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ACCOUNTABILITY FOR CANADA'S COVID-19 RESPONSE

Use and misuse of research: Canada's response to covid-19 and its health inequalities

Sharmistha Mishra and colleagues examine how pandemic research contributed to a homogenised public health and clinical response to covid-19 in Canada and how it could have done better

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Canada had one of the lowest rates of covid-19 cases and deaths per population than most in the G10 group of industrialised countries.[1] But overall rates ignore underlying health inequalities—a consistent feature of the covid-19 pandemic across countries, within and outside the G10.[2] Across every G10 country, for example, economic marginalisation was associated with twofold to fourfold higher rates of covid deaths.[2]

Disproportionate risks of exposures and transmissions are shaped by physical and social networks[3]: how, under what context, and with whom infectious disease contacts take place. The same context that governs these networks often defines what happens after infection occurs: access to and quality of care and treatment within a healthcare system that is built with the same tools as the social and economic system that failed to mitigate disproportionate risks. Yet early in the pandemic, Canada, like most countries, largely applied public health measures universally across its decentralised public health system with little focus on how measures and strategies would, or would not, reach and apply to those most at risk.[4]

Lessons from the pandemic

In Canada, communities and individuals experiencing social and economic marginalisation and systemic racism shouldered the greatest burden of the covid-19 pandemic.[5] The highest rates of cases and deaths were among racially minoritised people, recent immigrants, lower wage essential workers, and those living in higher density and multigenerational households.[6 7] Infection risks were highest at the intersection of household density and workplaces, amplified by barriers to accessing testing, isolation support, and early rollout of vaccination and boosters.[8] In Canada's most populous province, Ontario, the income gap in covid-19 outcomes has not improved over time (fig 1).[9] Rates of covid-19 hospital admissions and deaths remained threefold higher in the lowest income neighbourhoods compared with highest income areas in each pandemic wave, despite the province eventually achieving "equality" in two dose vaccine coverage and usual measures of hybrid protection (known infection and vaccination) across income.[9] We examine the ways in which research may have contributed to homogenising public health responses to a heterogeneous epidemic and how research could have been used to shape more tailored health policies and implementation efforts.
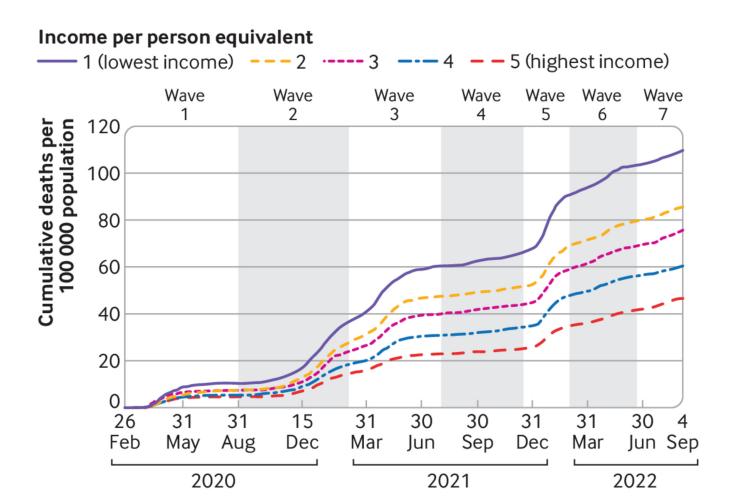
Fig 1 | Cumulative covid-19 related deaths per capita by neighbourhood income in Ontario, Canada (population 14 million) across seven waves of the pandemic. Neighbourhood level income accounts for household size and is adjusted for city level cost of living[9]

Research investments for a tailored covid-19 response

During covid-19, the fit between funding priorities and the urgent needs of decision makers for evidence on differential risks and health inequalities was mixed. Against a background of chronic underinvestment in research in Canada,[10] federal agencies invested C$795m (£465m; €545; $600m) in immediate funding in 2020 (compared with $568m in 2019), of which, 41.2% was for covid-19 research.

But none of the first set of rapidly funded projects focused on long term care, housing shelters, or essential workplaces outside healthcare settings, where outbreaks spread most rapidly.[11 12] Months later, a Centre for Research on Pandemic Preparedness and Health Emergencies was established within the health funding agency, along with funding calls to address health inequalities, including research led by and with Indigenous communities.

Yet early covid-19 funding still left gaps in the types of research resourced to inform the public health response, thus failing to adequately support areas known to be critical to pandemic management in the face of disproportionate infection risks: implementation science, qualitative or mixed methods research, and One Health or zoonotic research comprised 13 of 1158 funded covid-19 projects in 2020.[13 -17]

In April 2020 Canada's national public health agency established a Covid-19 Immunity Task Force to fund seroprevalence studies, combined with data harmonisation and data sharing, and it was among the first, in August 2020, to call for research with and among communities experiencing the highest risks.[18] However, efforts to involve Indigenous communities in the work of the task force were not successful, despite the establishment of an Indigenous Advisory Circle. The advisory circle closed in 2021, partly because of limited time to foster relationships and meaningful community engagement and to establish governance that recognised the communities' principles of ownership, control, access, and possession for data and biological samples.[19]

Covid-19 research in Canada also built on pre-existing infrastructure and networks, but most platforms—especially clinical trial platforms—lacked meaningful approaches to create inclusive space for diversity in study recruitment and reporting on social determinants of health.[20] For example, established research platforms, such as the Canadian Critical Care Trials Group used existing infrastructure to participate in international clinical trials of covid-19 therapeutics, but by the end of 2021 had yet to establish systematic data collection on social determinants of health.[21 22] Even now, community engagement as part of clinical trials to build sustainable mutual trust is limited to a few networks, such as the

HIV Clinical Trials Network and the newly formed CanTreatCOVID.[23 24]

Funding agencies have an opportunity to embed community engagement in future research so that findings serve the needs of those most at risk.[25] In 2023, the Canadian government invested C$2.2bn to establish research "hubs" to increase pandemic bioscience capacity. Yet this investment neglected any mention of health inequalities in epidemics, did not make its funding accountable to communities at disproportionate risk of epidemics, and did not invest in community partnerships to build trust.[26] By perpetuating the separation of biomedical research from community engagement, these ongoing investments risk failing to translate discoveries into reduced health inequalities and failing to innovate where it matters most.

Who led research to inform covid response?

Researchers' intersecting identities and lived experience shape the questions asked, how research is conducted, and interpretation of

results.[27 -30] In 2020, 35% of covid-19 projects funded by the health agency were led by women, similar to the proportion of women applicants in the previous two years.[31 32] But fewer women led the first set of rapid research projects funded in 2020 (26%). Data on Canadian covid-19 research funding and production across intersections of gender, racial identity, Indigenous identity, ethnicity, and lived experience are not available. But where data are available, they suggest a similar pattern as that seen across academia globally: fewer women published as first and senior authors in public health, and as first authors in biomedical research on covid-19 compared with non-covid-19 research (fig 2).[31] These data reflect the well documented challenges women researchers experienced to obtain grants and lead publications, partly because of the disproportionate caring responsibilities during lockdowns and school closures.[33 34]
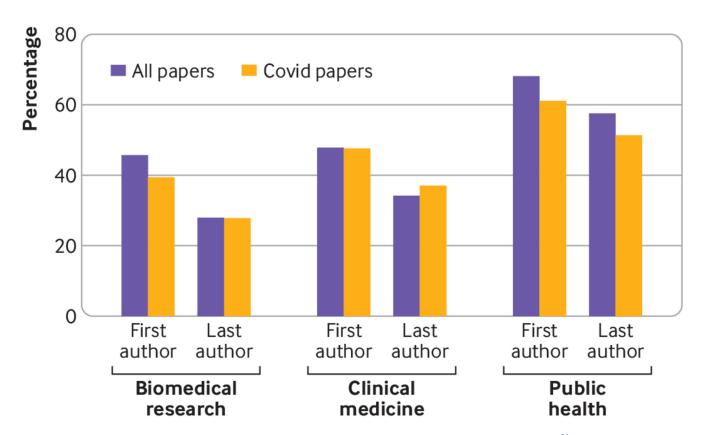

Fig 2 | Gender distribution of covid-19 research and other publications in Canada, 2020-22 (authors' updated analysis from Larivière et al[31])

Lack of scholarly diversity in putting research into action

Epidemiological and clinical research dominated the discourse at advisory and policy making tables, largely ignoring discussion on inequities early in the pandemic. Independent covid-19 science advisory committees of 10 to 50 people were established in early 2020 at the federal level[35 36] and in provinces like Ontario.[37] These advisory committees occasionally undertook new research as well as producing scientific reports for policy makers.[38] Most of the epidemiological modelling in this science advice simulated universal public health measures, but a few studies offered prioritisation strategies, such as those used to develop a hotspot vaccination policy.[39 -41]

While many advisory groups stated that equity was always central to their mission, their early outputs suggest otherwise.[42 -44] For example, in Ontario the advisory group reports documenting and discussing health inequalities and equity were not published until more than a year into the pandemic.[44] The first report by the federal public health agency on covid-19 inequalities came out 10 months into the pandemic,[5] but few reports included implementation science, qualitative research, or virology and zoonotic research.[42 43]

Outside the official advisory groups, more inclusive independent networks at various levels, such as the Royal Society of Canada, Wellesley Institute, and Health Commons, tackled—for example, embedding One Health perspectives,[45] mitigation strategies for

outbreaks among people experiencing homelessness,[12] community ambassador programmes,[46] and how systemic racism and colonisation shape epidemics and the response.[47 48] However, the domination of biomedical research across regional advisory committees meant that research on prioritised and tailored strategies did not gain sufficient traction to shift the discourse from homogeneous policies that were resourced and implemented at the regional level, especially during the first years of the pandemic.[4]

Tailoring research and data informed local responses

When community leadership and mobilisation led to research for a more tailored response, successes ensued. For example, Ontario's real time reporting of cases and vaccination coverage by neighbourhood, and across neighbourhood level social determinants of health,[8] enabled communities to access aggregated data to monitor the effect of, and to adapt, local strategies.[49 50]

A limitation to tailoring covid-19 responses was the lack of person level data collection inclusive of social determinants of health including racial identity and exposure risks such as occupation and housing. Such person level data are part of routine data systems in countries (eg, Denmark, Sweden) that were able to quickly provide some of the earliest and powerful evidence of health inequalities.[51 52] This limitation in data, alongside critical governance issues,[53] shows that Canada was not prepared to respond systematically to a pandemic shaped by health inequalities. Only in December 2021, did Statistics Canada begin to develop a disaggregated data action plan to break down data according to sex, gender, race, ethnicity, age, sexual orientation, and disability and combinations of these to reveal "uneven economic and social realities in Canada."[54] During the pandemic, a few jurisdictions, in partnership with community based organisations, attempted systematic collection of individual race based and socioeconomic data among people diagnosed with covid-19.[55] However, the rapid deployment of public health emergency measures occurred with limited time to build trust between communities and public health teams who were collecting the data as part of routine case investigation. Race based and socioeconomic data helped shape the local response in some cities, but completion rates within the surveillance data were low (60% were not asked or declined to answer).[55]

These lessons reiterate that a pandemic is not the optimal time to start these conversations and develop the meaningful relationships, trust, and capacity to move quickly to respond. If such conversations start only when there is an emergency, then research risks repeating the same failures.[29] To conduct research for a tailored public health response, research systems require community trust and models of data governance across diverse communities and settings to be built ahead of a public health emergency. An important exemplar is highlighted in the consideration of Indigenous data systems and governance: Indigenous self-determination and rights[56] must inform Indigenous governance of Indigenous data and the use of those data by Indigenous leadership.[57] Some structures and data governance systems were in place before the covid-19 pandemic, and these enabled timely sharing of relevant data and information for First Nations and Métis governance, self-determination and decision making.[58 -60] Systems and structures included up-to-date data on covid-19 testing and eventually vaccination specific to First Nations and Métis populations that could be accessed by First Nations and Métis organisations. These organisations shared data with their community leadership, just as similar data were being accessed by and shared with provincial and federal governments. First Nations communities and Métis governments were then able to tailor their pandemic response and track their population level experience with covid-19.[61] Responsiveness was based on decades

of relationship building, establishing data governance agreements with data holders, developing collaborative systems for data analysis and sharing, and building capacity, which collectively led to the ability to move quickly when needed.

However, there were also notable examples where these systems were not in place, including for diverse, self-identified Indigenous people living as part of urban Indigenous communities. Seeing a need, many health service and public health organisations, and governments serving these urban communities proposed self-identification processes connected to covid-19 testing and vaccination.[62]

Community and patient engaged research for covid-19

Despite a strong foundation, patient oriented research in Canada was not used early in the pandemic and often left the patient voice behind. In 2011, the Canadian Institutes of Health Research (CIHR) launched a strategy for patient oriented research[63] to foster research co-creation with patients and carers.[64] Before the pandemic, patients and carers reported being involved throughout the research process, from development to dissemination,[65] but they were not included in rapid research funding calls early in the pandemic.[66] Contributing factors were the rapid timelines and the effect of the pandemic on patient partners, including financial constraints, care giving responsibilities, and social isolation.[66] When patient voices were captured, they were from largely white, university educated women,[67] with rapid cycles of funding further exacerbating exclusion of patient voices across intersections of social and economic marginalisation. Uniform engagement strategies and digital platforms further excluded diverse voices.

Successful engagement strategies built on existing patient (box 1) and community partnerships with people experiencing social or economic marginalisation. For example, the Strategy for Patient-Oriented Research (SPOR) Evidence Alliance, funded by CIHR, used its longstanding partnerships to develop over 60 rapid covid-19 reviews for decision makers.[63] Similarly, the Qanuinngitsiarutiksait study, involving researchers and Inuit community partners, built on existing work to track covid-19 infections and ensure equitable testing and vaccine access.[68] If such engagement strategies had been incorporated broadly, the public health response could have been much better at meeting individual needs. Future efforts should focus on co-creating collaborative spaces, providing remuneration, facilitating multilingual and accessible participation, providing a point person for contact, ensuring sufficient time to build relationships, and prioritising funding calls for patient oriented research.

Box 1: How existing patient networks facilitated covid-19 research and implementation

The Qanuinngitsiarutiksait study

The study began in 2015 and was led by Inuit elders from Nunavut and living in Manitoba and Nunavut, and representatives of Manitoba Inuit Association and the University of Manitoba. It was developed as a study belonging to and at the service of the Inuit community in Manitoba. This project was conducted to use Manitoba's administrative data housed at the University of Manitoba to define a cohort of Inuit people who used Manitoba health services, track their service use over time, and identify needs.

The co-creation approach and a commitment to honour Inuit Qaujimajatuqangit (Inuit traditional knowledge) over the years of the study facilitated subsequent pandemic response. For example, the study cohorts informed pandemic response in Manitoba and were used to track equitable access to testing and vaccine. The Manitoba Inuit Association was invited for the first time to sit at a provincially led decision making table with a mandate to coordinate policies and care for those with

covid-19. The study team was able to advocate for regular reporting to the Manitoba Inuit Association on the number of covid-19 tests and cases in the Inuit community living in Manitoba and accessing health services in Manitoba, which was the only jurisdiction in Canada to partner with an urban Inuit organisation in pandemic planning and service delivery.

Canadian Arthritis Patient Alliance (CAPA)

CAPA was launched by patients with arthritis in 2001 to provide a voice for patients in arthritis care and research in Canada. It has a longstanding history of patient engagement in research, including identification of patient priorities for research and co-creation of research that is relevant to patients.

CAPA was active during covid-19 in identifying research priorities for its community and partnering with researchers on research completion and dissemination. For example, in January 2021, it worked with researchers and the Canadian Rheumatology Association to develop a decision aid for people with autoimmune rheumatic disease who were considering the covid-19 vaccine. When the vaccines first became available, questions were raised about their safety and effectiveness in those with autoimmune disorders, who were not included in the initial clinical trials. The decision aid responded to voiced concerns from patients about whether to be vaccinated or wait. CAPA was able to rapidly mobilise participants to co-develop the tool and to disseminate it broadly.

* CAPA received funding from various organisations, including industry.

Questions for a national covid inquiry

In every epidemic in history, there was inequality.[69] Covid-19 was never going to be different and we were never, "all in it together." Communities and connected researchers called early attention to the need to design a more nuanced public health response—detailing structural solutions, prioritised allocation, and tailored programmes to address differences in risks. But the research community stood in its own way (box 2). Early rapid research and networks that were accountable to disproportionately affected communities were late to materialise and late to the advisory and decision making tables.

Box 2: Reshaping how we do research in epidemics

Canada's research funding agencies

- Invest in pandemic research infrastructure before next pandemic, focusing on effective strategies that increase, entrench, and systematically evaluate:
  - Diversity and retention in the research workforce
  - Scholarship across disciplines and domains with a long history of examining differential risks of transmission, and working on health inequities and social justice
  - Community and patient engagement at all stages of pandemic research funding programmes—from setting research priorities to reporting on research impact
- Pre-formed rapid research calls that directly and explicitly focus on underlying social determinants of health in epidemics
- Accountability through reporting of effect of funding on communities experiencing disproportionate risks and on health inequalities

Pandemic science and scholarly advisory groups

- Ensure expertise in health inequalities and social justice, across disciplines and domains, in leadership roles as well as production of science advice
- Scientific advisory groups should have patient and community engagement, including in prioritising topics for science advice
- Advisory groups should be held accountable by ensuring a transparent reporting structure with decision makers at various levels or jurisdictions
- Timely synthesis and generation of pandemic reports on health inequalities to inform tailored strategies should be prioritised

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Research should nurture mutual trust and partnership with communities before epidemics hit

- Community supported legislation (federal and regional level) and community led implementation and governance (regional and community level) in the collection, sharing, and rigorous use of socioeconomic, occupational, household, and race based data to inform and evaluate each aspect of a pandemic response
- Federal investment and community partnership and oversight applies to disease surveillance and health administrative data platforms as well as clinical trial platforms
- Platforms should ensure communities have access to their granular local data on differential risks and intervention access to tailor community and locality specific response

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A national covid-19 inquiry should consider the extent to which the extent, or lack of pandemic focus on social determinants of health, social justice, and differential risks of transmission led to success and failure to tailor protective measures and contributed to morbidity and mortality and health inequalities, and how the timing of research on inequalities influenced pandemic policies. It should also consider how far patients and communities were engaged in research and research use and the lessons for inclusivity and trust in all aspects of pandemic research, from study design to methods, interpretation of results, and dissemination, and what mechanisms can promote uptake of research and development of science advice that is inclusive of diverse voices and lived experience in public health decision making.

To avoid repeating history and perpetuating the status quo, pandemic research must be intentional and active in reducing inequalities that shape and are amplified by epidemics. At the centre of research in service of communities, are data about communities and for communities. Research in support of a more specific and tailored response requires our ecosystem—from funders to networks to researchers—to meaningfully develop community trust and support community leadership before the next pandemic.

Key messages

- Early in the pandemic, Canada largely applied public health measures universally with little focus on reaching those most at risk
- Research, and its use, failed to challenge these universal policies, especially early in the pandemic
- Existing infrastructure for patient engagement was critical to reshape research priorities, but patient engagement was left behind in early research
- Relationships with communities need to be built before the next emergency to avoid repeating the same failures

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Health Canada, and the Public Health Agency of Canada /covid-19 Immunity Task Force to conduct covid-19 research in long term care homes, and is an investigator in the SPOR Evidence Alliance. SES was a member of the Royal Society of Canada COVID-19 Task Force. SM received funding from the Canadian Institutes of Health Research to conduct COVID-19 research. SM and JW were volunteer members of the Ontario Modelling Consensus Table, under the umbrella of the Ontario Science Advisory Board.

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