

New or normal? Privacy, Public Health and the Pandemic
McGill Research Group on Health and Law Interdisciplinary Panel
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The right to privacy has been on many people's lips since the start of the COVID-19 pandemic. Many raise the need to defend citizens' private spheres against intrusions occurring in the name of public health. Meanwhile, others stress the fact that privacy protections may hinder public health efforts and may need to be relaxed to maintain health and life. Still, some suggest that privacy protection and public health need not conflict. Once more, the familiar dilemma of how to balance collective public health objectives with individual civil rights presents challenges. Making explicit the individual versus population considerations is at the heart of public health ethics, a field that examines the different groups that can benefit from or be harmed by various decisions, and determines how to maximize the benefits and mitigate the harms (with privacy being one among other potential harms) while ensuring there is proportionality in how measures are applied and that the distribution of benefits and harms is fair.

The right to privacy is not a new concept. It is protected by Charters of Rights and, in the province of Quebec, the Civil Code, and is the object of a web of federal and provincial legislation. Is it up to the challenges the COVID-19 pandemic throws its way? Does the pandemic change what we can and should expect in terms of our privacy? Do current privacy rules and policies in Canada provide useful tools to reinforce public health strategies or, on the contrary, do solid privacy protections hinder the work of public health authorities? Does privacy law need to adapt or is it business as usual for this criticized concept in the middle of a reform at the federal level? In its 2019–2020 Report, the Office of the Privacy Commissioner of Canada (OPCC) wrote that "the COVID-19 pandemic makes the significant gaps in our legislative framework all the more striking" (4).

Questions about rights, privacy protection and public health have arisen for instance in relation to contact-tracing apps, proof of medical condition as a basis for exemptions to public health orders, and the differential privacy implications of pandemic responses for those who are most vulnerable—the poor, front-line workers, people of colour, and the elderly. During this presentation, panelists from fields of law, public health and engineering technology will consider issues around privacy and public health arising in the context of the current pandemic. Among the discussions at the intersection of privacy and public health are those surrounding exposure notification applications—or "contact tracing" apps—, such as the federal COVID Alert app. Governments are acutely aware that strong privacy protections are crucial to the success of such applications. For instance, the Government of Canada ensures that its app collects and stores only random codes that cannot be connected to the identity of the phone owner and that the app has no way of knowing the person's location, name, address, phone contacts or health information (2). Despite these reassurances, only 5.5 million Canadians (about one fifth of 31.5 million Canadian smartphone users) have downloaded the COVID Alert app as of December 2, 2020 (3). The need for privacy enhancing technologies for use in the health care sector becomes more pressing than ever. The use of privacy enhancing technologies can indeed enable and accelerate broader data access for research and for analytical purposes. It can also allow public health surveillance to be conducted in a way that minimizes privacy risks. While several approaches can be used in this respect, the pandemic has revealed – with a few exceptions – a lack of preparation in terms of having the necessary infrastructure in place when it became needed and in terms of the availability of necessary rapid data access processes. The post-pandemic period is the opportunity to build these infrastructure and processes expeditiously.

Although discussions around COVID-19 and privacy have naturally attracted discussion around new technologies, there are other dilemmas to consider. For instance, the pandemic has meant that people are

more regularly required to surrender aspects of their anonymity in the name of public health. This happens when, for instance, family health issues must be disclosed to schools and teachers and inevitably become known to a whole class, when we must leave our name and contact information when dining in a restaurant, when employers ask employees to fill online forms indicating the date and times they will enter the workplace or ask them to communicate a COVID-19 diagnosis, and when we submit to health monitoring measures in airports, summer camps, schools, or workplaces. As the OPCC notes, new ways of delivering (and maintaining) services such as telemedicine also bring to the forefront risks to confidentiality caused by potential security breaches; online teaching may reveal sensitive information about students' disabilities or other issues (4). Release of private information may even be considered necessary to protect particularly vulnerable populations. First Nations communities in British Columbia, for instance, have sought access to information on COVID-19 cases that might impact their community by emphasizing that the pandemic affects the health of Indigenous populations disproportionately compared to the rest of the population (1).

A careful consideration of these issues may shed light on the interplay between protecting the health of the population and addressing individual privacy concerns, as well as on the capacity of legal frameworks and new technologies to respond to and mitigate apparent tensions. COVID is a syndemic that disproportionately harms those in low-resource racialized neighborhoods, isolated elderly, women, persons with disabilities, people experiencing homelessness and those living in poverty, who are less able to protect themselves from the pandemic. By mitigating potential harms to individual rights and freedoms, including the right to privacy, it is possible to strike the right balance that enables adequately promoting public safety, protecting marginalized groups, safeguarding fragile health systems, and reducing direct COVID-related and collateral excess mortality. The pandemic provides a window of opportunity to rethink the structural weaknesses in the system and build a better post-COVID society that protects individual rights and freedoms while creating more supportive systems and environments that foster community resilience, equity and justice for all.

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- 3) Government of Canada, *Download Covid Alert Today*, online: <https://www.canada.ca/en/public-health/services/diseases/coronavirus-disease-covid-19/covid-alert.html>
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