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Baseline Assessment of Canadians' Health Data Literacy and Values Related to Health Data Sharing – Research Report

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September 2023

This public opinion research report presents the results of an online survey, focus groups and in-depth interviews conducted by Earnscliffe Strategy Group on behalf of the Public Health Agency of Canada. The quantitative research was conducted in May to July 2023 and the qualitative research was conducted from August to September 2023.

Cette publication est aussi disponible en français sous le titre : Évaluation de référence de la littératie en matière de données sur la santé et des valeurs liées au partage de données sur la santé au sein de la population canadienne.

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Évaluation de référence de la littératie en matière de données sur la santé et des valeurs liées au partage de données sur la santé au sein de la population canadienne.

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Executive summary

Earnscliffe Strategy Group (Earnscliffe) is pleased to present this report to the Public Health Agency of Canada summarizing the results of quantitative and qualitative research undertaken to gain an understanding of Canadians' literacy of and values toward health data sharing.

COVID-19 highlighted issues that make it a challenge to collect, access, share, and use health data for the benefit of Canadians. Reliable, timely, and relevant public health data – including public health, health system and population health data – are crucial for informed public health emergency responses, policymaking, and overall improved health outcomes for Canadians. Despite health data being collected and shared now, notable gaps that can cause harm have been identified.

As part of the Safe Restart Agreement between provinces/territories (PTs) and the federal government, the Government of Canada provided funding to improve and modernize data management across Canada. The Minister of Health was tasked through their mandate letter in 2021 and later through Budget 2022 commitments, to establish a world-class health data system that is timely, usable, open-by-default, connected, and comprehensive.

To support this, PHAC led the co-development of a Pan-Canadian Health Data Strategy (PCHDS) with federal, provincial and territorial (FPT) partners to identify common commitments and actions to advance the sharing and use of health data and digital health tools. The key components of this work have been incorporated into other ongoing efforts, including the [Working Together to Improve Health Care for Canadians](#) plan and a [Joint FPT Action Plan on Health Data and Digital Health](#) to drive collective progress on five specific commitments related to health data, the latter of which was endorsed by Health Ministers in October 2023.

During the co-development of the PCHDS, public and stakeholder insights were required. Previous engagement focused on targeted stakeholders to raise awareness and solicit feedback on the content of the Expert Advisory Group's report and to inform co-development with PTs. This phase of engagement ran from June to November 2021 and included over 450 participants from research, health workforce, software/digital, privacy/regulators, and patient groups.

That stakeholder consultation revealed, among many observations, the importance of engaging patients and individuals as key to improving data literacy and securing support for health data sharing. Through the Working Together Plan, FPT governments (with the exception of Quebec) have committed to work together to build data literacy and social license through meaningful engagement.

Public Opinion Research provides insights to build and improve policies, processes, and practices to optimize health data sharing. The findings will provide a measure of knowledge related to health data literacy, and awareness and attitudes regarding health data sharing, that can inform the design/development of health data literacy and public engagement programs.

The overall objective of this study was to measure Canadians’ knowledge related to data literacy and attitudes regarding health data sharing to inform the design/development of health data literacy and public engagement programs

To meet the research objectives, Earnscliffe conducted a two-phased research project. The quantitative research will be used to:

- Assess the baseline of health data literacy among Canadians;
- Determine the social license parameters of health data sharing; and,
- Define the trust points (conditions or requirements) for health data sharing and use.

For the quantitative phase, we conducted 944 interviews by telephones using Computer Aided Telephone Interviewing (CATI) system and 3,068 interviews online using an opt-in panel. The field work for the survey was conducted by our subcontractor, Leger, and conducted from May 3 to July 9, 2023. The survey was offered in English and in French. The average length of the CATI interview was 20 minutes and the average length of the online interview was 13 minutes. The data was weighted to be reflective of the Canadian population using the most recent numbers from Statistics Canada.

To complement the survey, qualitative research was conducted to understand:

- Which specific uses and users fall within and outside of social license of health data collection, access, sharing and use; and
- The conditions required for social license and to build and/or maintain trust in a Learning Health System.

The field work was conducted from August 28 to September 6, 2023.

For the qualitative phase we conducted twelve online focus groups. Five groups were conducted with adults over the age of 18 with one in each of the following regions: Atlantic Canada (New Brunswick, Nova Scotia, Prince Edward Island, Newfoundland and Labrador), Ontario, Quebec, Prairies (Manitoba, Saskatchewan, Alberta), British Columbia/North (Yukon, Northwest Territories, Nunavut). Another five groups were pan-Canadian in nature and done with the following equity-deserving groups: visible minorities, Indigenous peoples, newcomers to Canada, those living with a physical disability, and members of the LGBTQ2IA+ community. Finally, the last two groups were done with informed patient advocates.

Participants were also provided with incentives in recognition of their time. Appendix B provides greater detail on how the groups were recruited, while Appendix G provides the discussion guide used to facilitate the focus groups and Appendices E and F provide the screeners used for recruiting the focus groups.

For the purposes of this report, it is important to note that qualitative research is a form of scientific, social policy, and public opinion research. Focus group research is not designed to help a group reach a consensus or to make decisions, but rather to elicit the full range of ideas, attitudes, experiences, and opinions of a selected sample of participants on a defined topic at a particular point in time. Because of the small numbers involved, the participants cannot be

expected to be thoroughly representative in a statistical sense of the larger population from which they are drawn, and findings cannot reliably be generalized beyond their number.

The key findings of this research are presented below.

Contextual impressions of health care in Canada

- The discussion groups began with a general question about the state of the health care system today. Participants fairly consistently indicated having great concerns, or rather fears, about access to services and delays in tests or treatments. Few voluntarily raised anything to do with health data.
- Universality and the fact that it is free (or key parts of the system are) are what most identify as the best things about our health care system.
- When asked whether the Canadian health care system needs to modernize, participants seemed to feel that there are certain things that need to modernize (see the Contextual impressions section in the Detailed findings), but other challenges such as sufficient funding and attraction and retention of health care professionals often seemed more pressing issues.
 - Many offered that once you get into being treated, the care seems quite modern (i.e., abilities, treatments, etc.).

Familiarity and comfort with sharing health data

- Survey respondents were asked how familiar they were with the term health data. Only one-in-ten (10%) say they are very familiar with the term, while another three-in-ten (30%) say they are somewhat familiar.
 - Focus group participants were often reluctant to declare themselves familiar with the term, but most assumed it meant personal health information sometimes offering one or more examples such as diagnosis, medications, or lab results.
- Echoing the self-assessed rates of familiarity with health data, when asked about how clear of an understanding they have of what is meant by health data, one-in-ten (9%) report a strong understanding whereas one third (33%) report a decent understanding. The number of those who say they are not at all familiar (25%) with the term is slightly higher than those who say they do not really know what is meant by health data (19%).
- When it comes to how prepared respondents felt to have discussions about health data, a plurality (39%) say they are somewhat prepared.
- When asked about their comfort with health data sharing, the number of respondents who say they are somewhat or very comfortable (27%) is less than those who say they are

somewhat or very uncomfortable (31%). It is also worth noting that a quarter (23%) of respondents say that their level of comfort depends on other variables – a finding explored extensively in the qualitative research and summarized in the bullets below.

- In the focus groups, comfort with sharing health data was conditional for all participants. One principle that was unanimous was that a patient's relevant health data must be available to the providers giving that patient care. The discussions among the patient advocates demonstrated a much more thorough knowledge of health data and how it is or is not shared, as well as much greater engagement and passion on the topic.
 - Beyond that, a variety of conditions were frequently raised pertaining to participants' comfort with sharing health data: that individuals conducting the tests need not see a patient's full history; that the information be de-identified; that there be clarity surrounding third party access or use; and that, for research, it would depend on who is doing it. It is worth highlighting that Indigenous participants were particularly sensitive to sharing their health information (de-identified or not), relating to larger issues with trust and confidence in the government.
- When asked about how important it is that health data is made available to health professionals and policymakers, a plurality of respondents felt that it was very important that this data be shared with scientists conducting health-related research (46%) and health care providers other than a family doctor (46%). About one third (32%) of respondents were less inclined to say that it was very important that those responsible for developing health systems and public health policies have access.

Understanding health data sharing and its current status in Canada

- Respondents were provided with a list of options and asked which they would consider health data. Although all potential categories were selected by at least one third of respondents, the most likely to be selected were: illnesses, conditions, allergies, or prescribed medications (51%); lab results (50%); the history of visits to medical facilities (48%); and basic metrics such as blood pressure, heart rate, and blood sugar (47%).
 - When offered a definition of health data provided by PHAC, just over half (54%) of respondents say that this is exactly what they think of when they hear the term health data, while a third (32%) note that it is more than what they thought.
- Shown the same list, most participants agreed that all were or probably were, examples of what might be considered health data. There were a few who did say they did not consider these examples (see Exhibit 10) to be health data and these participants tended to define health data as being strictly personal information about one's health.
- When it comes to the question of how well health data is currently being shared, almost no respondents (4%) say that it is currently being shared well, with one-in-five (18%) indicating they think it is shared somewhat well. Instead, a plurality of respondents say that it is being shared either somewhat or very poorly (39%).

- In the focus groups, perceptions of how well or poorly health data is currently being shared were diverse and dependent upon the type of information being considered as well as heavily coloured by personal experience.
 - Some immediately went to describing positive experiences where a family doctor, hospital, specialist and/or lab relayed information instantly to each other, or cited experiences with provincial/territorial health applications such as MyChart that enabled them to know more about and monitor their own health data relating to a specific condition or situation.
 - Others were more inclined to feel the way health data is shared is antiquated, inefficient, and puts too much onus on a patient who is often ill-equipped or ill-informed.
- Participants tended to feel the sharing of personal health data is one important aspect of the health system that needs modernization, even if that is not seen as the most pressing challenge to the system.

Perceived problems and benefits with health data sharing

- Respondents were presented with a series of potential scenarios (see Exhibit 14) and asked to rate how serious of a problem they think each is. The issues most likely to be qualified as a very serious problem are: the lack of authority clearly responsible for data oversight (42%), that health care providers do not always have access to all of a person's health information (42%), and that persons cannot easily access all of their own health data (40%).
- Through the focus groups it emerged that, fundamentally, participants indicated wanting whatever personal health data of theirs that is relevant to some health care provider's needs to be fully and instantly made available to the provider and they want that data to be protected and used responsibly.
 - The expectation was that all of this is generally the case, but data breaches and misuse were often cited as signs that there are challenges to be addressed or monitored.
- Respondents were given seven scenarios (see Exhibit 25) which highlighted potential benefits of health data sharing. In all scenarios tested, over three quarters of respondents feel that it would be at least a somewhat significant benefit, if not a very significant one. Of note, three scenarios saw over half of respondents say it would be a very significant benefit: ensuring people have a health record that follows them throughout their life and is accessible to any of their health care providers (63%), enabling health care providers to better coordinate what they are doing for a person (58%), and helping improve the quality and cost-effectiveness of care in hospitals and other health care settings (54%).

- When it comes to their data being used for purposes other than their own care, participants indicated wanting more control, more restriction, and more understanding of what is being used by whom. Most indicated that it is possible to satisfy these requests and consent to their de-identified health data being used in a variety of settings and for a variety of purposes.
- Respondents were additionally presented with six different statements (see Exhibit 33) pertaining to different aspects of health data sharing. All received majority agreement except the statement about confidence in existing safeguards to protect medical records, which only saw 45% saying they strongly or somewhat agreed.
- Participants in the focus groups were also asked about the same statement pertaining to confidence in existing safeguards and the reaction was mixed. Most would go so far as to say they either hoped or expected this was the case, but some were quite uncomfortable with declaring their confidence. A few were actually inclined to disagree and suggested they felt their health data was not consistently protected from such threats.
- The strained degree of confidence did not seem to mean that participants do not want personal health data shared, or investments made to modernize that sharing. Some said that there will always be a concern, with one citing online banking as an example where they would have the same concern but still want online banking to be done.

Improving health data sharing

- When provided with the Government of Canada's priorities for enabling a high-performing health data system (see Exhibit 40), at least seven-in-ten respondents either supported or strongly supported all three priorities tested with virtually none opposing them.
- While over half of respondents in all regions surveyed said they are either very or somewhat comfortable with their health data being shared if progress occurred in all the three aforementioned areas, between 9 and 15 percent of respondents noted that it depends – something explored in-depth in the qualitative component of the study and summarized in the bullets below.
- The reaction in the focus groups was almost unanimously positive as well, although there were some questions or qualifiers raised even by those in support of the priorities:
 - How patients would control their data was a question and/or a concern for some;
 - Who is meant by authorized users would matter to many; and,
 - That all users need to be forced to high standards for data security.
- Among the patient advocates, there was a more explicit concern about how health data may sometimes be misused even by those authorized to access the information. The most common concerns were about health care providers seeing information about frequency of visits, or specific conditions (particularly mental health) or substance use (with opioids specifically mentioned) and treating the patient in a less respectful, professional, or open-

minded manner as a result, possibly stigmatizing the patient. Some described it as a need to adjust behaviours and mindsets, if restricting the information is impractical for the best medical treatment or decisions.

- When asked about the importance of four conditions for providing consent to health data sharing, over 85% of all respondents said each condition was somewhat, if not very, important. The most important, with three quarters (75%) saying it was very important, was that consent must be voluntary.
- When asked about how important it is for respondents to be asked for consent in three hypothetical scenarios surrounding the usage of health data by scientists, policymakers, and managers in health systems, over three quarters of respondents say that it is at least somewhat, if not very, important that they are asked for consent in each case.

Target Audiences

- In addition to the general population, this study looked at the perspectives of informed patient advocates and a number of equity deserving groups (Indigenous, visible minorities, newcomers to Canada, people living with a disability, and 2SLGBTQ+ individuals). While the group-specific findings are summarized here, in the bulk of the report these findings are noted in the qualitative sections and/or in the other demographic differences below each table.
- Trends or unique findings noted among equity deserving groups that differed from the general population include:
 - Access to health care seemed to be particularly problematic for Indigenous persons, particularly those living on reserve. They spoke of a tiered system that lacks in service of or is racist/discriminatory towards Indigenous peoples. With respect to health data, views were divergent. While most were comfortable with sharing their data with their health care professionals, levels of comfort differed with respect to sharing more broadly. While some were comfortable sharing health data for public health and the greater good, others were much less comfortable, especially with sharing health data with the government. There was broad concern about security and safeguarding the information.
 - For those living with physical disabilities, access to and sharing health data, at a minimum, with themselves and their health care professionals, was seen as particularly important given their extensive use of the health care system. They felt it would help simplify information sharing (and take the onus off them to remember everything) as they navigate the system and interventions with different health care professionals, and for some in rural communities and/or across provinces. However, there was perhaps a stronger desire for regular consent and ensuring access is equitable to all; they argued that many do not have the necessary technology or technical competency to access health data digitally.
 - Conversations in the visible minority groups did not differ from the general population in any noteworthy way. While the term “discrimination” came up once, it was not in

the context of cultural or racial discrimination, but rather in the context of discrimination on the basis of health information.

- While newcomers to Canada shared many of the same views/sentiments generally, the main difference was in the sense that the health care system has not been updated. Newcomers seemed to be slightly more accepting of the introduction of newer approaches (i.e., mobile clinics and a basic fee for service). They also voiced their concern regarding the challenge with recognition of the credentials of health care professionals trained abroad as they argued this could help with the recruitment gap.
- For the most part, 2SLGBTQ2+ participants held views that were not different from those heard in other groups. However, there was one sentiment that a few raised that suggested a unique concern. A small number of participants expressed a fear of health data being used by policymakers or political decision-makers who had ideological views about 2SLGBTQ2+. As one put it, the fear was that someone would see this as a condition to be cured. It heightened their sensitivity to the purpose of data access, to de-identification and to the specific types of people who would have access to the data, but as with concerns raised in other groups, it was generally discussed within the context of describing a need for strict rules and protections, rather than opposition to health data being used at all.

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Signed:

Date: September 20, 2023



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