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ACCOUNTABILITY FOR CANADA'S COVID-19 RESPONSE

How Canada's decentralised covid-19 response affected public health data and decision making

Tania Bubela and colleagues examine how fragmented responsibilities and accountability for public health data hindered Canada's pandemic response

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Canada's public health system was reformed after its 2003 severe acute respiratory syndrome (SARS) outbreak, which was the worst outside of Asia with 438 cases and 44 deaths.¹ Ensuing national and provincial inquiries led to the creation of the national Public Health Agency of Canada (PHAC) to coordinate Canada's preparation for and response to public health threats.² Subnational public health agencies were also created or strengthened to function as regional centres for disease control.¹ These actions should have put Canada in a good position to respond to the covid-19 pandemic.³⁴

Despite these reforms, Canada experienced serious failures during the covid-19 pandemic failures. Memories faded rapidly after SARS, and if history is not to repeat itself, government and health system leaders must strengthen the country's public health and healthcare systems in preparation for the next threat. Health authorities as well as all Canadians need to reflect on the crises of the past three years-what went well and why; what caused pandemic response failures, and what were their consequences? Here, in the first of a series of articles examining Canada's response and setting out suggestions for a national inquiry, we examine the limitations of the country's decentralised structure for public health decision making and missed lessons from the 2003 SARS-CoV-1 outbreak, particularly with regard to data infrastructure.⁵ Other articles in the series examine how research and data failed to inform public health responses tailored to community and population needs,⁶ the predictable failures in long term care,⁷ and Canada's role in global vaccine inequity.⁸

Devastating effect of covid-19 in Canada

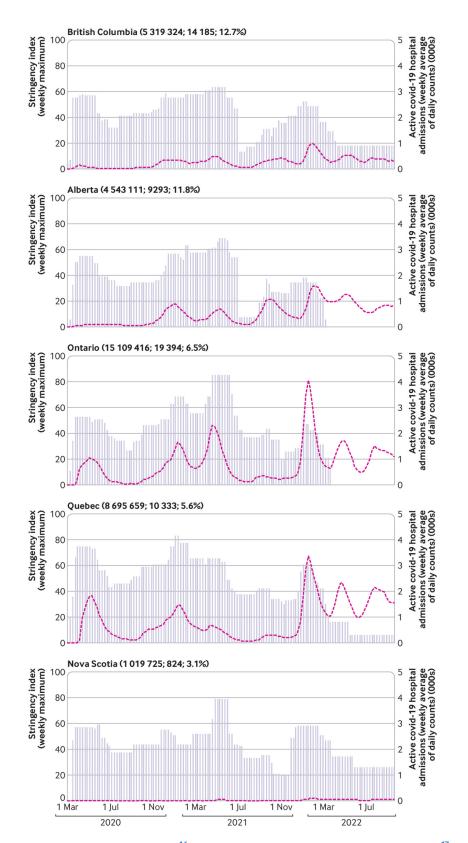
Canada's cumulative confirmed covid-19 death rate, as of June 2023, was 1372 per million population,

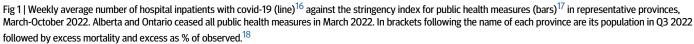
exceeding the global average of 855 per million but lower than the UK at 3362 per million.⁹ Although international case comparisons are difficult because of differences in testing, definitions, and reporting, Canada fared worse than Australia (814 deaths per million) and better than the US (3332 deaths per million), similarly federated countries with decentralised health systems.⁹ Differences may derive from social norms that reflect compliance with public health measures. Globally, countries with stricter norms and punishments for deviating from those norms, experienced fewer cases and deaths.^{10 11}

Cases and excess death rates over the pandemic varied widely across Canada's 13 provinces and territories (table 1),¹⁵ which are diverse in terms of geography, population density, ethnic diversity, and size, as well as the timing and sequencing of protective measures taken throughout successive waves from January 2020 to February 2022 (fig 1).¹⁸ The 40 million people living in Canada are largely concentrated in cities along its southern border with the United States; 18% of the population is dispersed throughout rural and remote regions. Canada's first SARS-CoV-2 case was in a returning traveller in Toronto, Ontario, in January 2020, and the first community transmission was found on 5 March 2020 in Vancouver, British Columbia. Subsequently, community transmission was found in other provinces and territories, leading all to declare states of emergency in March 2020. The federal government (and some provinces and Indigenous communities) implemented border and travel restrictions, with testing, quarantine, and isolation requirements ending for those entering Canada on 1 October 2022.¹⁹Box 1 outlines some covid-19 highs and lows for Canada.

Table 1 | Population, total covid-19 deaths and vaccine doses administered to June 2023 in Canadian territories, provinces, and provinces with public health agencies¹²⁻¹⁴

Region	2023 Population (1000s)	No of covid-19 deaths, June 2023	No of vaccine doses (1000s)
Territories:			
Yukon	44	32	93
Northwest	46	22	103
Nunavut	41	7	77
British Columbia	5399	5430	14 344
Prairie provinces:			
Alberta	4647	5682	10 059
Saskatchewan	1431	1952	2630
Manitoba	1215	2483	3001
Ontario	15 386	16 438	38745
Quebec	8787	17 728	23 470
Atlantic provinces:			
Newfoundland and Labrador	532	336	1265
New Brunswick	825	877	1757
Nova Scotia	1038	839	2236
Prince Edward Island	174	96	39
Canada	39 566	51 921	98 171





Box 1: Highs and lows of covid-19 response in Canada

Highs

- Public health leadership included women at each level of decision making.²⁰
- Canada became one of the most vaccinated countries with >83% of the population receiving at least one vaccine dose in February 2023.²¹ After Health Canada approved Pfizer-BioNTech and the Moderna covid-19 vaccine in December 2020, rollout was prioritised for indigenous populations and those living and working in long term care homes
- Research collaborations from basic science through to clinical and health services research emerged rapidly to address urgent questions of seroprevalence ²²(eg, covid-19 Immunity Task Force), correlates of infection and immunity, and outbreak mitigation factors and engagement of patients in research conduct such as knowledge synthesis

Lows

- Failure to learn from previous reports led to failure to protect older adults and staff in long term care homes and among the highest proportions of deaths in this sector globally²³
- Challenges to access and delivery of effective covid-19 medications such as tocilizumab, remdesivir, and ritonavir-nirmatrelvir resulted in provinces and hospitals rationing use^{24 25}
- An exodus of exhausted and distressed healthcare workers, coupled with inadequate training paths for replacements, produced a critical workforce shortage that is ongoing^{26 -28 5}
- Canada lacked a coordinated system for evidence generation and use across government jurisdictions^{4 29}
- Lack of research infrastructure embedded within the healthcare system limited Canada's ability to participate in or lead clinical trials or other international studies³⁰
- Lack of a clear and standardised approach to case definitions and testing contributed to inability to share use of data and make decisions³¹
- Absence of data sharing agreements across federal and provincial or territorial jurisdictions³² slowed or limited data sharing

Lessons from the pandemic

How did fragmentation and decentralisation contribute to covid-19 outcomes?

Canada faces systemic challenges in evidence informed public health decision making, partly because of its complex, decentralised governance of healthcare and public health (appendix).³³ Within Canada's disaggregated federation, constitutional responsibility for public health is shared between a national, federal government and 10 provincial governments. The three territories (Yukon, Northwest, and Nunavut) derive their responsibility for aspects of health from their founding federal legislation. Within each province and territory, healthcare and public health systems operate side by side, and here we focus on public health, which, in 2019 accounted for only 5.2% of Canada's total health spending.³⁴

SARS brought international attention to shortfall in the Canadian public health system. After the 2003 outbreak, the country's handling of SARS was described as an "international embarrassment."³⁵ The chair of the National Advisory Committee on SARS and Public Health, David Naylor, described "squabbling among jurisdictions, dysfunctional relationships among public health officials from the three levels of government (federal, provincial/territorial, and municipal), an inability to collect and share epidemiological data, and ineffective leadership" – which, taken together, held hostage the health of Canadians.¹³⁶

PHAC was created in 2004 in response to concerns about Canada's ability to respond effectively to public health threats, with a commitment to reduce health inequalities, while recognising that public health was a shared responsibility across government levels.³⁷ PHAC is responsible for developing national clinical and public health guidelines, technical advice, border quarantine services, and specialised services for early testing of emerging pathogens.³⁸ However, it lacks the powers to direct provincial and territorial health agencies or other bodies with similar mandates to implement its recommendations.

In Ontario, Public Health Ontario (PHO), an arm's length scientific and technical organisation created after SARS,³⁹ led data and surveillance reporting and laboratory testing for covid-19, starting in early January 2020. Like other provincial public health agencies, the PHO does not create policy but its work informs provincial and local policies and guidelines—for example, through covid-19 surveillance, scientific and technical information, laboratory testing, and evidence synthesis of best practices.

Although each province or territory has a chief medical or public health officer, they can delegate public health decisions, responsibilities, and implementation to regional or municipal health authorities, with or without sufficient resources.⁴⁰ This means that decision makers at different jurisdictional levels lack coordination in a pandemic. For example, each province or territory devised its own interventions and timelines for protective measures such as school closures, border controls and closures, prohibition of gatherings, and masking requirements, leading to substantial variation in policy and practice across the country, widely varying hospital admission rates, and public confusion (fig 1).^{17 29} 41 42

Some health professionals joined official advisory committees across the country (appendix). Others engaged in social media, sometimes becoming trusted voices that challenged public health leaders. The conflicting messaging undermined public trust over time.43 Organisations representing health professionals, including the Canadian Medical Association, Canadian Nurses Association, and Canadian Pharmacist Association, called for improvements in the shortages of drugs and personal protective equipment, workplace conditions, harassment, and burnout that were affecting health workforces, long term care staffing and conditions, and for vaccination access and coverage.44-46 Federal and provincial health professional associations both amplified the distribution of public health guidance and released their own to support decision making.⁵⁰ Most notably, provincial associations enabled the rapid pivot to virtual care. However, overall the advocacy by health professions' leadership remained fragmented and hampered by inadequate data production, access, and use across provincial, territorial, and regional jurisdictions.

In the absence of a coordinated pandemic planning authority, the supporting evidence and rationale for different rules in different places were often unclear. PHAC provided national guidance⁴⁷ on infection prevention and other control measures as well as national vaccine guidelines through the National Advisory Committee on Immunisations (NACI). NACI made evidence based recommendations ⁴⁸ on covid-19 vaccine eligibility but had no responsibility for implementation. Each province or territory then created its own vaccine eligibility plans, allocation, and mandates. For example, vaccine mandates in Ontario applied only to those working in long term care homes while in New Brunswick, Newfoundland, Nova Scotia, and Yukon vaccines were required for

those working in healthcare, the public sector, long term care, and schools.⁴⁹ Similarly, provincial public health authorities differed in their guidance on masks, school closures, curfews, and lockdowns.^{29 50} Outbreak investigation, management, and risk mitigation happened at local and municipal levels. Adding to the complexity, in some provinces, entities such as school boards and acute care hospitals implemented mandates to augment provincial public health guidance.

While some variation may be justified given localised risk factors, insufficient pooling of data and analyses during the pandemic made it hard to understand these variations or share their rationale with the public. PHAC and some provincial public health organisations used their own researchers to conduct knowledge syntheses and primary research whereas other provinces created scientific advisory committees with external membership.^{42 51} Indeed, in Ontario, medical academics persuaded the government to establish an expert, public facing scientific advisory committee that was able to challenge public health leadership.

Deficiencies in data and data infrastructure for decision making

Public health data derive from multiple sources, including electronic health records, administrative data on healthcare services utilisation, and public health surveillance data, including testing data and genomics data, such as viral sequencing. All government levels collect, access, and use these data to some degree, but data were in short supply to support public health decision making during covid-19. This situation will persist without major reform. The national auditor reported that when the covid-19 pandemic began, PHAC "did not have regulations or finalized agreements with the provinces and territories to clearly outline what public health surveillance information to share and how to share it,"³² including case level information on vaccine safety with Health Canada, vaccine developers, and the World Health Organization,³² delaying information sharing on vaccine safety.

In addition, public health decisions across jurisdictions in Canada were hampered by outdated health information systems and lack of integration and interoperability between data sources after eight years and C\$130m (£76m; €90m; \$98m) of investment failed to establish a pan-Canadian technical solution for public health data.⁵² The numerous pieces of federal, provincial, and territorial legislation covering health information or privacy create a "legal interoperability" challenge, which was amplified by "human interoperability" challenges related to risk averse interpretations of those laws by data custodians. A clearer vision for a public health data system in Canada will require coordination and interoperability of systems under the control of disparate and geographically distanced organisations to support analyses and public health decision making.^{53 54} Data may not need to be pooled or moved across jurisdictions, but access to those data could be enabled through federated data structures.

As the pandemic progressed, public confusion arose from jurisdictional inconsistencies in advice and case reporting.⁵⁵ Most jurisdictions routinely reported the raw number of covid-19 cases. More detailed information about the demographics or location of cases was often more guarded because of privacy concerns, meaning that public health agencies did not respond to community interest about local risk and tailoring of implementation strategies to mitigate covid-19 risks was slow or non-existent. Lack of local data contributed to a lack of understanding of local transmission dynamics and contributed to loss of public trust over time.³¹ Similarly, contact tracing information was not centralised within provinces or territories. Collection of data on ethnicity, occupation, and other factors was slow to evolve, and in some places never happened, even though this was clearly related to virus spread.⁶

Data sharing lagged even for non-personal data such as viral genomes, which is perplexing given funder commitments to health and genomic data sharing.^{56 57} For example, Canada was one of the slowest industrialised countries to submit SARS-CoV-2 genome sequences to Global Initiative on Sharing All Influenza Data (GISAID), which supports public health decision making through global surveillance of SARS-CoV-2 variants.⁵⁸ The rationale for limited sharing included that data might be misinterpreted, partly because of differences in data related practices. For example, provinces had different policies about testing eligibility, test types-PCR or rapid antigen tests-and how test results were reported. Variation made it difficult to compare case rates, which was partly addressed by reporting the proportion of tests that gave positive results ("test positivity"). Lack of testing had broader implications for attribution of deaths to covid, further complicated by definitions of death "with" versus death "from" covid-19 across time and jurisdiction. While these concerns could be overcome with good data documentation, or data and testing standards, inconsistent and changing definitions during the pandemic created public confusion and distrust.

Questions for a covid-19 inquiry

A national inquiry in 2023 is critical. Consistent with reports both before and after this pandemic, ^{59 60} we call for a culture of data sharing that enables diverse use by a broader range of users. Public health in Canada will benefit from a common vision and harmonised approach to generation, use, and analysis of data to guide public health decision making and population health benefit.⁵⁹

Providing some hope for action, the federal government is requiring collaboration on better data sharing as part of a proposed C\$46bn increase in transfer payments to the provinces to support healthcare systems.⁶¹ It includes C\$505m over five years for national data partners to work with provinces and territories on improving "how health information is collected, shared, used and reported to Canadians to promote greater transparency on results, and to help manage public health emergencies."⁶² While welcome, given past experience, we are sceptical that this further call for collaboration on data sharing will be sufficient.

We need tailored public health responses to emergencies, which requires data that are fit for purpose and transparent collection and use in decision making. The public must be involved in these decisions through direct consultations and inclusion of community organisations. If cooperation does not occur spontaneously, the federal government needs to use its spending, convening, and other powers to spur action. To this end, a national, public covid-19 inquiry should consider the extent to which deficiencies in data collection, definition consistency, data gaps, and sharing hampered public health responses and how a lack of clarity in roles and responsibilities and coordination of public health decision making contributed to pandemic impact.

It should also examine data sharing relationships between PHAC and provincial or territorial public health authorities and whether the federal government should compel certain data sharing for pandemic preparedness and response. This needs to be accompanied by improved access to public health data by independent experts who can hold public health decision making to account and by the public and community to improve local relevance and transparency to enhance public trust. More broadly, the inquiry should consider the role of science advice in developing public health measures and replicable models that best included public engagement and political and public trust.

One of the benefits of Canada's federation and decentralised governance in public health is the natural experiments that can occur from which we can identify best practices. To identify them, Canada's data governance must be overhauled to ensure systematised sharing of data to support better and more coordinated decision making.⁶³ During covid-19, the public became increasingly concerned about oscillating and jurisdictionally inconsistent measures, whose implementation was increasingly politicised.^{64 65} Public health agencies can rebuild public trust through transparency and inclusion in decision making, data collection, sharing, access, and use. Without reform, the new proposed data infrastructure investments on the part of Canada's federal government will be wasted.

Key messages

- Canada's public health system was insufficiently prepared for the covid-19 pandemic
- Public health decisions and outcomes varied across jurisdictions and were hampered by outdated health information systems and lack of integration
- Decentralisation of public health decision making has benefits such as tailoring interventions to local constituencies, but during a crisis, governance structures need to pivot to enable coordination and systematisation of data collection and analyses
- Gaps in data and decision structures created a vacuum, filled by science advisory committees with disparate roles, responsibilities, and accountabilities within different jurisdictions
- A shift to a culture of data access and shared analysis is needed to enhance health system learning and population health benefit, and for future crisis and pandemic preparedness

Contributors and sources: TB is a legal scholar with expertise in collective action impediments to research data and materials sharing. CMF is a health law and policy researcher with expertise in comparative analysis. KM is a quantitative health services and policy researcher with expertise in data governance and population data science. SM is an infectious disease physician and researcher with expertise in infectious disease epidemiology and programme science. SES is a geriatrician researcher, with expertise in knowledge mobilisation and evidence synthesis. TB, SM and SES conceived the paper. All authors contributed to drafting manuscript sections as well as editing. All authors are guarantors of the article.

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Web appendix: Public health structures and advisory bodies