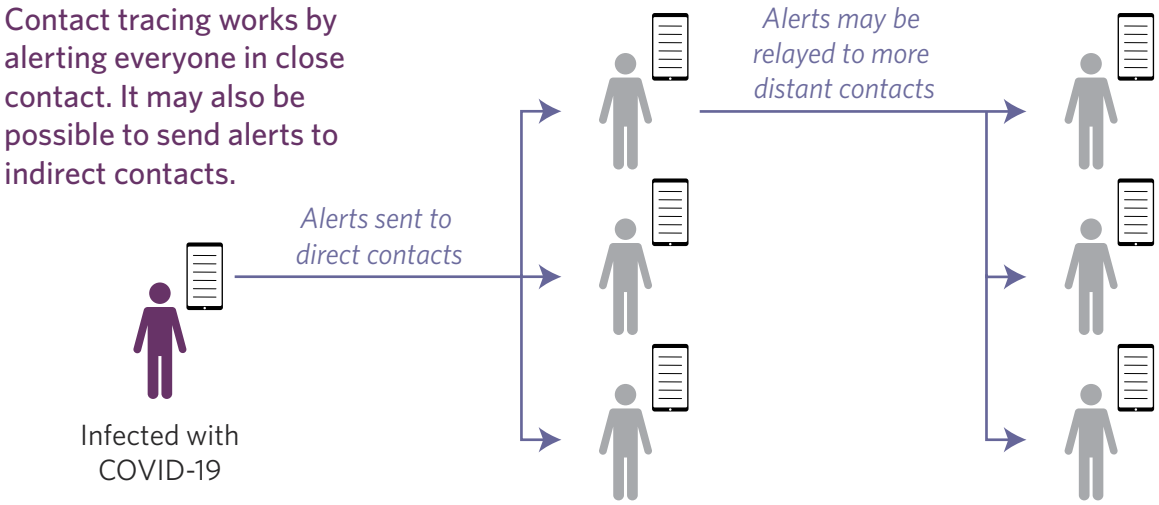


Figure redrawn from BBC News. NHS rejects Apple-Google coronavirus app plan. April 27, 2020.

Choices about app use for pandemic management

There are a number of options on how app technology can be deployed. For example, the use of these apps can be mandatory or optional, with most governments choosing the latter. The information storage can be centralized, in a single database, or stored locally on an individual's phone. Related to that, there are options about who can have access to what level of data and under what circumstance. The amount and type of data collected by the app can range from minimal information on contacts, to that minimal information plus location history plus other activities such as telecom information, social media, wearables, self-reporting daily symptom surveys, 811 phone calls, and credit card use. The identification of cases can come through self-report or through official channels such as medical or public health professionals. Notification of contacts of those cases can flow to contacts only or both to contacts and public health officials. Finally, there are choices to be made about recommended actions following notification of an exposure, such as self-isolation, and enforcement of those recommendations.

While this identifies the range of options, there are limits to the technology (e.g. on true distance measured using Bluetooth or other means) that will affect the validity of these approaches. It is likely that there would be many people notified of "contact" who were not really subject to exposure because, for example, the app cannot detect plexiglass or even a wall between the "case" and the "contact". There is the potential

for fraud or abuse, and of course by the very nature of this being new applications of technology, there is limited information available on the reliability and accuracy of these apps. The effectiveness of apps also will depend on what proportion of the population is willing to install them, use them, and routinely carry their phone (on the assumption that adoption will be optional). One study from the UK suggested that while the apps can be effective in controlling disease spread, adoption by 60% of the population would likely be needed for true pandemic suppression. Finally, and related to the above, success with the use of apps will depend on public acceptance and compliance, which in large part will likely be driven by trust.

9d. Trade-offs

Scenarios and trade-offs are best understood as characterizing potential policy responses in terms of their potential effects on different interests, groups, rights or practices. They reflect, then, a combination of the potential harms and the policy options.

This deliberation considers the scenario of **using smart phone apps to assist with pandemic management.** Formulated as a policy option, this scenario has the potential to reduce population harms related to the social controls imposed as a result of COVID-19, such as current harms to business, employment and the economy, and current limits to freedom of movement. At the same time, there is the potential to *increase* harms related to loss of privacy as well as population harms related to the virus, as there will be a risk of new outbreaks; harms related to the need to revert to greater social controls; and harms to specific population groups that do not opt in because of having no phone, no cell reception, etc.

The table on the following page summarizes the different dimensions of apps, the options for implementation, and the pros and cons of each.

Dimension	Options	Trade-offs
App purpose	No purpose Assist traditional person-based contract tracing Replace traditional contact tracing	Traditional contact tracing is effective but not easily scalable. App-only tracing could create an automatic process but is likely to lead to many false-positives.
App use	Mandatory for the whole population Mandatory for certain high-risk groups Optional	Optional will erode the overall effectiveness of the app and thus increase the possibility of an increase in cases leading to return to heavier social controls. Mandatory interferes with autonomy and privacy.
App imple-mentation and management	Private sector Government Non-profit University Combination	There may be interest in data use that extend beyond pandemic management. Technologies that are introduced may tend to remain, creating a new potential for ongoing surveillance.
Anonymization of data	Fully anonymized Anonymized except with explicit consent Not anonymized	Fully anonymized protects privacy but also limits the utility for public health professionals to follow up. Anonymized except in the case of explicit consent will have more utility but will be limited to people who opt for that. Fully open exposes privacy risk to people who have had no contact with a case.
Responsibility for housing the data	Remains on phone Government Other public agency Private sector	Organizations may be tempted to use data for other purposes. Different arrangements may have more or less potential for a breach.
Accessibility of data for contact tracing	Accessible to public health Only accessible if disclosed by the individual	Reporting through public health or medical professionals requires identifiable data. Self-reporting diminishes the utility of the app.
Notification of exposed individuals	Notified directly by app Notified by public health professional	Notification through an app is simple, but may not lead to the required action, and will include false positives. People may be less comfortable with being notified through an app rather than by a person.
Ongoing storage and use of data	Deleted in a stated short time (e.g. one month) Retained and used only for analyses related to the pandemic Retained for analyses related to the pandemic and broader research	Putting a strict limit on data collection and use will increase privacy and autonomy, and reduce the potential for extra-ordinary surveillance measures to be normalized. Ongoing data storage and use will enable researchers to learn as much as possible from this pandemic to inform planning for the future.

10. Your role in the deliberation

During the deliberation, you and your fellow participants will bring your own perspectives to the discussion. You are not expected to be an expert on this topic.

You will be asked to discuss some of the issues related to sharing and researching linked data with the other participants. These may include issues such as:

- Under what conditions is it acceptable to combine public and private data for research?
- What kind of authorizations need to be in place to share sensitive data sets?

We hope that you will bring your opinions, values, and ideas about data and privacy to the deliberation. You will work together to make recommendations that can be used to more effectively inform policy decisions on data access regulations.

To facilitate discussion, we ask that you follow these ground rules:

- Keep an open mind
- Participate in respectful deliberation
- Listen to others, and try not to interrupt
- Avoid cross-talk
- Ask for clarification
- Try to justify your opinions.