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

Prepared for the Public Health Agency of Canada

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Canada 

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 Earncliffe 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, Earncliffe 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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I hereby certify as a representative of Earncliffe Strategy Group that the final deliverables fully comply with the Government of Canada political neutrality requirements outlined in the Communications Policy of the Government of Canada and Procedures for Planning and Contracting Public Opinion Research. Specifically, the deliverables do not include information on electoral voting intentions, political party preferences, standings with the electorate or ratings of the performance of a political party or its leaders.

Signed:

Date: September 20, 2023



Stephanie Constable
Principal, Earncliffe

Introduction

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.

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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 promoting 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 was required to provide insights necessary to build and improve policies, processes, and practices to optimize health data sharing. The findings will provide a measure of knowledge related to data literacy, and awareness and attitudes regarding health data sharing, that can be said to inform the design/development of health data literacy programs going forward.

The overall objective of this study was to measure Canadians’ knowledge related to data literacy and attitudes regarding health data sharing that can inform the design/development of health data literacy programs, and inform the FPT action on digital health and health data.

Methodology

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.

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

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The breakdown of qualitative sessions by target audience, region and language is summarized in the table below:

Exhibit 1: Qualitative session breakdown.

Target Audience	Atlantic Canada (EN)	Quebec (FR)	Ontario (EN)	Prairies (EN)	British Columbia/North (EN)	Total
Canadians 18+	1	1	1	1	1	5
Informed Patient Advocates	2 Pan-Canadian groups					2
Equity Deserving Groups	5 Pan-Canadian groups; 1 of each target audience					5
Total						12

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. 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.

Detailed findings

The following report presents the analysis of both the quantitative and qualitative research. It is divided into five main sections:

- Contextual impressions of health care in Canada;
- Familiarity and comfort with sharing health data;
- Understanding health data sharing and its current status in Canada;
- Perceived problems and benefits with health data sharing; and,
- Improving health data sharing.

Within each section, the narrative of the results is presented based on the initial quantitative research with the insights of the follow-up qualitative research woven throughout. Details about the survey design, methodology, sampling approach, and weighting of the results may be found in the Quantitative Methodology Report in Appendix A. Appended data tables provide results of findings across a much broader range of demographics and attitudes. Details about the focus group design, methodology, and analysis may be found in the Qualitative Methodology Report in Appendix B. Except where specifically identified, the qualitative findings represent the combined results across the various audiences and for both

English and French. Quotations used throughout the report were selected to bring the analysis to life and provide unique verbatim commentary from participants across the various audiences.

Guidance for interpreting the data presented in the tables

For the purposes of this report, within the tables included in the body of the report, column labels have been provided to identify statistically significant results.

Letters that are depicted under percentages indicate results that are significantly different than those found in the specific comparison columns indicated by the letter in the Column Labels. Uppercase letters indicate that the difference is significant at the 0.001 level, whereas lowercase letters indicate a difference at the 0.05 level.

Unless otherwise noted, differences highlighted are statistically significant at the 95% confidence level. The statistical test used to determine the significance of the results was the Z-test. Due to rounding, results may not add to 100%.

Finally, the abbreviation “AC” is used to represent Atlantic Canada in the tables below and represents an aggregate of respondents from New Brunswick (n=98), Nova Scotia (n=114), Prince Edward Island (n=16), and Newfoundland and Labrador (n=55).

Contextual impressions of health care in Canada

In the quantitative component of this study respondents were immediately streamed into questions on health data following a number of screening questions. For the qualitative component, however, participants began their conversations with a larger contextualizing conversation about health care in Canada.

Qualitative Insights

To start off the discussion groups, they began with a general question about the state of the health care system in Canada today. Across all groups, participants were fairly consistent in expressing concerns about the current state of the system. While the actual care received rarely tended to be a source of concern or criticism, most participants wanted to raise their concerns and fears about access to services and delays in tests or treatments. Access to services was certainly more acutely felt among those living in more rural and northern communities where access to services requires travel.

“Where you live determines your health care experience and care.” – Patient advocate

“I’m fond of our health care system. I’ve been disabled all my life and I give them a lot of credit for keeping me healthy. The hang ups are long wait times and because I am rural, it can be challenging to access some services without traveling some distance.” – Person living with a physical disability

When asked about what the best thing about Canada’s health care system was – and echoing results from other recent research projects – the answers were about the system’s

universality and the fact that it is free (or that key parts of the system are). That was interpreted as meaning that patients do not have the stress of having to pay an unaffordable bill or being denied treatment due to cost.

When forced to choose between describing the system as modern or outdated, participants were often torn and often sought to qualify their answer no matter which option they chose. Some noted feeling it was an impossible choice because there are some elements of the health care system that they see as being quite modern (e.g., treatments, abilities) and other things they see as being outdated (e.g., a system that has not kept up with demands).

“It’s not modern, but I’m not sure I’d say it’s outdated.” – Visible minority

“It’s struggling to meet demand, but is that really outdated?” – Adult, Ontario

“Some things are modern, but some things are definitely outdated. Guidelines have changed, for example, but my family doctor wants to stick with their own approach.” – Visible minority

“It’s outdated. It may have been one of the best before but since mass migration, we need to start updating it. Things like mobile clinics or charging a basic fee, say \$30 to \$40, but at least we’d be given the attention we need.” – Newcomer to Canada

At this point in the discussion, a few did organically raise health data. The use of health data was both mentioned as evidence that the system was outdated (e.g., paper copies) or that it was modern (e.g., the use of online tools or apps like My Chart).

“I’d say it’s outdated. Pharmacists diagnosing some things is great, but there is so much more that technology could enable.” – Adult, Ontario

“I don’t feel it is outdated. My health chart online is an example of modernizing.” – Adult, Prairies

“Steps have been taken like an app or a number to contact a doctor, but it feels like resources or money should be used.” – Adult, Prairies

“It’s fragmented and (information is) siloed. We don’t create the conditions for success.” – Patient advocate

When asked whether the Canadian health care system needs to modernize, the tendency was to feel that there are certain things that need to modernize. This was often situated within a larger context, however, which brought to the fore challenges such as sufficient funding and attraction and retention of health care professionals. In the face of these other issues, many participants were resistant to an exclusive focus on modernization. Indeed, there were many who offered that once you get into being treated, the way care is provided seems quite modern. As a result, it appears that the use of the term modernization without tying it specifically to health data did not tend to resonate as powerfully as it did when the discussion later turned to health data.

When it comes to what participants think would need to change for the system to be world class, responses were predominantly about enabling access and avoiding delays. Some also offered that certain types of health care were not being given sufficient priority or resources, with resources surrounding mental health being the most common example mentioned.

“It was strained before the pandemic and it only got much worse. My area made the news about how bad the (ER delays) were. (Because of access examples like that) I have a hard time seeing the positive right now.” Adult, Prairies

“I’m grateful that it is public, but it is very symptoms-based, rather than investigating root causes.” – Visible minority

“It’s crazy that we don’t have an EMR system provincially, let alone federally.” – Patient advocate

“Compensate doctors better. Make it work smoother, less frustratingly.” – Adult, Ontario

“The resources (for mental health care) do not live up to what they say is available.” – LGBTQ2IA

“It’s difficult to have quality but since COVID, it’s worse. It’s hard to get people. People are underqualified. It’s scary.” – Adult, Quebec

Familiarity and comfort with sharing health data

To begin the survey, respondents were asked how familiar they were with the term health data without any contextual information being provided. Only one-in-ten (10%) respondents say they are very familiar with the term, while another three-in-ten (30%) say they are somewhat familiar. At two-in-five (42%), those in Quebec were the most likely to say that they were only a little familiar with health data – higher than any other region.

Exhibit 2: Q5. How familiar are you with the term “health data”?

Q4. In which province or territory do you live?

Base: All respondents (n=4012)

Column % Column Comparisons	CAN (n=4012)	AC (n=283)	QC (n=931)	ON (n=1554)	MA (n=141)	SK (n=125)	AB (n=437)	BC (n=533)
Very familiar	10%	10%	7%	12%	12%	14%	9%	11%
	-	-	-	c	-	-	-	-
Somewhat familiar	30%	30%	23%	33%	30%	32%	33%	30%
	-	-	-	C	-	-	c	-
A little familiar	32%	28%	42%	29%	23%	34%	31%	30%
	-	-	B D E g H	-	-	-	-	-
Not at all familiar	25%	27%	25%	24%	33%	17%	24%	26%
DK/NR	3%	5%	2%	3%	2%	3%	3%	3%
Column Names	A	B	C	D	E	F	G	H

Other demographic differences

- Compared to their counterparts, respondents who identify as male (43%), speak English at home (44%), live in a medium or large urban community (43%), have a family doctor (42%), have a chronic health condition (44%), interact with their health care provider 6 to 11 times annually (47%) or more than 11 times (43%), or are themselves a care provider (44%) are more likely to say they are familiar with what is meant by “health data”.
- There is a correlation between familiarity and education and income, whereby familiarity increases as the level of education and income increases.
- Those who have an understanding of health data (73%) or say they are comfortable with health data being shared (52%) are also more likely than their counterparts to say they are familiar with health data.

Respondents were then asked how clear of an understanding they have of what is meant by health data, again without having any definitions or preamble provided. Echoing the self-assessed rates of familiarity with health data, one-in-ten (9%) report a strong understanding and one third (33%) report a decent understanding. That being said, the number of those who say they are not at all familiar (25%) is slightly higher than those who say they do not really know what is meant by health data (19%).

Exhibit 3: Q6. When you hear or read reference to “health data” without any other specifics, how clear an understanding do you have about what is meant by “health data”?

Q4. In which province or territory do you live?

Base: All respondents (n=4012).

Column %	CAN (n=4012)	AC (n=283)	QC (n=931)	ON (n=1554)	MA (n=141)	SK (n=125)	AB (n=437)	BC (n=533)
A strong understanding	9%	8%	9%	9%	10%	5%	8%	8%
A decent understanding	33%	29%	33%	34%	33%	46%	30%	32%
	-	-	-	-	-	b g	-	-
A vague understanding	38%	41%	40%	36%	29%	33%	41%	35%
I don't really know what is meant	19%	19%	16%	19%	24%	15%	19%	22%
DK/NR	2%	3%	1%	2%	3%	1%	2%	3%
Column Names	A	B	C	D	E	F	G	H

Other demographic differences

- Respondents who identify as male (44%) or are themselves a care provider (46%) are more likely than their counterparts to have a strong or decent understanding of what is meant by “health data”.
- Conversely, those who speak a language other than English or French at home (34%) are less likely to say that they have a strong or decent understanding of health data.
- As with familiarity, there is a correlation between understanding and education and income, as understanding increases alongside education level and income.
- Those who say they are comfortable with health data being shared (60%) are the most likely to say they have a strong or decent understanding health data.

Qualitative Insights

In the focus groups it was rare that participants organically raised anything to do with health data. Among the few who did, however, it was a mix of those who were appreciative when they witnessed a well-functioning data sharing system or those who shared frustration with having to deal with what they perceived to antiquated or disconnected health records systems.

Participants were often reluctant to declare themselves familiar with the term “health data,” with most assuming it meant personal health information. Diagnoses, medications, or lab results, were all offered by participants as potential examples of what they thought health data to be. Although a few did volunteer that they believe it relates to public health information such as vaccine uptake or the number of COVID cases, the public health or research aspect of the definition were typically not what participants were thinking when hearing the term.

In terms of whether or not respondents felt prepared to have discussions about health data, its generation, collection, sharing, usage, and reporting, a plurality (39%) say they are somewhat

prepared. Echoing findings noted above, respondents in Quebec were the most likely to say that they were not very prepared at two-in-five (40%).

Exhibit 4: Q7. How prepared do you feel you are to have conversations about how health data is generated, collected, shared, used, and reported?

Q4. In which province or territory do you live?

Base: All respondents (n=4012).

Column %	CAN (n=4012)	AC (n=283)	QC (n=931)	ON (n=1554)	MA (n=141)	SK (n=125)	AB (n=437)	BC (n=533)
Quite prepared	12%	9%	7%	15%	18%	13%	12%	14%
	-	-	-	C	c	-	c	C
Somewhat prepared	39%	44%	36%	41%	37%	44%	39%	37%
	29%	27%	40%	25%	23%	27%	29%	25%
Not very prepared	-	-	b D e g H	-	-	-	-	-
Not at all prepared	16%	16%	13%	17%	17%	11%	15%	20%
	-	-	-	-	-	-	-	c
DK/NR	4%	4%	4%	3%	6%	4%	5%	4%
Column Names	A	B	C	D	E	F	G	H

Other demographic differences

- Compared to their counterparts, respondents who identify as male (55%), have a household income of \$100 thousand or more (59%), live in a medium or large urban community (53%), have a family doctor (53%), have a chronic health condition (56%), interact with their health care provider 6 to 11 times annually (59%) or more than 11 times (58%), or are themselves a care provider (57%) are more likely to say they are quite or somewhat prepared to have conversations about how health data is generated, collected, shared, used, and reported.
- There is a correlation between this sense of preparedness and education, whereby self-reported preparedness increases as the level of education increases.
- Those who have an understanding of health data (81%) or say they are comfortable with health data being shared (73%) are also more likely than their counterparts to say they are familiar with health data.

After an introductory series of questions which got to basic understandings of health data, respondents were then asked a number of questions about their comfort with health data sharing. Overall, the number who say they are somewhat or very comfortable (27%) is less than those who say they are somewhat or very uncomfortable (31%).

This trend holds true across all regions except Quebec, where there are slightly more who say they are somewhat or very comfortable (31%) than somewhat or very uncomfortable (27%). At just over a quarter (27%) of respondents, those in Quebec are also the most likely to say they are neither uncomfortable nor comfortable.

It is also worth noting that a quarter (23%) of respondents say that their level of comfort depends on other variables, something discussed in the next question as well as addressed extensively in the qualitative research.

Exhibit 5: Q8. Generally speaking, how comfortable would you be with your health data being shared, or would you say your level of comfort depends upon something?

Q4. In which province or territory do you live?

Base: All respondents (n=4012).

Column %	CAN (n=4012)	AC (n=283)	QC (n=931)	ON (n=1554)	MA (n=141)	SK (n=125)	AB (n=437)	BC (n=533)
Very comfortable	9%	8%	12%	9%	10%	10%	5%	8%
	-	-	g	-	-	-	-	-
Somewhat comfortable	18%	17%	19%	17%	17%	16%	19%	16%
Neither uncomfortable nor comfortable	18%	12%	27%	16%	17%	13%	16%	18%
	-		B D f G h	-	-	-	-	-
Somewhat uncomfortable	17%	18%	17%	18%	15%	14%	16%	14%
Very uncomfortable	14%	17%	10%	14%	16%	20%	14%	15%
	-	c	-	c	-	c	-	c
It depends	23%	26%	13%	25%	24%	26%	28%	26%
	-	C	-	C	c	c	C	C
DK/NR	2%	3%	2%	2%	2%	1%	2%	3%
Column Names	A	B	C	D	E	F	G	H

Other demographic differences

- Compared to their counterparts, respondents who identify as male (31%), speak French at home (31%), have a family doctor (28%), or are themselves a care provider (30%) are more likely to say they are comfortable with their health data being shared.
- Those who have an understanding of health data (38%) are also more likely than their counterparts to say they are comfortable with their health data being shared.

Qualitative Insights

Participants expressed that their comfort with sharing health data was definitely conditional. One principle that was unanimous, however, was that a patient’s relevant health data must be available to those providing care for that patient.

The discussions with patient advocates demonstrated a much more thorough knowledge of not only what health data is, but also how it is or is not currently shared. Patient advocates were also much more passionate about the topic than the general population groups. Below is a summary of the primary conditions raised by participants on whether or not they would be comfortable with sharing health data:

- Although it was clearly preferred that lab results be shared with care providers, one common caveat was that individuals conducting the tests need not see a patient’s full history. In one way or another, the notion of restricting what patient information is shared to exclusively being only the minimal amount of information that is essential for the task at hand was frequently mentioned. This was a particular point of concern for some patient advocates who said that bias and misuse of information has sometimes caused patients harm and reducing the amount of information may help reduce that threat.

- While some were completely comfortable with their data being used for public health and health system management purposes, nearly all would be comfortable if the information was de-identified.
- One caveat that frequently arose was the concern over third party access or use, particularly with personally identifiable information. Examples included private sector researchers such as pharmaceutical companies, insurance companies, and politically motivated organizations seeking to use health data to justify an agenda with which some patients would not agree.
- Most were accepting or even enthusiastic about having their (de-identified) health data used for medical research, particularly if it helped people in similar circumstances (health conditions or socio-economically), but some were quite hesitant and indicated it would depend upon who was doing the research, what the end objective was and what kind of information they needed.
- Some Indigenous peoples and some of the LGBTQ2IA+ participants were particularly sensitive to sharing their health information (de-identified or not) which had more to do with trust and confidence in the federal government than with a discomfort with the notion or public benefit that would be derived from a Pan-Canadian system. One in the LGBTQ2IA+ group offered a fear that a government that did not support their community would “try to find a cure” for some sexual orientations.

“I am fine with being a statistic, but not an identifiable person.” – Adults, Prairies

“I want (my health data) to be shared with purpose. They need the information they need at that moment. They don't need to know I broke my ankle one time.” – Adults, Ontario

“I always thought that when you swiped your health card, all your info is there. I want my physio to provide a report to my doctor. It's tedious to keep repeating.” – Adult, Ontario

“If they are already (sharing my health data with researchers or public health officials), I've got discomfort with that. I didn't give my permission. It's a really sensitive, personal thing and you should be asked. I'd want the right to have it remain private.” – Adult, Ontario

“De-identifying is vital and it should go to just the people who need to know.” – Visible minority

“If it's anonymous, I don't care. It's what we need to make improvements.” – Visible minority

“I'm comfortable and in a position because I have lived in different communities to know that it is easier when I don't have to repeat myself every time. When I need it, it's important they have a way to get something for me in the system.” – Indigenous person

“The Government of Canada caught my eye. There is absolutely no reason why the Government should have my information. On a case-by-case basis, I would be comfortable providing consent and it will depend on the purpose, but my health data is not a free for all.” – Indigenous person

When asked about how important it is that health data is made available to a number of different options, a plurality of survey 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 government officials responsible for developing health systems and public health policies have access to this data. Of note, very few respondents say that it is not at all important that any of the tested groups have this data made available to them.

Exhibit 6: Q9-11. Based on what you know or feel about health data, how important is it that health data is available to each of the following?

Base: All respondents (n=4012).

Row %	Very important	Somewhat important	Not that important	Not at all important	DK/NR
Scientists conducting health-related research.	46%	37%	6%	5%	5%
	B C D E	C D E	d	-	-
Government officials responsible for developing health system and public health policies and programs.	32%	40%	12%	9%	6%
	C D E	A C D E	D E	E	-
Health care providers other than a family doctor or those in hospital settings, such as a pharmacist or dentist.	46%	40%	7%	3%	4%
	B C D E	C D E	D E	-	d
Column Names	A	B	C	D	E

Attitudes towards sharing health data with scientists conducting health-related research setting remains relatively consistent across regions.

Exhibit 7: Q9. Based on what you know or feel about health data, how important is it that health data is available to each of the following? “Scientists conducting health-related research.”

Q4. In which province or territory do you live?

Base: All respondents (n=4012).

Column %	CAN (n=4012)	AC (n=283)	QC (n=931)	ON (n=1554)	MA (n=141)	SK (n=125)	AB (n=437)	BC (n=533)
Very important	46%	44%	46%	47%	48%	44%	49%	44%
Somewhat important	37%	37%	39%	37%	32%	31%	36%	39%
Not that important	6%	6%	8%	6%	5%	10%	5%	5%
Not at all important	5%	5%	4%	4%	8%	10%	5%	5%
DK/NR	5%	9%	3%	6%	7%	5%	5%	8%
	-	c	-	-	-	-	-	c
Column Names	A	B	C	D	E	F	G	H

Other demographic differences

- Respondents who are 65 year or older (87%) or 18 to 34 years (86%), have a post-graduate degree (89%), live in a medium or large urban community (85%), do not identify as Indigenous (75%), are not born in Canada (88%), do not have a disability (85%), have a family doctor (85%) are more likely than their counterparts to believe it is important for data to be shared with scientists conducting health-related research.

- Conversely, those who have a household income of less than \$60,000 (82%) or interact with their health care provider fewer than three times per year (82%) are less likely to say it is important for data to be shared with scientists conducting health-related research.
- Those who have an understanding of health data (89%) or say they are comfortable with health data being shared (94%) are also more likely than their counterparts to say it is important for data to be shared with scientists conducting health-related research.

When it comes to sharing health data with government officials responsible for developing health system and public health policies and programs, at just over one third (36%), respondents in Ontario and B.C. are the most likely to say that it is very important while those in Saskatchewan (26%) and Quebec (24%) are the least likely to do so.

Exhibit 8: Q10. Based on what you know or feel about health data, how important is it that health data is available to each of the following?

“Government officials responsible for developing health system and public health policies and programs.”

Q4. In which province or territory do you live?

Base: All respondents (n=4012).

Column %	CAN (n=4012)	AC (n=283)	QC (n=931)	ON (n=1554)	MA (n=141)	SK (n=125)	AB (n=437)	BC (n=533)
Very important	32%	31%	24%	36%	32%	26%	31%	36%
	-	-	-	C	-	-	-	C
Somewhat important	40%	37%	42%	40%	40%	37%	39%	39%
Not that important	12%	15%	18%	9%	7%	16%	15%	8%
	-	d h	D e H	-	-	-	d h	-
Not at all important	9%	9%	10%	8%	10%	16%	9%	7%
DK/NR	6%	8%	5%	6%	11%	6%	5%	9%
Column Names	A	B	C	D	E	F	G	H

Other demographic differences

- Respondents who are 65 year or older (76%), have a post-graduate degree (82%), live in a medium or large urban community (74%), are not born in Canada (83%), are racially visible (81%), have a family doctor (74%), or are they themselves a care provider (75%) are more likely than their counterparts to believe it is important for data to be shared with government officials responsible for developing public health policies.
- Conversely, those who speak French at home (66%), have a high school education or less (68%), or interact with their health care provide fewer than three times per year (71%) are less likely to say it is important for data to be shared with government officials.
- Those who have an understanding of health data (77%) or say they are comfortable with health data being shared (85%) are also more likely than their counterparts to say it is important for data to be shared with government officials.

Attitudes towards sharing health data with health care providers other than a family doctor or those in a hospital setting remains relatively consistent across regions.

Exhibit 9: Q11. Based on what you know or feel about health data, how important is it that health data is available to each of the following?

“Health care providers other than a family doctor or those in hospital settings, such as pharmacist or dentist.”

Q4. In which province or territory do you live?

Base: All respondents (n=4012).

Column %	CAN (n=4012)	AC (n=283)	QC (n=931)	ON (n=1554)	MA (n=141)	SK (n=125)	AB (n=437)	BC (n=533)
Very important	46%	46%	45%	46%	43%	48%	53%	44%
Somewhat important	40%	41%	41%	40%	39%	37%	39%	40%
Not that important	7%	7%	9%	7%	5%	7%	4%	7%
	-	-	g	-	-	-	-	-
Not at all important	3%	2%	3%	3%	6%	6%	1%	3%
DK/NR	4%	5%	2%	4%	7%	3%	3%	6%
	-	-	-	c	c	-	-	c
Column Names	A	B	C	D	E	F	G	H

Other demographic differences

- Respondents who live in a medium or large urban community (88%), have a family doctor (88%), have a chronic health condition (88%), or are they themselves a care provider (89%) are more likely than their counterparts to believe it is important for data to be shared with other health care providers, such as pharmacists or dentists.
- Conversely, those who interact with their health care provide fewer than three times per year (85%) are less likely to say it is important for data to be shared with other health care providers, such as pharmacists or dentists.
- Those who have an understanding of health data (89%) or say they are comfortable with health data being shared (95%) are also more likely than their counterparts to say it is important for data to be shared with other health care providers, such as pharmacists or dentists.

Understanding health data sharing and its current status in Canada

Prior to providing a definition, respondents were asked which of the following, if any, 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%). Of note, one third (32%) of respondents selected all of the above while virtually none chose none of the above.

Exhibit 10: Q12. Which of the following, if any, do you think are considered health data?

Q4. In which province or territory do you live?

Base: All respondents (n=4012).

Column %	CAN (n=4012)	AC (n=283)	QC (n=931)	ON (n=1554)	MA (n=141)	SK (n=125)	AB (n=437)	BC (n=533)
Illnesses, conditions, allergies or prescribed medications a person has or has had	51%	51%	57%	49%	41%	54%	53%	47%
	-	-	d e h	-	-	-	-	-
Lab results for any sort of diagnostic tests done on a person such as blood tests or X-rays.	50%	52%	55%	48%	42%	52%	54%	46%
	-	-	d e h	-	-	-	-	-
History of visits to hospitals, clinics or other types of health services such as surgeries	48%	48%	48%	47%	38%	52%	53%	45%
Basic metrics such as blood pressure, heart rate, blood sugar	47%	48%	48%	46%	37%	52%	49%	44%
Vaccination rates for different communities or groups	41%	41%	46%	40%	32%	46%	40%	38%
Health care providers that have seen the person	37%	37%	42%	35%	25%	40%	37%	36%
	-	-	d e	-	-	-	-	-
Wait times for surgeries across different provinces and territories	33%	36%	39%	31%	25%	36%	33%	29%
	-	-	d e h	-	-	-	-	-
All of the above	32%	33%	24%	35%	39%	30%	34%	36%
	-	c	-	C	c	-	c	C
None of the above	1%	0%	1%	2%	3%	0%	0%	1%
	-	-	-	g	b g	-	-	-
DK/NR	4%	5%	3%	4%	6%	6%	2%	5%
Column Names	A	B	C	D	E	F	G	H

Other demographic differences

- Respondents who have a post-graduate degree, do not identify as 2SLGBTQ+, have a family doctor, have an understanding of health data, or are comfortable with data being shared are more likely than their counterparts to believe all or most of the possible data sources are considered health data.

Qualitative Insights

Participants were shown the same list of different types of health information contained in the survey question above and asked whether they consider any or all of them to be health data.

The first three – illnesses, conditions, allergies, or prescribed medications; lab results; and basic metrics such as blood pressure – were basically unanimously accepted as fitting into what was assumed to be health data.

For the most part, participants agreed that the other examples were or probably were, examples of what might be considered health data as well. There were a few who did say they did not consider these to be health data and these participants tended to define health data as being strictly personal information about one’s health.

Following this, respondents were then offered the following definition of health data:

“Health data is any type of information about a person that is useful for diagnosing, monitoring, or treating a person. Health data also includes information about public health events, how our health systems are working and information about communities.”

In response, just over half (54%) 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.

Exhibit 11: Q13. How does this definition of health data differ from what you tend to think of when you hear the term health data?

Q4. In which province or territory do you live?

Base: All respondents (n=4012).

Column %	CAN (n=4012)	AC (n=283)	QC (n=931)	ON (n=1554)	MA (n=141)	SK (n=125)	AB (n=437)	BC (n=533)
There is less to health data than what I thought	7%	8%	9%	7%	7%	8%	7%	6%
This is exactly what I think of when I hear the term health data	54%	52%	47%	56%	59%	50%	58%	58%
	-	-	-	c	-	-	c	c
There is more to health data than what I thought	32%	32%	39%	31%	23%	38%	27%	27%
	-	-	d e g h	-	-	-	-	-
DK/NR	7%	8%	5%	7%	11%	5%	7%	10%
	-	-	-	-	-	-	-	c
Column Names	A	B	C	D	E	F	G	H

There are no important demographic differences.

Among the third (32%) of respondents who answered that there is more to health data than they thought, three-in-five (61%) say that the definition offered was a little more than they thought, while just over a third (36%) say it is a lot more.

Exhibit 12: Q14. Is that a little more or a lot more?

Q4. In which province or territory do you live?

Base: Those who answered that there is more to health data than they thought at Q13 (n=955).

Column %	CAN (n=959)	AC (n=62)	QC (n=277)	ON (n=359)	MA (n=27)	SK (n=29)	AB (n=91)	BC (n=111)
A little more	61%	55%	64%	58%	55%	71%	65%	62%
A lot more	36%	40%	36%	37%	45%	25%	33%	34%
DK/NR	3%	5%	1%	5%	0%	4%	2%	4%
Column Names	A	B	C	D	E	F	G	H

There are no important demographic differences.

Very few respondents (4%) say that health data 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%).

Exhibit 13: Q15. To the best of your knowledge, how well or poorly do you think this sort of health data is currently being shared between providers and between provinces and territories?

Q4. In which province or territory do you live?

Base: All respondents (n=4012).

Column %	CAN (n=4012)	AC (n=283)	QC (n=931)	ON (n=1554)	MA (n=141)	SK (n=125)	AB (n=437)	BC (n=533)
Very well	4%	4%	3%	4%	5%	5%	3%	3%
Somewhat well	18%	14%	20%	18%	18%	17%	20%	15%
Neither poorly nor well	20%	21%	21%	20%	16%	19%	20%	19%
Somewhat poorly	27%	29%	30%	27%	27%	33%	24%	24%
Very poorly	12%	10%	10%	13%	8%	10%	11%	14%
DK/NR	19%	22%	14%	19%	26%	16%	21%	25%
	-	c	-	c	c	-	c	C d
Column Names	A	B	C	D	E	F	G	H

Other demographic differences

- Though still the minority, compared to their counterparts, respondents who identify as male (25%), are not born in Canada (27%), are racially visible (25%), are they themselves care providers (24%), have an understanding of health data (35%), or are comfortable with data being shared (35%) are more likely to believe that health data is currently being shared well between providers and between provinces and territories.

Qualitative Insights

The level of comfort with sharing health data was definitely conditional for all participants and one principle that was unanimous was that a patient's relevant health data must be available to the providers giving that patient care.

Perceptions of how well or poorly health data is currently being shared were diverse, complicated, 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 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. In these cases, these examples were cited as evidence of how good it is when health data is shared optimally, even as many recognized there may only be pockets where this is occurring.

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. Some talked about the continued archaic use of paper files and faxes, or the inability for a patient to have access to all their information, or the dangers of failing to remember some pertinent information or to store information accurately and in a way that is easily accessible by another health provider – particularly in some other region or province. Overall, 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.

“How information is passed is archaic. They still use paper!” – LGBTQ2IA+

“In terms of what data is shared, it should only be what is relevant to what that organization needs to know to help me.” – Patient advocate

“I am comfortable using it for any purpose as long as it's anonymous. I don't know why they would need to know names. In the end, it's for the good of everyone. When your name gets out, there could be repercussions especially visits to hospital, mental health issues, possibility of not getting the job you want.” – Adult, Atlantic Canada

“In some places, I have to explain things over and over, but in other places, they know everything and I love that.” – LGBTQ2IA+

“Some share well. Some share poorly. Out of province or moving from one province to another is a big problem. I moved from Manitoba to Alberta and my OB didn't share info and my family doctor from Manitoba didn't provide vaccine information and I didn't know in Alberta, so I got more (vaccine doses) than I needed.” – Adult, Prairies

Perceived problems and benefits with health data sharing

When presented with a series of potential scenarios and asked to rate how serious of a problem they think it is, the issues most likely to be qualified as a very serious problem by respondents 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%).

It is worth noting that, across all potential issues tested (62-74%), at least three-in-five respondents ranked each as at least a somewhat serious problem if not a very serious problem. At the same time, very few respondents rate any of the potential issues tested as not a problem at all (4-7%).

Exhibit 14: Q15-25. For each of the following, how significant a problem do you feel this is in Canada today, if at all?

Base: (n=from 1966 to 2079).

Row %	A very serious problem	A somewhat serious problem	A problem, but not a serious one	Not a problem at all	DK/NR
There is no authority clearly responsible for data oversight, protection and use in Canada’s health sector. (n=2013)	42%	32%	9%	4%	12%
	B C D E	C D E	D	-	c D
Health care providers do not always have access to all of a person’s health information. (n=2056)	42%	35%	11%	4%	7%
	b C D E	C D E	D E	-	D
Persons cannot easily access all of their own health data. (n=1978)	40%	35%	16%	5%	6%
	b C D E	C D E	D E	-	-
Health data is stored in different databases that are often not connected with each other, even if that data is related to the same person. (n=2079)	36%	38%	11%	4%	10%
	C D E	C D E	D	-	D
There is no agreement for when and how data is to be shared between health care professionals, across health settings or across jurisdictions. (n=2037)	36%	38%	12%	4%	10%
	C D E	C D E	D	-	D
Data about a person are not easily shared between care providers or health care facilities. (n=1966)	33%	38%	14%	5%	10%
	C D E	acde	D E	-	D
Public health officials can’t easily access data they need to provide timely and informed recommendations, such as during public health emergencies. (n=2051)	33%	36%	14%	7%	11%
	C D E	C D E	D e	-	D
Researchers can’t easily access the health data they need to research new health treatments and solutions. (n=2031)	29%	37%	14%	6%	14%
	C D E	A C D E	D	-	D
Communities do not have a complete picture of the health of their citizens	27%	39%	18%	6%	11%
	C D E	A C D E	D E	-	D

or increasing health inequities. (n=1974)					
Data needed by health policy-makers in government are not easily shared between different levels of government. (n=2037)	24%	38%	17%	7%	14%
	C D E	A C D E	D e	-	D

Other demographic differences

- Respondents who identify as female are more likely than those who identify as male to believe it is a serious problem that health care providers do not always have access to all of a person’s health information (80% versus 75%), public health officials can’t easily access data they need to provide timely and informed recommendations (71% versus 66%), and communities do not have a complete picture of the health of their citizens or increasing health inequities (70% versus 62%).
- At 76%, those who speak French at home are the most likely to believe it is a serious problem that data about a person are not easily shared between care providers or health care facilities.
- Those who have a post-graduate degree are more likely than their counterparts to think that health care providers do not always have access to all of a person’s health information (82%), persons cannot easily access all of their own health data (82%), and communities do not have a complete picture of the health of their citizens or increasing health inequities (73%) are serious problems.
- Fewer respondents who have a household income of less than \$60,000, interact with their health care provider five times a year or less, or feel uncomfortable with data being shared believe that most potential problems listed are serious.
- Conversely, respondents who have a family doctor, have a chronic health condition, or who have an understanding of health data are more likely to believe most of the potential problems listed are serious.

Very few respondents say that having health data stored in different databases is not a problem at all – the one exception being those in Saskatchewan, where 14% say so.

Exhibit 15: Q16. For each of the following, how significant a problem do you feel this is in Canada today, if at all?

“Health data is stored in different databases that are often not connected with each other, even if that data is related to the same person.”

Q4. In which province or territory do you live?

Base: (n=2079).

Column %	CAN (n=2079)	AC (n=142)	QC (n=474)	ON (n=799)	MA (n=77)	SK (n=76)	AB (n=245)	BC (n=262)
Not a problem at all	4%	4%	5%	3%	4%	14%	6%	3%
	-	-	-	-	-	c D h	-	-
A problem, but not a serious one	11%	9%	12%	11%	16%	18%	10%	11%
A somewhat serious problem	38%	36%	42%	37%	41%	35%	37%	39%
A very serious problem	36%	37%	35%	38%	22%	27%	34%	39%
DK/NR	10%	14%	6%	11%	17%	6%	12%	9%
Column Names	A	B	C	D	E	F	G	H

A majority of respondents across all regions say that it is at least a somewhat serious problem, if not a very serious problem, that data about a person are not easily shared between care providers or health care providers.

Exhibit 16: Q17. For each of the following, how significant a problem do you feel this is in Canada today, if at all?

“Data about a person are not easily shared between care providers or health care facilities.”

Q4. In which province or territory do you live?

Base: (n=1966).

Column %	CAN (n=1966)	AC (n=135)	QC (n=437)	ON (n=790)	MA (n=64)	SK (n=65)	AB (n=218)	BC (n=250)
Not a problem at all	5%	9%	3%	5%	9%	11%	5%	5%
A problem, but not a serious one	14%	12%	15%	14%	14%	20%	12%	15%
A somewhat serious problem	38%	31%	40%	38%	40%	28%	42%	33%
A very serious problem	33%	32%	35%	33%	19%	27%	31%	36%
DK/NR	10%	16%	6%	10%	17%	13%	10%	12%
	-	c	-	-	c	-	-	-
Column Names	A	B	C	D	E	F	G	H

Over half of respondents in all regions except Saskatchewan (47%) think that the inability of policy-makers in government to access health data is at least a somewhat serious problem, if not a very serious one.

Exhibit 17: Q18. For each of the following, how significant a problem do you feel this is in Canada today, if at all?

“Data needed by health policy-makers in government are not easily shared between different levels of government.”

Q4. In which province or territory do you live?

Base: (n=2037).

Column %	CAN (n=2037)	AC (n=141)	QC (n=499)	ON (n=757)	MA (n=75)	SK (n=77)	AB (n=209)	BC (n=275)
Not a problem at all	7%	7%	7%	6%	12%	7%	3%	8%
A problem, but not a serious one	17%	11%	21%	16%	11%	26%	21%	14%
A somewhat serious problem	38%	44%	40%	37%	34%	29%	36%	37%
A very serious problem	24%	22%	21%	28%	20%	18%	25%	23%
DK/NR	14%	16%	11%	14%	22%	20%	14%	17%
Column Names	A	B	C	D	E	F	G	H

When it comes to the question of individuals being able to access their own personal health data, almost half of respondents in Manitoba (48%) and Ontario (44%) say it is a very serious problem, compared with only 29% in Alberta who say the same.

**Exhibit 18: Q19. For each of the following, how significant a problem do you feel this is in Canada today, if at all?
“Persons cannot easily access all of their own health data.”**

Q4. In which province or territory do you live?

Base: (n=1978).

Column %	CAN (n=1978)	AC (n=150)	QC (n=466)	ON (n=751)	MA (n=62)	SK (n=64)	AB (n=219)	BC (n=262)
Not a problem at all	5%	5%	4%	5%	0%	6%	8%	5%
A problem, but not a serious one	16%	19%	19%	14%	10%	14%	16%	15%
A somewhat serious problem	35%	32%	36%	32%	28%	31%	42%	36%
A very serious problem	40%	37%	38%	44%	48%	41%	29%	38%
	-	-	-	g	-	-	-	-
DK/NR	6%	7%	3%	6%	14%	9%	5%	6%
	-	-	-	-	c	-	-	-
Column Names	A	B	C	D	E	F	G	H

Over seven-in-ten of Canadians in all regions feel that health care providers not always having access to a person’s health information is either a somewhat or very serious problem.

**Exhibit 19: Q20. For each of the following, how significant a problem do you feel this is in Canada today, if at all?
“Health care providers do not always have access to all of a person’s health information.”**

Q4. In which province or territory do you live?

Base: (n=2056).

Column %	CAN (n=2056)	AC (n=144)	QC (n=485)	ON (n=795)	MA (n=72)	SK (n=50)	AB (n=232)	BC (n=276)
Not a problem at all	4%	3%	3%	4%	4%	1%	5%	6%
A problem, but not a serious one	11%	10%	12%	12%	12%	17%	10%	8%
A somewhat serious problem	35%	32%	40%	33%	44%	38%	36%	32%
A very serious problem	42%	47%	41%	43%	28%	35%	42%	43%
DK/NR	7%	9%	4%	7%	12%	10%	7%	11%
	-	-	-	-	-	-	-	c
Column Names	A	B	C	D	E	F	G	H

Although respondents in Quebec are approximately as likely to say that public health officials being unable to easily access data to make informed regulations is a somewhat or very serious problem, they are the most likely (at 20%) to say that it is a problem, but not a serious one among all regions.

Exhibit 20: Q21. For each of the following, how significant a problem do you feel this is in Canada today, if at all?

“Public health officials can’t easily access data they need to provide timely and informed recommendations, such as during public health emergencies.”

Q4. In which province or territory do you live?

Base: (n=2051).

Column %	CAN (n=2051)	AC (n=161)	QC (n=501)	ON (n=782)	MA (n=68)	SK (n=54)	AB (n=207)	BC (n=273)
Not a problem at all	7%	4%	5%	6%	11%	3%	12%	9%
A problem, but not a serious one	14%	16%	20%	11%	14%	14%	13%	10%
	-	-	d h	-	-	-	-	-
A somewhat serious problem	36%	38%	38%	34%	30%	37%	40%	33%
A very serious problem	33%	30%	31%	36%	32%	35%	27%	33%
DK/NR	11%	13%	6%	12%	12%	10%	9%	16%
	-	-	-	c	-	-	-	C
Column Names	A	B	C	D	E	F	G	H

While over half of respondents in all regions say that researchers not having access to the health data they need to do research is at least a somewhat serious problem, if not a very serious one, 14% are uncertain or preferred not to say.

Exhibit 21: Q22. For each of the following, how significant a problem do you feel this is in Canada today, if at all?

“Researchers can’t easily access the health data they need to research new health treatments and solutions.”

Q4. In which province or territory do you live?

Base: (n=2031).

Column %	CAN (n=2031)	AC (n=132)	QC (n=486)	ON (n=792)	MA (n=65)	SK (n=69)	AB (n=221)	BC (n=263)
Not a problem at all	6%	4%	5%	5%	9%	10%	6%	6%
A problem, but not a serious one	14%	16%	16%	14%	11%	16%	14%	10%
A somewhat serious problem	37%	48%	40%	36%	35%	26%	38%	32%
A very serious problem	29%	18%	26%	33%	24%	28%	25%	32%
DK/NR	14%	14%	12%	12%	21%	20%	16%	20%
Column Names	A	B	C	D	E	F	G	H

Respondents in Manitoba (42%) and Ontario (30%) are the most likely to say that communities not having a complete picture of the health of their citizens is a very serious problem. By contrast, those in Quebec are both the least likely to say the same (19%) and the most likely to say that it is a problem, but not a serious one (26%).

Exhibit 22: Q23. For each of the following, how significant a problem do you feel this is in Canada today, if at all?

“Communities do not have a complete picture of the health of their citizens or increasing health inequities.”

Q4. In which province or territory do you live?

Base: (n=1974).

Column %	CAN (n=1974)	AC (n=133)	QC (n=466)	ON (n=779)	MA (n=64)	SK (n=54)	AB (n=204)	BC (n=272)
Not a problem at all	6%	6%	6%	5%	6%	2%	11%	5%
A problem, but not a serious one	18%	15%	26%	17%	11%	19%	15%	13%
	-	-	d g h	-	-	-	-	-
A somewhat serious problem	39%	40%	39%	37%	25%	38%	43%	42%
A very serious problem	27%	28%	19%	30%	42%	27%	21%	29%
	-	-	-	C	c g	-	-	c
DK/NR	11%	11%	10%	11%	16%	14%	10%	10%
Column Names	A	B	C	D	E	F	G	H

Echoing trends witnessed above, respondents in Quebec are the most likely (18%) to say that there being no agreement for when and how data is shared between health care professionals is a problem, but not a serious one. Given that Quebec has a relatively similar percentage of respondents who say that this is a somewhat or very serious problem as other regions, this is likely explained by the lower rates of respondents saying they do not know or preferring not to respond compared to other regions.

Exhibit 23: Q24. For each of the following, how significant a problem do you feel this is in Canada today, if at all?

“There is no agreement for when and how data is to be shared between health care professionals, across health settings or across jurisdictions.”

Q4. In which province or territory do you live?

Base: (n=2037).

Column %	CAN (n=2037)	AC (n=147)	QC (n=463)	ON (n=771)	MA (n=77)	SK (n=52)	AB (n=221)	BC (n=301)
Not a problem at all	4%	6%	5%	4%	5%	3%	6%	3%
A problem, but not a serious one	12%	10%	18%	10%	13%	17%	10%	9%
	-	-	d h	-	-	-	-	-
A somewhat serious problem	38%	44%	41%	37%	30%	38%	38%	35%
A very serious problem	36%	27%	29%	39%	33%	30%	33%	42%
	-	-	-	C	-	-	-	C
DK/NR	10%	12%	7%	9%	19%	12%	13%	12%
Column Names	A	B	C	D	E	F	G	H

Seven-in-ten or more respondents in all regions except Manitoba (63%) say that the lack of clear authority responsible for data oversight and protection in Canada’s health sector is a somewhat or very serious problem. While the absolute numbers are small, the three prairie provinces are the most likely to say that this is not a problem at all: Saskatchewan (9%), Manitoba (7%), and Alberta (6%).

Exhibit 24: Q25. For each of the following, how significant a problem do you feel this is in Canada today, if at all?

“There is no authority clearly responsible for data oversight, protection and use in Canada’s health sector.”

Q4. In which province or territory do you live?

Base: (n=2013).

Column %	CAN (n=2013)	AC (n=144)	QC (n=455)	ON (n=788)	MA (n=81)	SK (n=69)	AB (n=225)	BC (n=247)
Not a problem at all	4%	3%	4%	5%	7%	9%	6%	1%
	-	-	-	-	-	h	-	-
A problem, but not a serious one	9%	6%	11%	9%	15%	14%	11%	4%
A somewhat serious problem	32%	32%	36%	30%	18%	31%	31%	38%
A very serious problem	42%	43%	41%	43%	45%	39%	40%	42%
DK/NR	12%	16%	8%	14%	15%	7%	12%	15%
Column Names	A	B	C	D	E	F	G	H

Qualitative Insights

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.

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.

For all the potential 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 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%).

Exhibit 25: Q26-32. For each of the following, how much of a benefit do you feel this would be, if at all?

Base: (n=from 2706 to 2805).

Row %	A very significant benefit	A somewhat significant benefit	A benefit, but only a small one	Not a benefit at all	DK/NR
Ensuring people have a health record that follows them throughout their lives and is accessible to any of their health care providers across Canada. (n=2738)	63%	24%	6%	2%	5%
	B C D E	C D E	D	-	D
Enabling health care providers to better coordinate what they are doing for a person. (n=2725)	58%	29%	5%	1%	6%
	B C D E	C D E	D	-	D
To help improve quality and cost-effective care in our hospitals and other care settings. (n=2706)	54%	30%	7%	2%	6%
	B C D E	C D E	D	-	D
Enabling people to make more informed decisions about their personal health and achieve their personal health objectives. (n=2731)	48%	34%	10%	2%	6%
	B C D E	C D E	D E	-	D
To help governments anticipate and respond to public health events such as an outbreak of influenza or other virus. (n=2731)	46%	31%	11%	5%	6%
	B C D E	C D E	D E	-	-
To make it easier for health researchers to investigate problems and develop solutions. (n=2745)	44%	37%	9%	3%	7%
	B C D E	C D E	D	-	D
Enabling more informed decisions about the health of our communities, including reducing inequities. (n=2805)	40%	35%	12%	4%	9%
	b C D E	C D E	D e	-	D

Other demographic differences

- Respondents who identify as female are more likely than those who identify as male to believe it would be a significant benefit to enable people to make informed decisions about their personal health and achieve their person health objectives (85% versus 81%).
- Those who have a post-graduate degree are more likely than their counterparts to think that it would be a significant benefit to enable people to make informed decisions about their personal health and achieve their person health objectives (88%), and to make it easier for health researchers to investigate problems and develop solutions (87%).
- At 87%, respondents whose household income is \$100 thousand or more are also more likely to believe making it easier for health researchers to investigate problems and develop solutions would be a significant benefit.
- Those who say they have a chronic health condition are more likely to believe the following would offer significant benefits: enable providers to better coordinate what they are doing for a person (92%); ensure people have a health record that follows them throughout their lives

and is accessible to any of their health care providers across Canada (91%); to make it easier for health researchers to investigate problems and develop solutions (84%); and to help governments anticipate and respond to public health events (81%).

- Enabling more informed decisions about the health of our communities is more likely to be a significant benefit to those who live in a medium or large urban community (77%), are not born in Canada (80%), or identify as 2SLGBTQ+ (83%).
- Respondents who are 65 years or older, do not identify as Indigenous, have a family doctor, have a chronic health condition, have an understanding of health data, or are comfortable with data being shared are more likely to believe most of the potential benefits tested would be significant benefits.
- Conversely, fewer respondents who are 18 to 34 years of age, interact with their health care provider five times a year or less, or feel uncomfortable with data being shared believe that most of the potential benefits would be significant benefits.

Over four-in-five respondents in all regions say that enabling people to make more informed decisions about their personal health would be a somewhat or very significant benefit. At 3% respondents in Atlantic Canada are the least likely to say that it is a benefit, but only a small one, compared to other regions.

Exhibit 26: Q26. For each of the following, how much of a benefit do you feel this would be, if at all?

“Enabling people to make more informed decisions about their personal health and achieve their personal health objectives.”

Q4. In which province or territory do you live?

Base: (n=2731).

Column %	CAN (n=2731)	AC (n=196)	QC (n=644)	ON (n=1049)	MA (n=107)	SK (n=79)	AB (n=292)	BC (n=358)
A very significant benefit	48%	50%	45%	51%	45%	40%	46%	48%
A somewhat significant benefit	34%	38%	36%	33%	34%	40%	36%	32%
A benefit, but only a small one	10%	3%	12%	10%	9%	12%	11%	8%
	-	-	B	b	-	b	b	-
Not a benefit at all	2%	1%	3%	2%	4%	2%	2%	2%
DK/NR	6%	8%	4%	5%	9%	6%	5%	10%
	-	-	-	-	-	-	-	c d
Column Names	A	B	C	D	E	F	G	H

While two thirds (65%) of respondents in Saskatchewan say that communities not having a full picture of their health data is a somewhat or very serious problem – a rate similar to other regions – they are the most likely (12%) to say that enabling more informed decisions about the health of communities would not be a benefit at all.

Respondents from Quebec, on the other hand, were the least likely to say that communities not having a complete picture of their health data was a very serious problem (19%) and the most likely to say that is a problem, but not a serious one (26%). When asked about the benefits of enabling more informed decisions about the health of our communities, however, almost three-quarters (73%) say it is a very or somewhat significant benefit.

Exhibit 27: Q27. For each of the following, how much of a benefit do you feel this would be, if at all?

“Enabling more informed decisions about the health of our communities, including reducing inequities.”

Q4. In which province or territory do you live?

Base: (n=2805).

Column %	CAN (n=2805)	AC (n=202)	QC (n=641)	ON (n=1094)	MA (n=85)	SK (n=95)	AB (n=314)	BC (n=367)
A very significant benefit	40%	35%	40%	40%	43%	37%	39%	42%
A somewhat significant benefit	35%	43%	33%	36%	27%	28%	38%	36%
A benefit, but only a small one	12%	8%	16%	12%	12%	12%	9%	8%
Not a benefit at all	4%	3%	4%	4%	3%	12%	6%	3%
DK/NR	9%	10%	6%	10%	15%	10%	8%	11%
Column Names	A	B	C	D	E	F	G	H

At least four-in-five respondents across all regions say that having a health record that follows a patient throughout their life is at least a somewhat significant benefit, with over three-in-five in each saying that it is a very significant benefit. Importantly, very few say that there is no benefit at all.

Exhibit 28: Q28. For each of the following, how much of a benefit do you feel this would be, if at all?

“Ensuring people have a health record that follows them throughout their lives and is accessible to any of their health care providers across Canada.”

Q4. In which province or territory do you live?

Base: (n=2738).

Column %	CAN (n=2738)	AC (n=191)	QC (n=651)	ON (n=1044)	MA (n=95)	SK (n=89)	AB (n=303)	BC (n=360)
A very significant benefit	63%	63%	63%	63%	60%	68%	64%	61%
A somewhat significant benefit	24%	21%	26%	24%	22%	16%	23%	26%
A benefit, but only a small one	6%	7%	6%	6%	4%	9%	7%	5%
Not a benefit at all	2%	0%	2%	1%	1%	1%	2%	1%
DK/NR	5%	8%	3%	6%	12%	6%	4%	6%
Column Names	A	B	C	D	E	F	G	H

Similar to the perceived benefits of having a health record follow a patient throughout their life, enabling health care providers to better coordinate the care they offer is seen as at least a somewhat significant benefit by at least four-in-five respondents across all regions. It is further

felt that this would be a very significant benefit by over half of respondents in all regions surveyed, with virtually none saying that it would not be a benefit at all.

**Exhibit 29: Q29. For each of the following, how much of a benefit do you feel this would be, if at all?
“Enabling health care providers to better coordinate what they are doing for a person.”**

Q4. In which province or territory do you live?

Base: (n=2725).

Column %	CAN (n=2725)	AC (n=192)	QC (n=618)	ON (n=1069)	MA (n=103)	SK (n=85)	AB (n=283)	BC (n=372)
A very significant benefit	58%	57%	60%	59%	60%	52%	57%	58%
A somewhat significant benefit	29%	28%	28%	29%	23%	34%	31%	29%
A benefit, but only a small one	5%	4%	7%	5%	5%	2%	6%	5%
Not a benefit at all	1%	2%	2%	1%	0%	0%	2%	1%
DK/NR	6%	8%	3%	6%	12%	12%	5%	7%
	-	-	-	-	c	c	-	-
Column Names	A	B	C	D	E	F	G	H

Improving quality and cost-effective care in hospitals is felt to be either a very or a somewhat significant benefit by respondents across regions, with over half in all regions except Saskatchewan (41%) saying that it is a very significant benefit.

**Exhibit 30: Q30. For each of the following, how much of a benefit do you feel this would be, if at all?
“To help improve quality and cost-effective care in our hospitals and other care settings.”**

Q4. In which province or territory do you live?

Base: (n=2706).

Column %	CAN (n=2706)	AC (n=183)	QC (n=632)	ON (n=1054)	MA (n=92)	SK (n=84)	AB (n=288)	BC (n=368)
A very significant benefit	54%	56%	53%	56%	51%	41%	55%	54%
A somewhat significant benefit	30%	28%	32%	28%	31%	35%	31%	30%
A benefit, but only a small one	7%	7%	7%	8%	9%	14%	6%	5%
Not a benefit at all	2%	3%	3%	2%	2%	1%	3%	3%
DK/NR	6%	6%	5%	6%	8%	8%	5%	9%
Column Names	A	B	C	D	E	F	G	H

When asked about the possibility of using health data to help governments anticipate and respond to public health events such as an outbreak, a majority of respondents in all regions saw at least a somewhat significant benefit if not a very significant one. At a quarter (23%) of respondents, those in Saskatchewan are the most likely to feel that it is a benefit but only a small one.

Exhibit 31: Q31. For each of the following, how much of a benefit do you feel this would be, if at all?

“To help governments anticipate and respond to public health events such as an outbreak of influenza or other virus.”

Q4. In which province or territory do you live?

Base: (n=2731).

Column %	CAN (n=2731)	AC (n=198)	QC (n=648)	ON (n=1058)	MA (n=95)	SK (n=82)	AB (n=289)	BC (n=356)
A very significant benefit	46%	43%	44%	47%	50%	39%	50%	49%
A somewhat significant benefit	31%	32%	32%	32%	32%	22%	29%	31%
A benefit, but only a small one	11%	10%	14%	10%	10%	23%	12%	7%
Not a benefit at all	-	-	h	-	-	d h	-	-
DK/NR	5%	7%	6%	5%	3%	9%	6%	4%
DK/NR	6%	8%	4%	7%	5%	8%	4%	9%
Column Names	A	B	C	D	E	F	G	H

Over two thirds of respondents in every region feel that making it easier for health researchers to investigate problems and develop solutions is at least a somewhat significant benefit, if not a very significant one. Unlike the other scenarios tested above, respondents in some regions were more likely to say that this is only a somewhat significant benefit (Atlantic Canada and Manitoba) than a very significant one.

Exhibit 32: Q32. For each of the following, how much of a benefit do you feel this would be, if at all?

“To make it easier for health researchers to investigate problems and develop solutions.”

Q4. In which province or territory do you live?

Base: (n=2745).

Column %	CAN (n=2745)	AC (n=193)	QC (n=629)	ON (n=1056)	MA (n=94)	SK (n=84)	AB (n=319)	BC (n=365)
A very significant benefit	44%	39%	44%	45%	40%	35%	45%	48%
A somewhat significant benefit	37%	43%	37%	37%	41%	34%	39%	32%
A benefit, but only a small one	9%	8%	11%	8%	8%	15%	8%	7%
Not a benefit at all	3%	3%	4%	2%	1%	6%	3%	3%
DK/NR	7%	7%	4%	8%	9%	9%	6%	10%
DK/NR	-	-	-	-	-	-	-	c
Column Names	A	B	C	D	E	F	G	H

A majority of respondents agreed, or strongly agreed, with the all the statements tested except the one that pertained to confidence in existing safeguards. For that specific statement, 45% agreed or strongly agreed, 25% were neutral, and 25% disagreed or strongly disagreed.

Exhibit 33: Q33-38. Please indicate how strongly you agree or disagree with each of the following statements.

Base: (n=from 2987 to 3080).

Row %	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	DK/NR
Health care providers require timely and easy access to a person's health data so they can provide high quality health care. (n=2987)	53%	33%	9%	1%	1%	4%
	B C D E F	C D E F	D E F	-	-	D E
I have no problem with health data being shared with researchers as long as it is completely anonymous and the user cannot possibly identify whose health data it is. (n=3069)	41%	35%	12%	4%	4%	4%
	B C D E F	C D E F	D E F	-	-	-
I am comfortable with health care providers sharing my personal health data with other health care providers that care for me. (n=3080)	41%	40%	10%	3%	2%	3%
	C D E F	C D E F	D E F	e	-	e
I have no problem with health data being shared to inform government decisions as long as it is anonymous and the user cannot possibly identify whose health data it is. (n=3008)	36%	36%	13%	5%	6%	4%
	C D E F	C D E F	D E F	-	-	-
Failing to share health data can sometimes harm people or leave communities without the data they need to care for the population. (n=3055)	32%	43%	13%	4%	2%	6%
	C D E F	A C D E F	D E F	e	-	D E
I am confident that safeguards are in place to protect my medical records and other health data from being seen by people who aren't allowed to see them. (n=3007)	13%	32%	25%	17%	8%	6%
	E F	A C D E F	A D E F	A E F	-	-

Other demographic differences

- Respondents who are 65 years or older, speak French at home, have a post-graduate degree, have a household income of \$100 thousand or more, are not racially visible, have a family doctor, have a chronic health condition, have an understanding of health data, or are comfortable with data being shared are more likely to agree with most of the statements regarding health data sharing.
- Conversely, fewer respondents who are 18 to 34 years of age or interact with their health care provider five times a year or less, agree with most of the perceptual statements regarding health data sharing.

Qualitative Insights

Asked whether they are able to agree with the statement, “I am confident that safeguards are in place to protect my medical records and other health data from being seen by people who aren’t allowed to see them” 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 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.

A vast majority of respondents across all regions surveyed either agreed or strongly agreed with the statement that health care providers require timely and easy access to a person’s health data in order to provide high quality care. Virtually no one strongly disagreed.

Exhibit 34: Q33. Please indicate how strongly you agree or disagree with each of the following statements.

“Health care providers require timely and easy access to a person’s health data so they can provide high quality health care.”

Q4. In which province or territory do you live?

Base: (n=2987).

Column %	CAN (n=2987)	AC (n=216)	QC (n=690)	ON (n=1162)	MA (n=106)	SK (n=98)	AB (n=322)	BC (n=389)
Strongly agree	53%	55%	63%	49%	45%	53%	52%	47%
	-	-	D e g H	-	-	-	-	-
Agree	33%	28%	27%	35%	40%	38%	33%	34%
	-	-	-	c	-	-	-	-
Neither agree nor disagree	9%	9%	6%	10%	8%	6%	10%	9%
Disagree	1%	2%	1%	1%	0%	0%	2%	2%
Strongly disagree	1%	1%	1%	1%	3%	0%	1%	1%
DK/NR	4%	5%	3%	4%	4%	3%	2%	6%
Column Names	A	B	C	D	E	F	G	H

A majority across all regions surveyed either agree or strongly agree that they are comfortable with health care providers sharing their personal health data with other health care providers, respondents in Quebec were the most likely to strongly agree at 47% – this compared with 37% in B.C. and 34% in Manitoba.

Exhibit 35: Q34. Please indicate how strongly you agree or disagree with each of the following statements.

“I am comfortable with health care providers sharing my personal health data with other health care providers that care for me.”

Q4. In which province or territory do you live?

Base: (n=3080).

Column %	CAN (n=3080)	AC (n=217)	QC (n=711)	ON (n=1193)	MA (n=109)	SK (n=91)	AB (n=337)	BC (n=416)
Strongly agree	41%	41%	47%	38%	34%	44%	44%	37%
	-	-	d h	-	-	-	-	-
Agree	40%	39%	39%	42%	39%	29%	40%	43%
Neither agree nor disagree	10%	9%	8%	11%	12%	15%	9%	11%
Disagree	3%	4%	2%	3%	5%	4%	3%	3%
Strongly disagree	2%	2%	1%	3%	4%	3%	3%	1%
DK/NR	3%	6%	2%	3%	6%	6%	1%	5%
Column Names	A	B	C	D	E	F	G	H

The only statement in which there was notable disagreement, at least one-in-five in all regions disagree or strongly disagree that they have confidence in the existing safeguards to protect medical records. This number rises to a third (32%) of respondents from Atlantic Canada.

Exhibit 36: Q35. Please indicate how strongly you agree or disagree with each of the following statements.

“I am confident that safeguards are in place to protect my medical records and other health data from being seen by people who aren't allowed to see them.”

Q4. In which province or territory do you live?

Base: (n=3007).

Column %	CAN (n=3007)	AC (n=216)	QC (n=710)	ON (n=1153)	MA (n=104)	SK (n=98)	AB (n=324)	BC (n=397)
Strongly agree	13%	17%	14%	12%	9%	15%	10%	12%
Agree	32%	23%	31%	33%	32%	38%	34%	34%
Neither agree nor disagree	25%	20%	27%	26%	27%	14%	24%	23%
Disagree	17%	24%	16%	17%	8%	17%	17%	13%
	-	e h	-	-	-	-	-	-
Strongly disagree	8%	8%	6%	8%	10%	11%	9%	7%
DK/NR	6%	7%	5%	5%	13%	6%	7%	11%
	-	-	-	-	-	-	-	d
Column Names	A	B	C	D	E	F	G	H

A majority of respondents in all regions agree that failing to share health data can sometimes harm people or leave communities without the data they need to care for the population.

Exhibit 37: Q36. Please indicate how strongly you agree or disagree with each of the following statements.

“Failing to share health data can sometimes harm people or leave communities without the data they need to care for the population.”

Q4. In which province or territory do you live?

Base: (n=3055).

Column %	CAN (n=3055)	AC (n=206)	QC (n=707)	ON (n=1190)	MA (n=110)	SK (n=90)	AB (n=336)	BC (n=410)
Strongly agree	32%	34%	31%	32%	32%	31%	31%	34%
Agree	43%	40%	41%	44%	39%	28%	44%	45%
Neither agree nor disagree	13%	14%	16%	13%	15%	19%	13%	9%
Disagree	4%	4%	5%	3%	3%	8%	4%	3%
Strongly disagree	2%	2%	3%	2%	2%	5%	3%	2%
DK/NR	6%	6%	5%	7%	10%	9%	4%	8%
Column Names	A	B	C	D	E	F	G	H

Exhibit 38: Q37. Please indicate how strongly you agree or disagree with each of the following statements.

“I have no problem with health data being shared with researchers as long as it is completely anonymous and the user cannot possibly identify whose health data it is.”

Q4. In which province or territory do you live?

Base: (n=3069).

Column %	CAN (n=3069)	AC (n=206)	QC (n=696)	ON (n=1204)	MA (n=112)	SK (n=91)	AB (n=345)	BC (n=409)
Strongly agree	41%	45%	45%	39%	47%	37%	42%	38%
Agree	35%	31%	34%	36%	29%	35%	34%	37%
Neither agree nor disagree	12%	12%	11%	13%	11%	9%	12%	10%
Disagree	4%	5%	5%	5%	3%	8%	4%	5%
Strongly disagree	4%	3%	2%	4%	5%	5%	5%	4%
DK/NR	4%	6%	3%	3%	5%	6%	3%	6%
Column Names	A	B	C	D	E	F	G	H

Over two thirds of respondents in each region say they either agree or strongly agree with the notion that it is not a problem if their health data is shared to inform government decisions so long as it is completely anonymous.

Exhibit 39: Q38. Please indicate how strongly you agree or disagree with each of the following statements.

“I have no problem with health data being shared to inform government decisions as long as it is anonymous and the user cannot possibly identify whose health data it is.”

Q4. In which province or territory do you live?

Base: (n=3008).

Column %	CAN (n=3008)	AC (n=225)	QC (n=709)	ON (n=1151)	MA (n=96)	SK (n=100)	AB (n=324)	BC (n=398)
Strongly agree	36%	42%	36%	35%	42%	41%	35%	36%
Agree	36%	30%	35%	38%	31%	32%	33%	38%
Neither agree nor disagree	13%	14%	13%	13%	12%	11%	16%	11%
Disagree	5%	6%	6%	5%	2%	9%	5%	4%
Strongly disagree	6%	3%	7%	5%	8%	2%	7%	5%
DK/NR	4%	5%	3%	5%	3%	5%	4%	5%
Column Names	A	B	C	D	E	F	G	H

Improving health data sharing

Following this, respondents were asked about a number of potential government priorities to gauge their level of support or opposition to each. At least seven-in-ten respondents either supported or strongly supported all three priorities tested, with virtually none strongly opposing them.

Exhibit 40: Q40-42. For each of them, please indicate how strongly you support or oppose governments focussing on that priority.

Base: CAWI respondents (n=3040).

Row %	Strongly support	Support	Neither support nor oppose	Oppose	Strongly oppose	DK/NR
Make sure people have access to, and control over, their own health data. (n=3040)	49%	34%	10%	3%	1%	4%
	B C D E F	C D E F	D E F	E	-	d E
Make sure health data are available to those authorized to support a person's care. (n=3040)	45%	39%	9%	2%	1%	4%
	b C D E F	C D E F	D E F	-	-	D E
Enable secure access to health data by authorized users who need health data to conduct medical research, improve the health care system, or make decisions affecting public health in a community. (n=3040)	32%	41%	15%	4%	3%	6%
	C D E F	A C D E F	D E F	e	-	D E

Other demographic differences

- Respondents who are 65 years or older, have a post-graduate degree, have a household income of \$100,000 or more, are not racially visible, have a family doctor, have a chronic

health condition, have an understanding of health data, or are comfortable with data being shared are more likely to support each of the way the Government of Canada is proposing to modernize health systems in Canada than their counterparts.

- Conversely, fewer respondents who are 18 to 34 years of age or interact with their health care provider five times a year or less, support the ways the Government of Canada is modernizing the health system.

Support for people having access to, and control over, their own health data was strong across all regions surveyed with at least four-in-five respondents saying they either supported or strongly supported it with virtually none strongly opposing it.

Exhibit 41: Q40. For each of them, please indicate how strongly you support or oppose governments focussing on that priority.

“Make sure people have access to, and control over, their own health data.”

Q4. In which province or territory do you live?

Base: CAWI respondents (n=3040).

Column %	CAN (n=3040)	AC (n=214)	QC (n=694)	ON (n=1186)	MA (n=107)	SK (n=95)	AB (n=333)	BC (n=407)
Strongly support	49%	49%	52%	49%	44%	48%	48%	46%
Support	34%	32%	28%	36%	39%	40%	34%	36%
Neither support nor oppose	10%	12%	12%	9%	11%	8%	13%	7%
Oppose	3%	3%	3%	2%	0%	0%	3%	3%
Strongly oppose	1%	1%	1%	1%	0%	1%	1%	1%
DK/NR	4%	3%	3%	4%	6%	4%	2%	7%
Column Names	A	B	C	D	E	F	G	H

Support for making health data available to those authorized to support a person’s care was strong across all regions surveyed with at least four-in-five respondents saying they either supported or strongly supported it with virtually none strongly opposing it.

Exhibit 42: Q41. For each of them, please indicate how strongly you support or oppose governments focussing on that priority.

“Make sure health data are available to those authorized to support a person’s care.”

Q4. In which province or territory do you live?

Base: CAWI respondents (n=3040).

Column %	CAN (n=3040)	AC (n=214)	QC (n=694)	ON (n=1186)	MA (n=107)	SK (n=95)	AB (n=333)	BC (n=407)
Strongly support	45%	52%	46%	45%	46%	43%	43%	39%
Support	39%	31%	39%	38%	37%	44%	41%	42%
Neither support nor oppose	9%	10%	10%	9%	8%	8%	11%	9%
Oppose	2%	2%	2%	2%	2%	0%	2%	1%
Strongly oppose	1%	1%	1%	1%	1%	2%	2%	2%
DK/NR	4%	4%	2%	5%	6%	3%	2%	6%
Column Names	A	B	C	D	E	F	G	H

Support for enabling secure access to health data by authorized users to conduct medical research, improve the health care system, or make decisions affecting the community was strong across all regions surveyed with at least two thirds of respondents saying they either supported or strongly supported it few opposing it.

Exhibit 43: Q42. For each of them, please indicate how strongly you support or oppose governments focussing on that priority.

“Enable secure access to health data by authorized users who need health data to conduct medical research, improve the health care system, or make decisions affecting public health in a community.”

Q4. In which province or territory do you live?

Base: CAWI respondents (n=3040).

Column % Column Comparisons	CAN (n=3040)	AC (n=214)	QC (n=694)	ON (n=1186)	MA (n=107)	SK (n=95)	AB (n=333)	BC (n=407)
Strongly support	32%	30%	36%	31%	36%	21%	31%	33%
Support	41%	38%	38%	42%	38%	50%	44%	39%
Neither support nor oppose	15%	17%	15%	16%	17%	13%	15%	14%
Oppose	4%	5%	4%	3%	2%	4%	2%	4%
Strongly oppose	3%	2%	3%	2%	3%	7%	3%	2%
DK/NR	6%	7%	4%	6%	4%	6%	5%	8%
Column Names	A	B	C	D	E	F	G	H

Qualitative Insights

When provided with the Government of Canada’s priorities for making a high-performing health data system, reaction was almost unanimously positive, 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.

“Sounds great and ambitious, but some, like seniors, will have problems and I don’t see anything about asking.” – Patient advocate

“A really good outcome, but it does not take into account [what was shared on misuse and stigmatizing by authorized users].” – Patient advocate

“I really don’t know if they are implementing the safeguards, but I know they exist and I expect they are.” – LGBTQ2IA+

“All the organizations using the data have to be forced to the highest security standards.” – Patient advocate

There was also a certain level of skepticism among patient advocates about whether the Government could achieve these priorities. Asked what they see as the main hurdles, patient advocates pointed to:

- **Transparency.** Transparency broadly, and in terms of process, challenges, data sharing, etc.
- **Being in concert with the provinces.** Patient advocates expressed a variety of concerns related to a collaborative federal/provincial system. They pointed to their understanding of provincial governments' need for health transfers but with conditions around management independence and some provinces' resistance to collaborate with the federal government. Patient advocates in Quebec expressed their concern about the lack of participation from the provincial government in Quebec.

"In terms of the national focus, there is an asterisk. The asterisk being that we [province of Quebec] have to participate in pan-Canadian initiatives. With Act 5 respecting health and social services information, we hope they will share with CIHI. We have to remind them [the provincial government]. It is very appropriate and a good aspiration, but it needs to include Quebec equally. We have to work on that. We need this. If the rest of Canada has a new COVID strain, we need to know about it." – Patient advocate

- **Fluidity of the process.** The conversation usually revolved around a sense that one needs to advocate for themselves to navigate the system and that information-sharing is limited. The aspiration is for a process that is more "fluid" and in sync; one that flows from one interaction/intervention to the next.

"When our patients call us, it's usually to navigate the system. It's complex, fragmented, siloed. The information and data do not follow the patient." – Patient advocate

- **Cultural change** (in health care system to improve and deliver better health care to Canadians). Participants often spoke of a need to change the culture in health care to be patient centric. They suggested the culture change needs to start from the question, "what is the public missing?"

"It's impenetrable. I always feel I'm at the exterior of a machine." – Patient advocate

"Patients come last. We need to understand the system and reorganize." – Patient advocate

"We forgot somewhere along the way that the people we are caring for are vulnerable and then we ask them to navigate the system which isn't the best time to ask this of people." – Patient advocate

- **Norms related to data sharing.** Participants spoke of the need for confidentiality and unidentified information; access to the data especially for the patient; that the greater population needs to benefit from the learning; that we all need to be on the same system; and that the system needs to be protected (highly secure).

- **Health care professionals’ compensation.** Consistent through most groups, there was a sense that one of the challenges in health care currently is non-competitive salaries which participants cite as a reason health care professionals are leaving to practice elsewhere.
- **Accountability** and a sense that it is not there now for a variety of reasons (i.e., unions, too much protection).
- **Competing political agendas.** Patient advocates in Quebec cited the competing priorities of different governments (at federal and provincial levels) and a need to set those aside.

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 – a point which was elaborated on in the next table.

Exhibit 44: Q43. If progress occurred in all three of those areas focussing on how your health data is shared, generally speaking, how comfortable would you be with your health data being shared in this way, or would you say your level of comfort depends upon something else?

Q4. In which province or territory do you live?

Base: CAWI respondents (n=3040).

Column %	CAN (n=3040)	AC (n=214)	QC (n=694)	ON (n=1186)	MA (n=107)	SK (n=95)	AB (n=333)	BC (n=407)
Very comfortable	25%	26%	23%	27%	19%	26%	25%	26%
Somewhat comfortable	38%	36%	44%	37%	42%	32%	39%	34%
Neither uncomfortable nor comfortable	13%	9%	14%	13%	11%	13%	16%	12%
Somewhat uncomfortable	5%	4%	5%	4%	9%	5%	3%	6%
Very uncomfortable	2%	1%	2%	2%	3%	4%	2%	3%
It depends	11%	15%	9%	11%	12%	12%	10%	12%
DK/NR	5%	9%	3%	6%	4%	9%	4%	7%
Column Names	A	B	C	D	E	F	G	H

Other demographic differences

- Compared to their counterparts, respondents who are 65 years or older (72%), speak French at home (68%), have a household income of \$100 thousand or more (71%), do not identify as Indigenous (65%), are not racially visible (65%), have a family doctor (66%), have a chronic health condition (68%), are more likely to say they are comfortable with their health data being shared if progress occurred in each way the Government of Canada is focussing on.

- Those who have an understanding of health data (70%) or who said they are comfortable with data being shared at the onset of the survey (84%) are also more likely than their counterparts to say they are comfortable with their health data being shared if progress occurred on each front.
- Conversely, those who have a high school education or less (59%) are less likely to say they are comfortable with their health data being shared despite any progress made.

Those respondents who chose “it depends” at the last question were provided with the option to elaborate on why. The top three reasons listed were: who the data is shared with (29%), the security of the data (24%), and the reasons why this data is being shared (17%). Please note, there are no regional breakdowns provided due to small sample sizes.

Exhibit 45: Q44. [IF Q43=6 “IT DEPENDS”] You mentioned that your comfort with the idea of health data being shared depends on the situation and/or other factors. What specifically does it depend on?

Base: (n=329).

Column %	CAN
Who it is shared with (e.g., where, who has access)	29%
Security (e.g., identity theft)	24%
Why it is being shared	17%
Anonymity	14%
Giving permission/consent (i.e., patient control over data)	14%
What is being shared	9%
Privacy and confidentiality	9%
The medical condition in question	3%
Trust	2%
How it is being shared	1%
Other	5%
DK/NR	11%

There are no other significant demographic differences.

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.

Exhibit 46: Q45-48. For each of the following possible rules regarding your consent, would you say it is very important to you, somewhat important to you, not very important to you or not at all important to you?

Base: All respondents (n=4012).

Row %	Very important	Somewhat important	Not that important	Not at all important	DK/NR
That your consent must be voluntary, meaning you must not be pressured or fooled into providing consent. (n=4012)	75%	18%	2%	0%	4%
	B C D E	C D E	D	-	C D
That the only people who can give consent on your behalf are you, or someone you have explicitly designated as being able to give consent on your behalf. (n=4012)	70%	22%	3%	1%	5%
	B C D E	C D E	D	-	C D
That your consent is only asked for after you know the ways your health data may be used. (n=4012)	61%	28%	4%	1%	6%
	B C D E	C D E	D	-	C D
That your consent is only asked for after you are told whether any data you are sharing includes or excludes information that identifies you, such as your name or address. (n=4012)	60%	27%	4%	1%	8%
	B C D E	C D E	D	-	C D

Other demographic differences

- Respondents who are 65 years or older, have a post-graduate degree, have a family doctor, have a chronic health condition, or have an understanding of health data are more likely to say that each of the possible rules are important to them than their counterparts.
- Conversely, fewer respondents who are 18 to 34 years of age or have a neutral level of comfort when it comes to data sharing say that each potential rule is important to them.

That the only people who can give consent on your behalf be you or someone explicitly designated to do so was deemed very important by at least two thirds of all respondents across all regions surveyed, with virtually none saying that it was not at all important.

Exhibit 47: Q45. For each of the following possible rules regarding your consent, would you say it is very important to you, somewhat important to you, not very important to you or not at all important to you?

“That the only people who can give consent on your behalf are you, or someone you have explicitly designated as being able to give consent on your behalf.”

Q4. In which province or territory do you live?

Base: All respondents (n=4012).

Column %	CAN (n=4012)	AC (n=283)	QC (n=931)	ON (n=1554)	MA (n=141)	SK (n=125)	AB (n=437)	BC (n=533)
Very important	70%	74%	73%	68%	68%	73%	73%	68%
Somewhat important	22%	18%	20%	23%	21%	18%	20%	22%
Not that important	3%	2%	3%	2%	2%	1%	3%	3%
Not at all important	1%	0%	0%	1%	1%	2%	0%	1%
DK/NR	5%	6%	3%	5%	8%	7%	4%	6%
Column Names	A	B	C	D	E	F	G	H

Over nine-in-ten respondents across all regions surveyed say that consent must be voluntary was at least somewhat, if not very, important. Again, virtually none say that it is not at all important.

Exhibit 48: Q46. For each of the following possible rules regarding your consent, would you say it is very important to you, somewhat important to you, not very important to you or not at all important to you?

“That your consent must be voluntary, meaning you must not be pressured or fooled into providing consent.”

Q4. In which province or territory do you live?

Base: All respondents (n=4012).

Column %	CAN (n=4012)	AC (n=283)	QC (n=931)	ON (n=1554)	MA (n=141)	SK (n=125)	AB (n=437)	BC (n=533)
Very important	75%	83%	74%	75%	76%	73%	77%	73%
Somewhat important	18%	11%	19%	18%	15%	19%	19%	18%
Not that important	2%	0%	3%	2%	3%	0%	1%	2%
Not at all important	0%	1%	0%	0%	0%	0%	0%	1%
DK/NR	4%	4%	3%	5%	6%	8%	2%	6%
Column Names	A	B	C	D	E	F	G	H

When it comes to consent only being asked for after you are told whether any data you are sharing includes or excludes information that identifies you, respondents were less likely to say that it is very important when compared to the previous two rules regarding consent. Furthermore, respondents in Manitoba (69%), Atlantic Canada (67%), and Alberta (65%), were more likely to say it is very important than those in Quebec (54%).

Exhibit 49: Q47. For each of the following possible rules regarding your consent, would you say it is very important to you, somewhat important to you, not very important to you or not at all important to you?

“That your consent is only asked for after you are told whether any data you are sharing includes or excludes information that identifies you, such as your name or address.”

Q4. In which province or territory do you live?

Base: All respondents (n=4012).

Column %	CAN (n=4012)	AC (n=283)	QC (n=931)	ON (n=1554)	MA (n=141)	SK (n=125)	AB (n=437)	BC (n=533)
Very important	60%	67%	54%	60%	69%	57%	65%	60%
	-	c	-	-	-	-	c	-
Somewhat important	27%	19%	31%	27%	19%	28%	24%	30%
	-	-	b	-	-	-	-	-
Not that important	4%	4%	6%	4%	3%	4%	3%	3%
Not at all important	1%	1%	1%	1%	0%	1%	1%	1%
DK/NR	8%	10%	9%	7%	9%	9%	7%	7%
Column Names	A	B	C	D	E	F	G	H

As with the rule of consent being only asked after being told if there is any identifying information included respondents in Quebec (56%) were the least likely to say that consent only being asked for after you know the ways your health data may be used was very important (this compared with 66% in Saskatchewan and 64% in Ontario).

Exhibit 50: Q48. For each of the following possible rules regarding your consent, would you say it is very important to you, somewhat important to you, not very important to you or not at all important to you?

“That your consent is only asked for after you know the ways your health data may be used.”

Q4. In which province or territory do you live?

Base: All respondents (n=4012).

Column %	CAN (n=4012)	AC (n=283)	QC (n=931)	ON (n=1554)	MA (n=141)	SK (n=125)	AB (n=437)	BC (n=533)
Very important	61%	62%	56%	64%	59%	66%	60%	63%
	-	-	-	c	-	-	-	-
Somewhat important	28%	25%	32%	27%	24%	22%	30%	25%
Not that important	4%	4%	5%	3%	5%	3%	4%	5%
Not at all important	1%	1%	1%	1%	0%	1%	0%	1%
DK/NR	6%	8%	6%	5%	12%	8%	6%	7%
Column Names	A	B	C	D	E	F	G	H

When asked about how important it is for respondents to be asked for consent in three hypothetical scenarios detailed in the table below, 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.

Exhibit 51: Q43-45. Knowing this, how important is it for you to be asked for your consent for sharing of this type of health data in each of the following situations?

Base: All respondents (n=4012).

Row %	Very important	Somewhat important	Not that important	Not at all important	DK/NR
When it is to be used by scientists conducting health-related research. (n=4012)	48%	33%	8%	4%	6%
	B C D E	C D E	D e	-	D
When it is to be used by government officials and policymakers responsible for developing health policies and programs. (n=4012)	43%	34%	11%	5%	8%
	B C D E	C D E	D E	-	D
When it is to be used by managers within health care systems monitoring how the health care system is performing. (n=4012)	42%	37%	9%	4%	7%
	B C D E	C D E	D e	-	D

Other demographic differences

- Respondents who are 65 years or older, have a post-graduate degree, have a family doctor, or have an understanding of health data are more likely to say that each scenario require consent.
- Conversely, fewer respondents who are 18 to 34 years of age say that each scenario requires consent.
- Consent requirements when data is used by government officials and policymakers is more important among those with a post-graduate degree (81%), who live in a medium or large urban community (78%), who are not born in Canada (82%), or who are racially visible (80%), than their counterparts.

Of the three scenarios provided, respondents were the most likely to say that being asked for consent is very important when health data is used by scientists conducting health-related research (at 48%).

Exhibit 52: Q43. For each of the following possible rules regarding your consent, would you say it is very important to you, somewhat important to you, not very important to you or not at all important to you?

“When it is to be used by scientists conducting health-related research.”

Q4. In which province or territory do you live?

Base: All respondents (n=4012).

Column %	CAN (n=4012)	AC (n=283)	QC (n=931)	ON (n=1554)	MA (n=141)	SK (n=125)	AB (n=437)	BC (n=533)
Very important	48%	48%	46%	51%	47%	46%	48%	45%
Somewhat important	33%	31%	37%	32%	34%	33%	32%	33%
Not that important	8%	8%	10%	6%	9%	6%	10%	8%
Not at all important	4%	6%	3%	5%	3%	4%	5%	6%
DK/NR	6%	7%	5%	6%	7%	11%	5%	8%
Column Names	A	B	C	D	E	F	G	H

While a majority of respondents across regions surveyed said it was somewhat, if not very, important to ask for consent when health data is to be used for developing health policies, respondents in Quebec were the least likely to say it was very important (at 38%) whereas those in Ontario were the most likely to say so (at 45%).

Exhibit 53: Q44. For each of the following possible rules regarding your consent, would you say it is very important to you, somewhat important to you, not very important to you or not at all important to you?

“When it is to be used by government officials and policymakers responsible for developing health policies and programs.”

Q4. In which province or territory do you live?

Base: All respondents (n=4012).

Column %	CAN (n=4012)	AC (n=283)	QC (n=931)	ON (n=1554)	MA (n=141)	SK (n=125)	AB (n=437)	BC (n=533)
Very important	43%	44%	38%	45%	42%	43%	43%	43%
	-	-	-	c	-	-	-	-
Somewhat important	34%	30%	35%	34%	35%	34%	36%	37%
Not that important	11%	10%	14%	9%	11%	11%	10%	9%
Not at all important	5%	8%	6%	4%	4%	4%	5%	4%
DK/NR	8%	9%	8%	8%	7%	9%	7%	7%
Column Names	A	B	C	D	E	F	G	H

Over three quarters of respondents say that asking for consent when health data is to be used by managers within health care systems is somewhat, if not very, important.

Exhibit 54: Q45. For each of the following possible rules regarding your consent, would you say it is very important to you, somewhat important to you, not very important to you or not at all important to you?

“When it is to be used by managers within health care systems monitoring how the health care system is performing.”

Q4. In which province or territory do you live?

Base: All respondents (n=4012).

Column %	CAN (n=4012)	AC (n=283)	QC (n=931)	ON (n=1554)	MA (n=141)	SK (n=125)	AB (n=437)	BC (n=533)
Very important	42%	41%	40%	44%	41%	43%	43%	41%
Somewhat important	37%	36%	39%	36%	39%	41%	39%	37%
Not that important	9%	10%	11%	8%	7%	7%	10%	10%
Not at all important	4%	5%	4%	4%	2%	2%	3%	4%
DK/NR	7%	8%	6%	8%	10%	7%	6%	8%
Column Names	A	B	C	D	E	F	G	H

Conclusion

People care about the health system in Canada and have opinions about it – this much was revealed in the focus groups. When posed a general question about the state of health care in Canada, participants were quick to point out both what they perceived to be pros (e.g., its universality, that large portions of it are free) and cons (e.g., wait times, access to services). Few naturally volunteered comments or questions about health data, how it is currently shared, or how its sharing could be improved – even when prompted with questions as to whether the health care system needs to modernize.

Put another way, while health care as an umbrella topic elicits much discussion, the specific issues surrounding if and how health data is used or shared are not top of mind. Only one-in-ten (10%) report that they are very familiar with the term, while a similar minority (9%) say they have a strong understanding of what is meant by it. Even if it does not dominate existing narratives surrounding health care, when prompted the idea that health data should be shared was considered important, if not very important, by a majority of respondents. Taken with the positive feelings surrounding the perceived benefits of sharing health data with health care providers, researchers, and policymakers, this suggests that momentum could be built surrounding this issue if greater public awareness of the topic were achieved.

Although there is an understanding of the benefits of health data sharing and how it could improve both individual and community health, the path towards an acceptance of greater health sharing is paved with conditional statements. Currently the scale is slightly weighted in favour of those saying they are somewhat or very uncomfortable (31%) with health data sharing, as opposed to those who say they are somewhat or very comfortable (27%) it.

Fortunately, the data suggests that there are ways in which comfort with sharing health data could be built. Here both the survey results and the discussions catalyzed in the focus groups showcased the importance of strong data safeguards, clear consent guidelines, and the de-identification or anonymization of data. Furthermore, they highlighted that many of these issues manifest to different degrees depending on the contextual confines of the community in question.

If most see the benefits of sharing health data, relatively few (4%) think this is currently being done well in Canada. Beyond this, and paralleling the conditions for improving comfort, there are concerns surrounding the existing protections with less than half (45%) of respondents agreeing or strongly agreeing that they have confidence in the existing safeguards to protect medical records. While this mixed reaction was echoed in the focus groups, the discussions underscored the important caveat that, for some, the importance of this data means that there will always be anxiety about what safeguards exist (e.g., in the same way that you might worry about the safety surrounding your online banking given what is at stake).

When provided with the Government of Canada's priorities for making a high-performing health data system, there was strong support across the board for all three tested with virtually none opposing them in both the quantitative and qualitative portions of the study. Ultimately, although awareness of the subject is low, when prompted people do care about questions of health data and do want it shared for both the individual and communal benefits it offers. If there currently

exist some barriers to establishing widespread comfort with this data being shared, there importantly exist means to overcoming them as well.

Appendix A: Quantitative methodology report

Survey methodology

Earnscliffe Strategy Group’s overall approach for this study was to conduct a mixed mode quantitative approach conducting 944 interviews by telephone using a CATI system and 3,068 interviews online using an opt-in panel. As both modes have known strengths and weaknesses when it comes to sampling, representativeness, and response bias – and given that the question under investigation pertained to digital literacy – a hybrid approach was adopted. After completing both samples, Earnscliffe compared the topline results to assess whether any significant differences exist. As the differences were in degree and not in kind, the decision was made to combine the two samples to create a combined dataset of the 4,000 interviews (with a variable identifying the mode of conduct of each case) and conduct analysis on the aggregate sample.

Questionnaire design

The questionnaires for this study were designed by Earnscliffe and provided to PHAC for feedback. The surveys were offered to respondents in both English and French and completed based on their preferences.

As the CATI interviews took longer to complete than the online ones, telephone respondents completed a shorter version of the questionnaire. This is noted in the sample sizes wherever applicable in the detailed findings.

Sample design and selection

The sampling plans for the study were designed by Earnscliffe in collaboration with PHAC. In addition to the division between CATI and online respondents noted above, it is worth noting that all respondents were Canadian adults aged 18 and older and that the overall profile was that of the general population.

For each of the two modes, specific quotas for age, gender and region were set as follows:

Region/Province	Actual	Quota (CATI)	Quota (CAWI)	Combined
Atlantic Canada	6.8%	68	204	272
Quebec	23.4%	235	705	940
Ontario	38.3%	385	1155	1540
Manitoba/Saskatchewan	6.5%	65	195	260
Alberta	11.2%	112	336	448
British Columbia	13.5%	135	405	540
TOTAL	100%	1000	3000	4000

Gender	Actual	Quota (CATI)	Quota (CAWI)	Combined
Female	51.4%	514	1542	2056
Male	48.6%	486	1458	1944
TOTAL	100%	1,000	3000	4000

Age	Actual	Quota (CATI)	Quota (CAWI)	Combined
18-34	27.3%	273	819	1092
35-54	34.1%	341	1023	1364
55+	38.6%	386	1158	1544
TOTAL	100%	1,000	3,000	4000

The table below shows the estimated incidence and expected cell sizes of each audience identified as being of specific interest.

Gender	Estimated Incidence	Quota (CATI)	Quota (CAWI)	Combined
Indigenous	5%	50	150	200
Visible minorities	25%	250	750	1000
Newcomers	4%	40	120	160
People living with a disability	22%	220	660	880
2SLGBTQ+	4%	40	120	160
TOTAL		600	1800	2400

Data collection

The surveys were conducted in English and in French, based on the respondent’s preference, between May 3 and July 9, 2023.

For the inclusion of cell phone users in the CATI sample an overlapping method was adopted. This means that the cell phone sample is not screened for dual landline and cell users. In this process, a respondent is included in the sample as long as they use a cell phone even though they may or may not have a landline.

The table below shows the Statistics Canada estimates for each of these segments (drawn from the 2019 Survey of Household Spending), the target number of interviews for each of these segments, and the proportion of the survey sample that would constitute using the overlapping method.

Segment	Actual Proportion*	Expected n	Expected % of Sample
Landline only (LLO)	8.7%	87	8.7%
Cellphone only (CPO)	45.1%	451	45.1%
Households with both	46.2%	462	46.2%
TOTAL	100%	1000	100%

For the online sample, the interviews were conducted using Leger’s platform and servers hosted in Canada. Leger’s Canadian consumer panel is comprised of over 175,000 12-month active panel members.

Targets/weighting

The data was weighted to reflect the general population in terms of region, age, and gender based on the most recent Census data available from Statistics Canada. A full breakdown of weighted versus unweighted distributions follows.

Region	Unweighted Sample	Weighted Sample
Atlantic Canada	283	270
Quebec	931	930
Ontario	1554	1557
Manitoba & Saskatchewan	266	251
Alberta	437	448
British Columbia	533	550

Gender	Unweighted Sample	Weighted Sample
Female	1981	2026
Male	1981	1933
Other	24	27

Age	Unweighted Sample	Weighted Sample
18-34	1084	1064
35-54	1494	1293
55+	1434	1656

Education	Unweighted Sample	Weighted Sample
High school or less	836	1145
College or university	2527	2437
Post-graduate degree	606	370

Household Income	Unweighted Sample	Weighted Sample
Under \$60,000	1236	1430
\$60,000 to just under \$100,000	1040	1030
\$100,000 or more	1288	1069

Indigenous Heritage	Unweighted Sample	Weighted Sample
Indigenous person, that is, First Nations (North American Indian), Métis or Inuk (Inuit)	150	163

Ethnicity	Unweighted Sample	Weighted Sample
White	3024	3129
South Asian	215	173
Chinese	236	198
Black	134	123

Latin American	72	66
Southeast Asian	50	43

Nonresponse

Respondents for the survey were selected from among those who have volunteered to participate in surveys by joining an opt-in panel. The notion of non-response is more complex than for random probability studies that begin with a sample universe that can, at least theoretically, include the entire population being studied. In such cases, non-response can occur at a number of points before being invited to participate in this particular survey, let alone in deciding to answer any particular question within the survey.

That being said, in order to provide some indication of whether the final sample is unduly influenced by a detectable nonresponse bias, we provide the tables below comparing the unweighted and weighted distributions of each sample’s demographic characteristics.

All weighting was determined based upon the most recent Census data available from Statistics Canada with a full breakdown of the weighted versus unweighted totals provided in the above section.

Quality controls

Prior to launching the survey, Earnscliffe tested the links to ensure programming matched the questionnaires. Leger conducted a pre-test of the surveys, and the data was reviewed by Earnscliffe prior to a full launch of the surveys. Upon completion of the pre-test, Earnscliffe reviewed the data to ensure all skip patterns were working and the questionnaire was easily understood by all respondents.

Reporting

Results with upper-case sub-script in the tables presented under a separate cover indicate that the difference between the demographic groups analysed are significantly higher than results found in other columns in the table. Uppercase letters indicate that the difference is significant at the 0.001 level, whereas lowercase letters indicate a difference at the 0.05 level. In the text of the report, unless otherwise noted, demographic differences highlighted are statistically significant at the 95% confidence level. The statistical test used to determine the significance of the results was the Z-test.

Results

Final dispositions

The response rate for the CATI survey was 9.2%. A full report is included in the table below:

Invalid Cases	155
Invitations mistakenly sent to people who did not qualify for the study	N/A
Incomplete or missing email addresses	155
Unresolved (U)	N/A
Email invitations bounce back	N/A
Email invitations unanswered	N/A
In-scope non-responding units (IS)	10,567
Non-response from eligible respondents	N/A
Respondent refusals	9,858
Language problem	597
Selected respondent not available (illness, leave of absence, vacation, other)	112
Early break-offs	N/A
Responding units (R)	1,072
Completed surveys disqualified - quota filled	128
Completed surveys disqualified for other reasons	N/A
Completed interviews	944
Potential sample (U+IS+R)	11639
Response rate = R / (U + IS + R)	9.2%

The response rate for the online survey was 12.5%. A full report is included in the table below:

Invalid Cases	621
Invitations mistakenly sent to people who did not qualify for the study	78
Incomplete or missing email addresses	543
Unresolved (U)	37,146

Email invitations bounce back	1,096
Email invitations unanswered	N/A
In-scope non-responding units (IS)	36,050
Non-response from eligible respondents	36,050
Respondent refusals	N/A
Language problem	N/A
Selected respondent not available (illness, leave of absence, vacation, other)	N/A
Early break-offs	N/A
Responding units (R)	5,294
Completed surveys disqualified - quota filled	2,226
Completed surveys disqualified for other reasons	N/A
Completed interviews	3,068
Potential sample (U+IS+R)	42,440
Response rate = R / (U + IS + R)	12.5%

Margin of Error

Respondents for the online survey were selected from among those who have volunteered to participate/registered to participate in online surveys. The data have been weighted to reflect the demographic composition of the Canadian population aged 18+. Because the online sample is based on those who initially self-selected for participation in the panel, no estimates of sampling error can be calculated for the entire sample. The treatment here of the non-probability sample is aligned with the Standards for the Conduct of Government of Canada Public Opinion Research for online surveys.

Appendix B: Qualitative methodology report

Methodology

The second phase of the research was qualitative and involved a series of twelve online 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.

There was one regional group and one group with informed patient advocates conducted in French. All were offered the opportunity to participate in their official language of choice irrespective of their location in Canada to accommodate those in official language minority communities (OLMCs).

The sessions were approximately 90 minutes in length and participants received the following honourariums to participate: adults 18+ (\$100), informed patient advocates (\$150), and equity deserving groups (\$125).

The table below shows the composition, date, and time of each group, as well as the number of participants per group.

Group #	Audience	Region/Language	Time	Number of Participants
Monday, August 28, 2023				
1	Adults 18+	Atlantic Canada (EN)	4:00 pm ET/5:00 pm AT/5:30 pm NT	6
2	Adults 18+	Prairies (EN)	7:00 pm ET/6:00 pm CT/5:00 pm MT	2
3	People living with a disability	National (EN)	6:00 pm ET/7:00 pm AT/7:30 pm NT/5:00 pm CT/4:00 pm MT/3:00 pm PT	5
4	Adults 18+	British Columbia/North (EN)	8:00 pm ET/7:00 pm CT/6:00 pm MT/5:00 pm PT	8
Tuesday, August 29, 2023				
5	Adults 18+	Quebec (FR)	5:00 pm ET	6

6	Adults 18+	Ontario (EN)	5:00 pm ET	8
7	Newcomers	National (EN)	7:00 pm ET/8:00 pm AT/8:30 pm NT/6:00 pm CT/5:00 pm MT/4:00 pm PT	8
8	Visible minorities	National (EN)	7:00 pm ET/8:00 pm AT/8:30 pm NT/6:00 pm CT/5:00 pm MT/4:00 pm PT	8
Wednesday, August 30, 2023				
9	Indigenous	National (EN)	7:00 pm ET/8:00 pm AT/8:30 pm NT/6:00 pm CT/5:00 pm MT/4:00 pm PT	8
10	Members of the LGBTQ2IA+ community	National (EN)	7:00 pm ET/8:00 pm AT/8:30 pm NT/6:00 pm CT/5:00 pm MT/4:00 pm PT	9
Wednesday, September 6, 2023				
11	Informed patient advocates	National (FR)	12:00 pm ET/1:00 pm AT/1:30 pm NT	7
12	Informed patient advocates	National (EN)	2:00 pm ET/1:00 pm CT/12:00 pm MT/11:00 am PT	6

Respondent’s name:	Interviewer:
Respondent’s phone number: (work)	Date:
Respondent’s phone number: (cell)	Validated:
Respondent’s email:	Quality
Sample source: panel random client referral	Central:
	On list:
	On quotas:

Recruitment

Participants were recruited using recruitment screeners (see Appendices E and F). For each focus group, 8 participants were recruited.

Our field work subcontractor, Quality Response, and their selected suppliers reached out to members of their respective databases first via email and followed up with telephone calls to pre-qualify participants for the regional and equity deserving groups. They then conducted telephone recruitment to supplement in each market.

For the informed patient advocates, PHAC provided a list of pre-screened candidates who were then contacted by Quality Response to confirm their participation.

Moderation

Two moderators were used to conduct the focus groups. Our team debriefed with PHAC after the first focus group to discuss the functionality of the discussion guide, any issues relating to recruitment, turnout, and technology. Members of PHAC were also invited to attend the focus groups as observers and were given the opportunity to ask questions via the moderator at the end of the session.

A note about interpreting qualitative research results

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. 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.

Glossary of terms

The following is a glossary of terms which explains the generalizations and interpretations of qualitative terms used throughout the report. These phrases are used when groups of participants share a specific point of view and emerging themes can be reported. Unless otherwise stated, it should not be taken to mean that the rest of participants disagreed with the point; rather others either did not comment or did not have a strong opinion on the question.

Generalization	Interpretation
Few	Few is used when less than 10% of participants have responded with similar answers.
Several	Several is used when fewer than 20% of the participants responded with similar answers.
Some	Some is used when more than 20% but significantly fewer than 50% of participants responded with similar answers.
Many	Many is used when nearly 50% of participants responded with similar answers.
Majority/Plurality	Majority or plurality are used when more than 50% but fewer than 75% of the participants responded with similar answers.
Most	Most is used when more than 75% of the participants responded with similar answers.
Vast majority	Vast majority is used when nearly all participants responded with similar answers, but several had differing views.
Unanimous/Almost all	Unanimous or almost all are used when all participants gave similar answers or when the vast majority of participants gave similar answers and the remaining few declined to comment on the issue in question.

Appendix C: Survey – CATI questionnaire

Landing Page

Thank you for agreeing to take part in this short survey on health information. We anticipate that the survey will take approximately 17 minutes to complete.

[NEXT]

Intro Page All Respondents

Background information

This research is being conducted by Earncliffe Strategies, a Canadian public opinion research firm on behalf of the Public Health Agency of Canada.

The purpose of this online survey is to collect opinions and feedback from Canadians that will be used by the Public Health Agency of Canada to help inform government policies, processes, and practices relating to Canadians’ health information.

How does the online survey work?

- You are being asked to offer your opinions and experiences through an online survey.
- We anticipate that the survey will take 17 minutes to complete.
- Your participation in the survey is completely voluntary.
- Your decision on whether or not to participate will not affect any dealings you may have with the Government of Canada.

What about your personal information?

- The personal information you provide to the Public Health Agency of Canada is governed in accordance with the *Privacy Act* and is being collected under the authority of section 4 of the *Department of Health Act* in accordance with the *Treasury Board Directive on Privacy Practices*. We only collect the information we need to conduct the research project.
- **Purpose of collection:** We require your personal information such as demographic information to better understand the topic of the research. However, your responses are always combined with the responses of others for analysis and reporting; you will never be identified.
- **For more information:** This personal information collection is described in the standard personal information bank [Public Communications – PSU 914](#), in Info Source, available online at infosource.gc.ca.
- **Your rights under the *Privacy Act*:** In addition to protecting your personal information, the *Privacy Act* gives you the right to request access to and correction of your personal information. For more information about these rights, or about our privacy practices, please contact the Public Health Agency of Canada's Privacy Coordinator privacy-vie.privee@hc-sc.gc.ca. You also have the right to file a complaint with the Privacy Commissioner of Canada if you think your personal information has been handled improperly.

What happens after the online survey?

The final report written by Earncliffe Strategies will be available to the public from Library and Archives Canada (<http://www.bac-lac.gc.ca/>).

If you have any questions about the survey, you may contact Earncliffe Strategies at info@earncliffe.ca.

Your input is greatly appreciated, and we look forward to receiving your feedback.

[CONTINUE]

Introduction for telephone interviews

Background information

Hi, my name is _____

I am calling from Earncliffe Strategies, a Canadian public opinion research firm, on behalf of the Public Health Agency of Canada.

We are conducting a survey to collect opinions and feedback from Canadians that will be used by the Public Health Agency of Canada to help inform government policies, processes, and practices relating to Canadians’ health information.

Your participation in the study is voluntary and completely confidential. All your answers will remain anonymous and will be combined with responses from all other respondents. We anticipate that the survey will take approximately 17 minutes to complete.

[CONTINUE]

Screening

1. Which gender do you identify as?
Female
Male
Other, please specify (open text box)
Prefer not to answer

2. In what year were you born?

[INSERT YEAR]

3. [IF REFUSES TO PROVIDE YOB] In that case, into which age category do you fall?

Under 18 [THANK AND TERMINATE]	1
18-24	2
25-34	3
35-44	4

45-54	5
55-64	6
65-74	7
75-84	8
85 or older	9
Prefer not to answer [THANK AND TERMINATE]	10

4. In which province or territory do you live in?

Newfoundland and Labrador	1
Nova Scotia	2
Prince Edward Island	3
New Brunswick	4
Quebec	5
Ontario	6
Manitoba	7
Saskatchewan	8
Alberta	9
British Columbia	10
Yukon	11
Nunavut	12
Northwest Territories	13
Prefer not to say [TERMINATE]	99

Survey

5. How familiar are you with the term “**health data**”?

Not at all familiar	1
A little familiar	2
Somewhat familiar	3
Very familiar	4
Don’t know/Prefer not to say	9

6. When you hear or read reference to “**health data**” without any other specifics, how clear an understanding do you have about what is meant by “health data”?

I don’t really know what is meant	1
A vague understanding	2
A decent understanding	3
A strong understanding	4
Don’t know/Prefer not to say	9

7. How prepared do you feel you are to have conversations about how health data is generated, collected, shared, used, and reported?

Not at all prepared	1
---------------------	---

Not very prepared	2
Somewhat prepared	3
Quite prepared	4
Don't know/Prefer not to say	9

8. Generally speaking, how comfortable would you be with your health data being shared, or would you say your level of comfort depends upon something?

Very uncomfortable	1
Somewhat uncomfortable	2
Neither uncomfortable nor comfortable	3
Somewhat comfortable	4
Very comfortable	5
It depends	6
Don't know/Prefer not to say	9

Based on what you know or feel about health data, how important is it that health data is available to each of the following? [RANDOMIZE ORDER]

9. Scientists conducting health-related research
 10. Government officials responsible for developing health system and public health policies and programs
 11. Health care providers other than a family doctor or those in hospital settings, such as pharmacist or dentist:

Not at all important	1
Not that important	2
Somewhat important	3
Very important	4
Don't know/Prefer not to say	9

12. Which of the following, if any, do you think are considered health data? [SELECT ALL THAT APPLY] [RANDOMIZE]

Illnesses, conditions, allergies or prescribed medications a person has or has had	1
Lab results for any sort of diagnostic tests done on a person such as blood tests or X-rays	2
Basic metrics such as blood pressure, heart rate, blood sugar	3
Health care providers that have seen the person	4
History of visits to hospitals, clinics or other types of health services such as surgeries	5
Vaccination rates for different communities or groups	6
Wait times for surgeries across different provinces and territories	7
NONE OF THE ABOVE	77
ALL OF THE ABOVE	88
Don't know/Prefer not to say	99

13. For the purposes of this survey, please consider the following definition of health data:

Health data is any type of information about a person that is useful for diagnosing, monitoring, or treating a person. Health data also includes information about public health events, how our health systems are working and information about communities.

How does this definition of health data differ from what you tend to think of when you hear the term health data?

- There is less to health data than what I thought 1
- This is exactly what I think of when I hear the term health data 2
- There is more to health data than what I thought 3
- Don’t know/Prefer not to say 9

14. To the best of your knowledge, how well or poorly do you think this sort of health data is currently being shared between providers and between provinces and territories?

- Very poorly 1
- Somewhat poorly 2
- Neither poorly nor well 3
- Somewhat well 4
- Very well 5
- Don’t know/Prefer not to say 9

For each of the following, how significant a problem do you feel each is in Canada today, if at all? [SPLIT SAMPLE: RANDOMLY SELECT 5 TO ASK RESPONDENT. RANDOMIZE ORDER.]

- 15. Health data is stored in different databases that are often not connected with each other, even if that data is related to the same person
- 16. Data about a person are not easily shared between care providers or health care facilities
- 17. Data needed by health policy-makers in government are not easily shared between different levels of government
- 18. Persons cannot easily access all of their own health data
- 19. Health care providers do not always have access to all of a person’s health information
- 20. Public health officials can’t easily access data they need to provide timely and informed recommendations, such as during public health emergencies
- 21. Researchers can’t easily access the health data they need to research new health treatments and solutions
- 22. Communities do not have a complete picture of the health of their citizens or increasing health inequities
- 23. There is no agreement for when and how data is to be shared between health care professionals, across health settings or across jurisdictions
- 24. There is no authority clearly responsible for data oversight, protection and use in Canada’s health sector

- Not a problem at all 1
- A problem, but not a serious one 2
- A somewhat serious problem 3
- A very serious problem 4
- Don’t know/Prefer not to say 9

There are a variety of ways that health data can be used. For each of the following, how much of a benefit do you feel this would be, if at all? [SPLIT SAMPLE: RANDOMLY SELECT 4 TO ASK RESPONDENT. RANDOMIZE ORDER.]

- 25. Enabling people to make more informed decisions about their personal health and achieve their personal health objectives
- 26. Enabling more informed decisions about the health of our communities, including reducing inequities
- 27. Ensuring people have a health record that follows them throughout their lives and is accessible to any of their health care providers across Canada
- 28. Enabling health care providers to better coordinate what they are doing for a person
- 29. To help improve quality and cost-effective care in our hospitals and other care settings
- 30. To help governments anticipate and respond to public health events such as an outbreak of influenza or other virus
- 31. To make it easier for health researchers to investigate problems and develop solutions

- | | |
|---------------------------------|---|
| Not a benefit at all | 1 |
| A benefit, but only a small one | 2 |
| A somewhat significant benefit | 3 |
| A very significant benefit | 4 |
| Don't know/Prefer not to say | 9 |

Please indicate how strongly you agree or disagree with each of the following statements. [SPLIT SAMPLE: RANDOMLY SELECT 3 TO ASK RESPONDENT. RANDOMIZE ORDER.]

- 32. Health care providers require timely and easy access to a person's health data so they can provide high quality health care
- 33. I am comfortable with health care providers sharing my personal health data with other health care providers that care for me
- 34. I am confident that safeguards are in place to protect my medical records and other health data from being seen by people who aren't allowed to see them
- 35. Failing to share health data can sometimes harm people or leave communities without the data they need to care for the population
- 36. I have no problem with health data being shared with researchers as long as it is completely anonymous and the user cannot possibly identify whose health data it is
- 37. I have no problem with health data being shared to inform government decisions as long as it is anonymous and the user cannot possibly identify whose health data it is

- | | |
|------------------------------|---|
| Strongly disagree | 1 |
| Disagree | 2 |
| Neither agree nor disagree | 3 |
| Agree | 4 |
| Strongly agree | 5 |
| Don't know/Prefer not to say | 9 |

Community-level health data have all personal information such as name, address and health card number removed so that no individual can be identified. Being able to analyze a large amount of community-level health data is helpful to improve health outcomes. Knowing this, how important

is it for you to be asked for your consent for sharing of this type of health data in each of the following situations? [RANDOMIZE ORDER]

- 38. When it is to be used by scientists conducting health-related research
- 39. When it is to be used by government officials and policymakers responsible for developing health policies and programs
- 40. When it is to be used by managers within health care systems monitoring how the health care system is performing

Not at all important	1
Not that important	2
Somewhat important	3
Very important	4
Don't know/Prefer not to say	9

Demographics

The next questions deal with health care that you and your immediate family may have received. By immediate family, we mean your parents and/or siblings, your spouse/partner and/or your children.

- 41. Do you have a regular primary care provider such as a family doctor or nurse practitioner?

Yes	1
No	2
DK/NR	9

- 42. Do you receive care from a variety of different health care providers, who all require access to your health information?

Yes	1
No	2
DK/NR	9

- 43. Do you currently have any chronic health condition – that is, any long-term condition, such as diabetes, that has been diagnosed by a health professional and that has lasted or is expected to last 6 months or longer?

Yes	1
No	2
DK/NR	9

- 44. Do you have primary or joint responsibility for providing care and/or assistance to any of the following people? (Note that the assistance we're referring to does NOT include employment/work done for pay. We are referring to voluntary assistance which might include taking the person to a medical appointment, meeting with their doctor, or any other voluntary activity that supports their health and wellbeing.) [SELECT ALL THAT APPLY]

Child(ren)	1
Parent(s)	2
Spouse	3
Relative	4
Friend	5
Neighbour	6
Someone else	7
NONE OF THE ABOVE	77
ALL OF THE ABOVE	88
Don't know/Prefer not to say	99

45. If you were to add up ALL of the times you interacted with a health care provider or the health care system over the past 12 months – whether getting prescriptions, seeing doctors, lab tests (bloodwork, x-ray), going to an emergency room for treatment, etc. – how many times would you estimate you did those things in total over the past year? (Note that if you saw a doctor twice and had bloodwork done once, that would be a total of 3 times.)

[RECORD OPEN-END NUMERIC RESPONSE]

46. What is the language you speak most often at home?

English	1
French	2
Other (SPECIFY)	3
Prefer not to answer	9

47. Which of the following best describes where you live:

An area with a population of less than 1,000	1
A small population centre (population between 1,000 and 29,999)	2
A medium population centre (population between 30,000 and 99,999)	3
A large urban population centre (population of 100,00 and over)	4
Prefer not to say	9

48. What is the highest certificate, diploma or degree that you have completed?

Grade 8 or less	1
Some high school	2
High school diploma or a high school equivalency certificate	3
Trades certificate or diploma	4
College, CEGEP or other non-university certificate or diploma (other than trades certificates or diplomas)	5
University certificate or diploma below bachelor's level	6
Bachelor's degree (e.g., B.A., B.A. (Hons), B.Sc., LL.B.)	7
University certificate, diploma or degree above bachelor's level	8
Prefer not to answer	9

49. Which of the following categories best describes your total household income for 2022? That is, the total income of all persons in your household combined, before taxes?

Under \$20,000	1
\$20,000 to just under \$40,000	2
\$40,000 to just under \$60,000	3
\$60,000 to just under \$80,000	4
\$80,000 to just under \$100,000	5
\$100,000 to just under \$150,000	6
\$150,000 and above	7
Prefer not to answer	9

50. Which of the following categories best describes your household? Please note that a “spouse / partner” refers to either someone you are married to or in a relationship with.

Unattached person living alone	1
Unattached person living alone with assistance	2
Person living with spouse / partner	3
Parent living with spouse / partner and children	4
Single parent living with children	5
Unattached person living with others who are not related	6
Unattached person living with family members other than children or spouse	7
Other (specify)	88
Don’t know/Prefer not to say	99

51. What is your racial and/or ethnic background? [SELECT ALL THAT APPLY.]

White	
South Asian (e.g., East Indian, Pakistani, Sri Lankan)	
Chinese	
Black	
Filipino	
Arab	
Latin American	
Southeast Asian (e.g. Vietnamese, Cambodian, Laotian, Thai)	
West Asian (e.g., Iranian, Afghan)	
Korean	
Japanese	
Other [SPECIFY]	88
Prefer not to answer	99

52. Are you First Nations, Métis or Inuk (Inuit)?

No, not First Nations, Métis or Inuk (Inuit)	1
Yes, First Nations (North American Indian)	2
Yes, Métis	3
Yes, Inuk (Inuit)	4
Prefer not to answer	99

53. Where were you born?

Born in Canada	1
Born outside Canada	2
Prefer not to answer	9

54. [IF BORN ELSEWHERE] How long have you lived in Canada?

Less than 5 years	1
5 years or more	2
Prefer not to answer	9

55. Do you identify as a person with a physical disability?

Yes	1
No	2
Prefer not to answer	9

56. Do you identify as a person who is at least one of 2SLGBTQ+?

Yes	1
No	2
Prefer not to answer	9

57. Do you feel you are racially visible in Canada (that is, non-Caucasian in race or non-white in colour)?

Yes	1
No	2
Prefer not to answer	9

[PRE-TEST ONLY ADD QUESTIONS A THRU J]

- A. Did you find any aspect of this survey difficult to understand? Y/N
- B. [IF A=YES] If so, please describe what you found difficult to understand.
- C. Did you find the way any of the questions in this survey were asked made it impossible for you to provide your answer? Y/N
- D. [IF C=YES] If so, please describe the problem with how the question was asked.
- E. Did you experience any difficulties with the language or wording? Y/N
- F. [IF E=YES] If so, please describe what difficulties you had with the language.
- G. Did you find any terms or expressions confusing? Y/N
- H. [IF G=YES] If so, please describe what terms or expressions you found confusing.
- I. Did you encounter any other issues during the course of this survey that you would like us to be aware of? Y/N
- J. [IF I=YES] If so, what are they?

This concludes the survey. Thank you for your participation!

Appendix D: Survey – CAWI questionnaire

Landing Page

Thank you for agreeing to take part in this short survey on health information. We anticipate that the survey will take approximately 17 minutes to complete.

[NEXT]

Intro Page All Respondents

Background information

This research is being conducted by Earncliffe Strategies, a Canadian public opinion research firm on behalf of the Public Health Agency of Canada.

The purpose of this online survey is to collect opinions and feedback from Canadians that will be used by the Public Health Agency of Canada to help inform government policies, processes, and practices relating to Canadians’ health information.

How does the online survey work?

- You are being asked to offer your opinions and experiences through an online survey.
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of the *Department of Health Act* in accordance with the *Treasury Board Directive on Privacy Practices*. We only collect the information we need to conduct the research project.

- **Purpose of collection:** We require your personal information such as demographic information to better understand the topic of the research. However, your responses are always combined with the responses of others for analysis and reporting; you will never be identified.
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What happens after the online survey?

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If you have any questions about the survey, you may contact Earncliffe Strategies at info@earncliffe.ca.

Your input is greatly appreciated, and we look forward to receiving your feedback.

[CONTINUE]

Introduction for telephone interviews

Background information

This research is being conducted by Earncliffe Strategies, a Canadian public opinion research firm on behalf of the Public Health Agency of Canada.

The purpose of this online survey is to collect opinions and feedback from Canadians that will be used by the Public Health Agency of Canada to help inform government policies, processes, and practices relating to Canadians' health information.

Your participation in the study is voluntary and completely confidential. All your answers will remain anonymous and will be combined with responses from all other respondents. We anticipate that the survey will take approximately 17 minutes to complete.

May we begin?

[CONTINUE]

Screening

1. Which gender do you identify as?

Female

Male

Other, please specify (open text box)

Prefer not to answer

2. In what year were you born?

[INSERT YEAR]

3. [IF REFUSES TO PROVIDE YOB] In that case, into which age category do you fall?

Under 18 [THANK AND TERMINATE]	1
18-24	2
25-34	3
35-44	4
45-54	5
55-64	6
65-74	7
75-84	8
85 or older	9
Prefer not to answer [THANK AND TERMINATE]	10

4. In which province or territory do you live in?

Newfoundland and Labrador	1
Nova Scotia	2
Prince Edward Island	3
New Brunswick	4
Quebec	5
Ontario	6
Manitoba	7
Saskatchewan	8
Alberta	9
British Columbia	10
Yukon	11
Nunavut	12
Northwest Territories	13
Prefer not to say [TERMINATE]	99

Survey

5. How familiar are you with the term “health data”?

Not at all familiar	1
A little familiar	2
Somewhat familiar	3
Very familiar	4
Don’t know/Prefer not to say	9

6. When you hear or read reference to “**health data**” without any other specifics, how clear an understanding do you have about what is meant by “health data”?

I don’t really know what is meant	1
A vague understanding	2
A decent understanding	3
A strong understanding	4
Don’t know/Prefer not to say	9

7. How prepared do you feel you are to have conversations about how health data is generated, collected, shared, used, and reported?

Not at all prepared	1
Not very prepared	2
Somewhat prepared	3
Quite prepared	4
Don’t know/Prefer not to say	9

8. Generally speaking, how comfortable would you be with your health data being shared, or would you say your level of comfort depends upon something?

Very uncomfortable	1
Somewhat uncomfortable	2
Neither uncomfortable nor comfortable	3
Somewhat comfortable	4
Very comfortable	5
It depends	6
Don’t know/Prefer not to say	9

Based on what you know or feel about health data, how important is it that health data is available to each of the following? [RANDOMIZE ORDER]

9. Scientists conducting health-related research
10. Government officials responsible for developing health system and public health policies and programs
11. Health care providers other than a family doctor or those in hospital settings, such as pharmacist or dentist:

Not at all important	1
Not that important	2
Somewhat important	3
Very important	4

Don’t know/Prefer not to say 9

12. Which of the following, if any, do you think are considered health data? [SELECT ALL THAT APPLY] [RANDOMIZE]

- Illnesses, conditions, allergies or prescribed medications a person has or has had 1
- Lab results for any sort of diagnostic tests done on a person such as blood tests or X-rays 2
- Basic metrics such as blood pressure, heart rate, blood sugar 3
- Health care providers that have seen the person 4
- History of visits to hospitals, clinics or other types of health services such as surgeries 5
- Vaccination rates for different communities or groups 6
- Wait times for surgeries across different provinces and territories 7
- NONE OF THE ABOVE 77
- ALL OF THE ABOVE 88
- Don’t know/Prefer not to say 99

13. For the purposes of this survey, please consider the following definition of health data:

Health data is any type of information about a person that is useful for diagnosing, monitoring, or treating a person. Health data also includes information about public health events, how our health systems are working and information about communities.

How does this definition of health data differ from what you tend to think of when you hear the term health data?

- There is less to health data than what I thought 1
- This is exactly what I think of when I hear the term health data 2
- There is more to health data than what I thought 3
- Don’t know/Prefer not to say 9

14. [IF MORE] Is that a little more or a lot more?

- A little more 4
- A lot more 5
- Don’t know/Prefer not to say 3

15. To the best of your knowledge, how well or poorly do you think this sort of health data is currently being shared between providers and between provinces and territories?

- Very poorly 1
- Somewhat poorly 2
- Neither poorly nor well 3
- Somewhat well 4
- Very well 5
- Don’t know/Prefer not to say 9

For each of the following, how significant a problem do you feel this is in Canada today, if at all? [SPLIT SAMPLE: RANDOMLY SELECT 5 TO ASK RESPONDENT. RANDOMIZE ORDER.]

16. Health data is stored in different databases that are often not connected with each other, even if that data is related to the same person
17. Data about a person are not easily shared between care providers or health care facilities
18. Data needed by health policy-makers in government are not easily shared between different levels of government
19. Persons cannot easily access all of their own health data
20. Health care providers do not always have access to all of a person’s health information
21. Public health officials can’t easily access data they need to provide timely and informed recommendations, such as during public health emergencies
22. Researchers can’t easily access the health data they need to research new health treatments and solutions
23. Communities do not have a complete picture of the health of their citizens or increasing health inequities
24. There is no agreement for when and how data is to be shared between health care professionals, across health settings or across jurisdictions
25. There is no authority clearly responsible for data oversight, protection and use in Canada’s health sector

- | | |
|----------------------------------|---|
| Not a problem at all | 1 |
| A problem, but not a serious one | 2 |
| A somewhat serious problem | 3 |
| A very serious problem | 4 |
| Don’t know/Prefer not to say | 9 |

There are a variety of ways that health data can be used. For each of the following, how much of a benefit do you feel this would be, if at all? [SPLIT SAMPLE: RANDOMLY SELECT 5 TO ASK RESPONDENT. RANDOMIZE ORDER.]

26. Enabling people to make more informed decisions about their personal health and achieve their personal health objectives
27. Enabling more informed decisions about the health of our communities, including reducing inequities
28. Ensuring people have a health record that follows them throughout their lives and is accessible to any of their health care providers across Canada
29. Enabling health care providers to better coordinate what they are doing for a person
30. To help improve quality and cost-effective care in our hospitals and other care settings
31. To help governments anticipate and respond to public health events such as an outbreak of influenza or other virus
32. To make it easier for health researchers to investigate problems and develop solutions

- | | |
|---------------------------------|---|
| Not a benefit at all | 1 |
| A benefit, but only a small one | 2 |
| A somewhat significant benefit | 3 |
| A very significant benefit | 4 |
| Don’t know/Prefer not to say | 9 |

Please indicate how strongly you agree or disagree with each of the following statements. [SPLIT SAMPLE: RANDOMLY SELECT 5 TO ASK RESPONDENT. RANDOMIZE ORDER.]

33. Health care providers require timely and easy access to a person's health data so they can provide high quality health care
34. I am comfortable with health care providers sharing my personal health data with other health care providers that care for me
35. I am confident that safeguards are in place to protect my medical records and other health data from being seen by people who aren't allowed to see them
36. Failing to share health data can sometimes harm people or leave communities without the data they need to care for the population
37. I have no problem with health data being shared with researchers as long as it is completely anonymous and the user cannot possibly identify whose health data it is
38. I have no problem with health data being shared to inform government decisions as long as it is anonymous and the user cannot possibly identify whose health data it is

Strongly disagree	1
Disagree	2
Neither agree nor disagree	3
Agree	4
Strongly agree	5
Don't know/Prefer not to say	9

The Government of Canada is currently working with the provinces and territories to improve health care for Canadians by modernizing health systems. Below are three ways to modernize our health systems, when it comes to health data specifically. For each of them, please indicate how strongly you support or oppose governments focussing on that priority. The first is...[RANDOMIZE].

39. Make sure people have access to, and control over, their own health data
40. Make sure health data are available to those authorized to support a person's care
41. Enable secure access to health data by authorized users who need health data to conduct medical research, improve the health care system, or make decisions affecting public health in a community

Strongly oppose	1
Oppose	2
Neither support nor oppose	3
Support	4
Strongly support	5
Don't know/Prefer not to say	9

42. If progress occurred in all three of those areas focussing on how your health data is shared, generally speaking, how comfortable would you be with your health data being shared in this way, or would you say your level of comfort depends upon something else?

Very uncomfortable	1
Somewhat uncomfortable	2
Neither uncomfortable nor comfortable	3
Somewhat comfortable	4

Very comfortable	5
It depends	6
Don’t know/Prefer not to say	9

43. [IF Q43=6 “IT DEPENDS”] You mentioned that your comfort with the idea of health data being shared depends on the situation and/or other factors. What specifically does it depend on? [OPEN END]

Giving permission to share your health data is known as providing consent. Certain rules usually apply to giving consent to share health data. For each of the following possible rules regarding your consent, would you say it is very important to you, somewhat important to you, not very important to you or not at all important to you? [RANDOMIZE]

- 44. That the only people who can give consent on your behalf are you, or someone you have explicitly designated as being able to give consent on your behalf
- 45. That your consent must be voluntary, meaning you must not be pressured or fooled into providing consent
- 46. That your consent is only asked for after you are told whether any data you are sharing includes or excludes information that identifies you, such as your name or address
- 47. That your consent is only asked for after you know the ways your health data may be used

Community-level health data have all personal information such as name, address and health card number removed so that no individual can be identified. Being able to analyze a large amount of community-level health data is helpful to improve health outcomes. Knowing this, how important is it for you to be asked for your consent for sharing of this type of health data in each of the following situations? [RANDOMIZE ORDER]

- 48. When it is to be used by scientists conducting health-related research
- 49. When it is to be used by government officials and policymakers responsible for developing health policies and programs
- 50. When it is to be used by managers within health care systems monitoring how the health care system is performing

Not at all important	1
Not that important	2
Somewhat important	3
Very important	4
Don’t know/Prefer not to say	9

Demographics

The next questions deal with health care that you and your immediate family may have received. By immediate family, we mean your parents and/or siblings, your spouse/partner and/or your children.

51. Do you have a regular primary care provider such as a family doctor or nurse practitioner?

Yes	1
No	2
DK/NR	9

52. Do you receive care from a variety of different health care providers, who all require access to your health information?

Yes	1
No	2
DK/NR	9

53. Do you currently have any chronic health condition – that is, any long-term condition, such as diabetes, that has been diagnosed by a health professional and that has lasted or is expected to last 6 months or longer?

Yes	1
No	2
DK/NR	9

54. Do you have primary or joint responsibility for providing care and/or assistance to any of the following people? (Note that the assistance we're referring to does NOT include employment/work done for pay. We are referring to voluntary assistance which might include taking the person to a medical appointment, meeting with their doctor, or any other voluntary activity that supports their health and wellbeing.) [SELECT ALL THAT APPLY]

Child(ren)	1
Parent(s)	2
Spouse	3
Relative	4
Friend	5
Neighbour	6
Someone else	7
NONE OF THE ABOVE	77
ALL OF THE ABOVE	88
Don't know/Prefer not to say	99

55. If you were to add up ALL of the times you interacted with a health care provider or the health care system over the past 12 months – whether getting prescriptions, seeing doctors, lab tests (bloodwork, x-ray), going to an emergency room for treatment, etc. – how many times would you estimate you did those things in total over the past year? (Note that if you saw a doctor twice and had bloodwork done once, that would be a total of 3 times.)

[RECORD OPEN-END NUMERIC RESPONSE]

56. What is the language you speak most often at home?

English	1
French	2
Other (SPECIFY)	3

Prefer not to answer 9

57. Which of the following best describes where you live:

An area with a population of less than 1,000 1
 A small population centre (population between 1,000 and 29,999) 2
 A medium population centre (population between 30,000 and 99,999) 3
 A large urban population centre (population of 100,00 and over) 4
 Prefer not to say 9

58. What is the highest certificate, diploma or degree that you have completed?

Grade 8 or less 1
 Some high school 2
 High school diploma or a high school equivalency certificate 3
 Trades certificate or diploma 4
 College, CEGEP or other non-university certificate or diploma (other than trades certificates or diplomas) 5
 University certificate or diploma below bachelor’s level 6
 Bachelor’s degree (e.g., B.A., B.A. (Hons), B.Sc., LL.B.) 7
 University certificate, diploma or degree above bachelor’s level 8
 Prefer not to answer 9

59. Which of the following categories best describes your total household income for 2022? That is, the total income of all persons in your household combined, before taxes?

Under \$20,000 1
 \$20,000 to just under \$40,000 2
 \$40,000 to just under \$60,000 3
 \$60,000 to just under \$80,000 4
 \$80,000 to just under \$100,000 5
 \$100,000 to just under \$150,000 6
 \$150,000 and above 7
 Prefer not to answer 9

60. Which of the following categories best describes your household? Please note that a “spouse / partner” refers to either someone you are married to or in a relationship with.

Unattached person living alone 1
 Unattached person living alone with assistance 2
 Person living with spouse / partner 3
 Parent living with spouse / partner and children 4
 Single parent living with children 5
 Unattached person living with others who are not related 6
 Unattached person living with family members other than children or spouse 7
 Other (specify) 88
 Don’t know/Prefer not to say 99

61. What is your racial and/or ethnic background? [SELECT ALL THAT APPLY.]

White	
South Asian (e.g., East Indian, Pakistani, Sri Lankan)	
Chinese	
Black	
Filipino	
Arab	
Latin American	
Southeast Asian (e.g. Vietnamese, Cambodian, Laotian, Thai)	
West Asian (e.g., Iranian, Afghan)	
Korean	
Japanese	
Other [SPECIFY]	88
Prefer not to answer	99

62. Are you First Nations, Métis or Inuk (Inuit)?

No, not First Nations, Métis or Inuk (Inuit)	1
Yes, First Nations (North American Indian)	2
Yes, Métis	3
Yes, Inuk (Inuit)	4
Prefer not to answer	99

63. Where were you born?

Born in Canada	1
Born outside Canada	2
Prefer not to answer	9

64. [IF BORN ELSEWHERE] How long have you lived in Canada?

Less than 5 years	1
5 years or more	2
Prefer not to answer	9

65. Do you identify as a person with a physical disability?

Yes	1
No	2
Prefer not to answer	9

66. Do you identify as a person who is at least one of 2SLGBTQ+?

Yes	1
No	2
Prefer not to answer	9

67. Do you feel you are racially visible in Canada (that is, non-Caucasian in race or non-white in colour)?

Yes	1
No	2
Prefer not to answer	9

[PRE-TEST ONLY ADD QUESTIONS A THRU J]

K. Did you find any aspect of this survey difficult to understand? Y/N

L. [IF A=YES] If so, please describe what you found difficult to understand.

M. Did you find the way any of the questions in this survey were asked made it impossible for you to provide your answer? Y/N

N. [IF C=YES] If so, please describe the problem with how the question was asked.

O. Did you experience any difficulties with the language or wording? Y/N

P. [IF E=YES] If so, please describe what difficulties you had with the language.

Q. Did you find any terms or expressions confusing? Y/N

R. [IF G=YES] If so, please describe what terms or expressions you found confusing.

S. Did you encounter any other issues during the course of this survey that you would like us to be aware of? Y/N

T. [IF I=YES] If so, what are they?

This concludes the survey. Thank you for your participation!

Appendix E: Recruitment screener – general population

Focus Group Summary

- Recruit 8 participants per group
- Groups are 90 minutes in length
- 12 groups in total:
 - Five groups with adults 18+; one in each of five regions: Atlantic Canada, Ontario, Quebec, Prairies (Manitoba, Saskatchewan, Alberta), British Columbia/North (Yukon, Northwest Territories, Nunavut)
 - Five pan-Canadian groups with equity deserving populations
 - One group with visible minorities (Q7)
 - One group with Indigenous peoples (Q8)
 - One group with newcomers (Q9 & Q10)
 - One group with people living with a physical disability (Q11)
 - One group with members of the LGBTQ2IA+ community (Q5 & Q6)
 - Two pan-Canadian groups with informed patient advocates
- Ensure good mix of other demos (province within regions, age, gender, income, education, urban/suburban/rural etc.)

Group #	Audience	Region/Language	Time
Monday, August 28, 2023			
1	Adults 18+	Atlantic Canada (EN)	4:00 pm ET/5:00 pm AT/5:30 pm NT
2	Adults 18+	Prairies (EN)	7:00 pm ET/6:00 pm CT/5:00 pm MT
3	People living with a disability	National (EN)	6:00 pm ET/7:00 pm AT/7:30 pm NT/5:00 pm CT/4:00 pm MT/3:00 pm PT
4	Adults 18+	British Columbia/North (EN)	8:00 pm ET/7:00 pm CT/6:00 pm MT/5:00 pm PT
Tuesday, August 29, 2023			
6	Adults 18+	Quebec (FR)	5:00 pm ET
7	Adults 18+	Ontario (EN)	5:00 pm ET
8	Newcomers	National (EN)	7:00 pm ET/8:00 pm AT/8:30 pm NT/6:00 pm CT/5:00 pm MT/4:00 pm PT
9	Visible minorities	National (EN)	7:00 pm ET/8:00 pm AT/8:30 pm NT/6:00 pm CT/5:00 pm MT/4:00 pm PT

Wednesday, August 30, 2023			
10	Indigenous	National (EN)	7:00 pm ET/8:00 pm AT/8:30 pm NT/6:00 pm CT/5:00 pm MT/4:00 pm PT
11	Members of the LGBTQ2IA+ community	National (EN)	7:00 pm ET/8:00 pm AT/8:30 pm NT/6:00 pm CT/5:00 pm MT/4:00 pm PT

Respondent’s name:	Interviewer:
Respondent’s phone number: (work)	Date:
Respondent’s phone number: (cell)	Validated:
Respondent’s email:	Quality
Sample source: panel random client referral	Central:
	On list:
	On quotas:

Hello/Bonjour, this is _____ calling on behalf of Earnscliffe, a national public opinion research firm. Would you prefer that I continue in English or French? Préférez-vous continuer en français ou en anglais ?

NOTE: If at this point the respondent prefers to respond in French, then the interviewer must be able to either proceed with the interview in French or read the following statement: « Je vous remercie. Quelqu’un vous rappellera bientôt pour mener le sondage/ le questionnaire/ la preselection en français. »

We are organizing a series of discussion groups on issues of importance on behalf of the Government of Canada, specifically the Public Health Agency of Canada. The Government would like to better understand Canadians’ views to help inform the development of future planning initiatives. We are looking for people who would be willing to participate in a 90-minute online discussion group. Up to 10 participants will be taking part and for their time, participants will receive an honorarium. May I continue?

Yes CONTINUE
 No THANK AND TERMINATE

Participation is voluntary. We are interested in hearing your opinions; no attempt will be made to sell you anything or change your point of view. The format is a ‘round table’ discussion led by a research professional. All opinions expressed will remain anonymous and views will be grouped together to ensure no particular individual can be identified. The information you provide will be administered according to the requirements of the *Privacy Act*, the *Access to Information Act*, and any other pertinent legislation.

I would like to ask you a few questions to see if you or someone in your household qualify to participate. This will take about three minutes. May I continue?

Yes CONTINUE
No THANK AND TERMINATE

Monitoring text:

READ TO ALL: “This call may be monitored or audio taped for quality control and evaluation purposes.

ADDITIONAL CLARIFICATION IF NEEDED:

To ensure that I (the interviewer) am reading the questions correctly and collecting your answers accurately;

To assess my (the interviewer) work for performance evaluation;

To ensure that the questionnaire is accurate/correct (i.e. evaluation of CATI programming and methodology – we’re asking the right questions to meet our clients’ research requirements – kind of like pre-testing)

If the call is audio taped, it is only for the purposes of playback to the interviewer for a performance evaluation immediately after the interview is conducted or it can be used by the Project Manager/client to evaluate the questionnaire if they are unavailable at the time of the interview – all audio tapes are destroyed after the evaluation.

1. Do you or does anyone in your immediate family or household work in any of the following areas?

	Yes	No
A marketing research firm	1	2
A magazine or newspaper, online or print	1	2
A radio or television station	1	2
A public relations company	1	2
An advertising agency or graphic design firm	1	2
An online media company or as a blog writer	1	2
In health care	1	2
The government, whether federal, provincial or municipal	1	2

IF “YES” TO ANY OF THE ABOVE, THANK AND TERMINATE

2. Which of the following age categories do you fall in to? Are you...? [ENSURE GOOD MIX]

Under 18 years	1	THANK AND TERMINATE
18-24 years	2	
25-29 years	3	
30-34 years	4	
35-39 years	5	
40-49 years	6	
50-59 years	7	
60-64 years	8	
65+ years	9	

3. In which province or territory do you live?

ATLANTIC CANADA	
Newfoundland and Labrador	1
Nova Scotia	2
New Brunswick	3
Prince Edward Island	4
QUEBEC	5
ONTARIO	6
PRAIRIES	
Manitoba	7
Saskatchewan	8
Alberta	9
BRITISH COLUMBIA/NORTH	
British-Columbia	10
Nunavut	11
Northwest Territories	12
Yukon	13

4. How would you describe the area in which you live? [ENSURE GOOD MIX]

Large urban population centre, that is, it has a population 100,000 or greater	1
Medium urban population centre, that is, it has a population of 30,000 to 99,999	2
Small urban population centre, that is, it has a population of 1,000 to 29,999	3
Rural area, that is, it has a population of less than 1,000	4
Remote area, that is, it has a population of less than 1,000 and you are isolated from other communities	5
Don't know/Prefer not to say	9

5. What gender do you identify with? [ENSURE GOOD MIX]

Male	1	
Female	2	
Non-binary person	3	ELIGIBLE FOR GROUP 11
Two spirit	4	ELIGIBLE FOR GROUP 11
Another gender identify	5	ELIGIBLE FOR GROUP 11
Prefer not to answer	9	

6. Do you identify as a member of the LGBTQ2IA+ community?

Yes	1	ELIGIBLE FOR GROUP 11
No	2	
Prefer not to answer	3	

7. What is your racial and/or ethnic background? [SELECT ALL THAT APPLY]

White	1
South Asian (e.g., East Indian, Pakistani, Sri Lankan)	2
Chinese	3
Black	4
Filipino	5
Arab	6
Southeast Asian (e.g., Vietnamese, Cambodian, Latoian, Thai)	7
West Asian (e.g., Iranian, Afghan)	8
Korean	9
Japanese	10
Other (please specify)	88
Prefer not to answer	99

IF 2,3,4,5,6,7,8,9, EILIGIBLE FOR VISIBLE MINORITIES (GROUP 9).

8. Are you First Nations, Metis or Inuk (Inuit)?

No, not First Nations, Metis, or Inuk (Inuit)	1	
Yes, First Nations (North American Indian)	2	
Yes, Metis	3	
Yes, Inuk (Inuit)	4	
Prefer not to answer	3	THANK AND TERMINATE

IF FIRST NATIONS, METIS, OR INUK (INUIT), ELIGIBLE FOR INDIGENOUS PEOPLES (GROUP 10).

9. Were you born in Canada?

Yes	1	SKIP TO Q11
No	2	ASK Q10
Prefer not to answer	3	THANK AND TERMINATE

10. [IF NOT] How long have you lived in Canada?

5 years or less	1	ELIGIBLE FOR GROUP 8
6 years or more	2	
Prefer not to answer	3	THANK AND TERMINATE

11. Do you identify as a person living with a physical disability?

Yes	1	ELIBIGIBLE FOR GROUP 3
No	2	
Prefer not to answer	9	

12. What is your current employment status? [ENSURE GOOD MIX]

Working full-time	1	
Working part-time	2	
Self-employed	3	
Retired	4	
Unemployed	5	
Student	6	
Other	7	
Prefer not to answer	9	THANK AND TERMINATE

13. Which of the following categories best describes your total household income; that is, the total income of all persons in your household combined, before taxes? [READ LIST]
[ENSURE GOOD MIX]

Under \$20,000	1	
\$20,000 to under \$40,000	2	
\$40,000 to under \$60,000	3	
\$60,000 to under \$80,000	4	
\$80,000 to under \$100,000	5	
\$100,000 to under \$150,000	6	
\$150,000 or more	7	
DK/NR	9	THANK AND TERMINATE

14. What is the highest certificate, diploma or degree that you have completed? [ENSURE GOOD MIX]

Grade 8 or less	1
Some high school	2
High school diploma or a high school equivalency certificate	3
Trades certificate or diploma	4
College, CEGEP or other non-university certificate or diploma other than trades certificate or diploma	5
University certificate or diploma below bachelor’s level	6
Bachelor’s degree (e.g., B.A., B.A. (Hons), B.SC., LL.B.)	7
University certificate, diploma or degree above bachelor’s level	8
Prefer not to answer	9

15. Have you participated in a discussion or focus group before? A discussion group brings together a few people in order to know their opinion about a given subject.

Yes	1	MAX 4 PER GROUP
No	2	SKIP TO Q18
Don’t know/Prefer not to answer	9	THANK AND TERMINATE

16. When was the last time you attended a discussion or focus group?

If within the last 6 months	1	THANK AND TERMINATE
If not within the last 6 months	2	CONTINUE
Don’t know/Prefer not to answer	9	THANK AND TERMINATE

17. How many of these sessions have you attended in the last five years?

If 4 or less	1	CONTINUE
If 5 or more	2	THANK AND TERMINATE
Don’t know/Prefer not to answer	9	THANK AND TERMINATE

This research will require participating in a video call online.

18. Do you have access to a computer, smartphone or tablet with high-speed internet which will allow you to participate in an online discussion group?

Yes	CONTINUE
No	THANK AND TERMINATE

19. Does your computer/smartphone/tablet have a camera that will allow you to be visible to the moderator and other participants as part of an online discussion group?

Yes CONTINUE
No THANK AND TERMINATE

20. Do you have a personal email address that is currently active and available to you?

Yes CONTINUE, PLEASE RECORD EMAIL
No THANK AND TERMINATE

INVITATION

21. Participants in discussion groups are asked to voice their opinions and thoughts. How comfortable are you in voicing your opinions in front of others? Are you...? (READ LIST)

Very comfortable	1	MINIMUM 4 PER GROUP
Fairly comfortable	2	CONTINUE
Comfortable	3	CONTINUE
Not very comfortable	4	THANK AND TERMINATE
Not at all comfortable	5	THANK AND TERMINATE
Don't know/Prefer not to answer	9	THANK AND TERMINATE

22. Sometimes participants are asked to read text, review images, or type out answers during the discussion. Is there any reason why you could not participate?

Yes	1	ASK Q23
No	2	SKIP TO Q25
Don't know/Prefer not to answer	9	THANK AND TERMINATE

23. Is there anything we could do to ensure that you can participate?

Yes	1	ASK Q22
No	2	THANK AND TERMINATE
Don't know/Prefer not to answer	9	THANK AND TERMINATE

24. What specifically? [OPEN END] **INTERVIEWER TO NOTE FOR POTENTIAL ONE-ON-ONE INTERVIEW**

25. Based on your responses, it looks like you have the profile we are looking for. I would like to invite you to participate in a small group discussion, called an online focus group, we are conducting at [TIME], on [DATE]. As you may know, focus groups are used to gather information on a particular subject matter. The discussion will consist of up to 10 people and will be very informal.

It will last up to 90 minutes and you will receive an incentive of... [MEMBERS OF THE GENERAL PUBLIC] \$100; [EQUITY DESERVING GROUPS] \$125; [INFORMED PATIENT ADVOCATES] \$150.

...as a thank you for your time. Would you be willing to attend?

Yes	1	RECRUIT
No	2	THANK AND TERMINATE
Don't know/Prefer not to answer	9	THANK AND TERMINATE

PRIVACY QUESTIONS

Now I have a few questions that relate to privacy, your personal information and the research process. We will need your consent on a few issues that enable us to conduct our research. As I run through these questions, please feel free to ask me any questions you would like clarified.

P1) First, we will be providing a list of respondents’ first names and profiles (screener responses) to the moderator so that they can sign you into the group. Do we have your permission to do this? I assure you it will be kept strictly confidential.

Yes	1	GO TO P2
No	2	GO TO P1A

We need to provide the first names and background of the people attending the focus group because only the individuals invited are allowed in the session and this information is necessary for verification purposes. Please be assured that this information will be kept strictly confidential. GO TO P1A

P1a) Now that I’ve explained this, do I have your permission to provide your first name and profile?

Yes	1	GO TO P2
No	2	THANK & TERMINATE

P2) A recording of the group session will be produced for research purposes. The recordings will be used by the research professional to assist in preparing a report on the research

findings and may be used by the Government of Canada to inform their work in this subject area.

Do you agree to be recorded for research and reporting purposes only?

Yes	1	THANK & GO TO P3
No	2	READ RESPONDENT INFO BELOW & GO TO P2A

It is necessary for the research process for us to record the session as the researchers need this material to complete the report.

P2a) Now that I've explained this, do I have your permission for recording?

Yes	1	THANK & GO TO P3
No	2	THANK & TERMINATE

P3) Employees from the Government of Canada may also be online to observe the groups.

Do you agree to be observed by Government of Canada employees?

Yes	1	THANK & GO TO INVITATION
No	2	GO TO P3A

P3a) It is standard qualitative procedure to invite clients, in this case, Government of Canada employees, to observe the groups online. They will be there simply to hear your opinions firsthand although they may take their own notes and confer with the moderator on occasion to discuss whether there are any additional questions to ask the group.

Do you agree to be observed by Government of Canada employees and employees of the creative agency?

Yes	1	THANK & GO TO INVITATION
No	2	THANK & TERMINATE

INVITATION

Wonderful, you qualify to participate in one of our discussion sessions. As I mentioned earlier, the group discussion will take place on [DATE] at [TIME] for up to 90 minutes.

Group #	Audience	Region/Language	Time
Monday, August 28, 2023			
1	Adults 18+	Atlantic Canada (EN)	4:00 pm ET/5:00 pm AT/5:30 pm NT
2	Adults 18+	Prairies (EN)	7:00 pm ET/6:00 pm CT/5:00 pm MT
3	People living with a disability	National (EN)	6:00 pm ET/7:00 pm AT/7:30 pm NT/5:00 pm CT/4:00 pm MT/3:00 pm PT
4	Adults 18+	British Columbia/North (EN)	8:00 pm ET/7:00 pm CT/6:00 pm MT/5:00 pm PT
Tuesday, August 29, 2023			
4	Informed patient advocates	National (FR)	12:00 pm ET/1:00 pm AT/1:30 pm NT
5	Informed patient advocates	National (EN)	2:00 pm ET/1:00 pm CT/12:00 pm MT/11:00 am PT
6	Adults 18+	Quebec (FR)	5:00 pm ET
7	Adults 18+	Ontario (EN)	5:00 pm ET
8	Newcomers	National (EN)	7:00 pm ET/8:00 pm AT/8:30 pm NT/6:00 pm CT/5:00 pm MT/4:00 pm PT
9	Visible minorities	National (EN)	7:00 pm ET/8:00 pm AT/8:30 pm NT/6:00 pm CT/5:00 pm MT/4:00 pm PT
Wednesday, August 30, 2023			
10	Indigenous	National (EN)	7:00 pm ET/8:00 pm AT/8:30 pm NT/6:00 pm CT/5:00 pm MT/4:00 pm PT
11	Members of the LGBTQ2IA+ community	National (EN)	7:00 pm ET/8:00 pm AT/8:30 pm NT/6:00 pm CT/5:00 pm MT/4:00 pm PT

Can I confirm your email address so that we can send you the link to the online discussion group?

We ask that you login a few minutes early to be sure you are able to connect and to test your sound (speaker and microphone). If you require glasses for reading, please make sure you have them handy as well.

As we are only inviting a small number of people, your participation is very important to us. If for some reason you are unable to attend, please call us so that we may get someone to replace you. You can reach us at [INSERT PHONE NUMBER] at our office. Please ask for [NAME]. Someone will call you in the days leading up to the discussion to remind you.

So that we can call you to remind you about the discussion group or contact you should there be any changes, can you please confirm your name and contact information for me?

First name
Last Name
email
Daytime phone number
Evening phone number

If the respondent refuses to give his/her first or last name, email or phone number please assure them that this information will be kept strictly confidential in accordance with the privacy law and that it is used strictly to contact them to confirm their attendance and to inform them of any changes to the discussion group. If they still refuse THANK & TERMINATE.

Appendix F: Recruitment screener – informed patient advocates

Focus Group Summary

- Recruit 8 participants per group
- Groups are 90 minutes in length
- 12 groups in total:
 - Five groups with adults 18+; one in each of five regions: Atlantic Canada, Ontario, Quebec, Prairies (Manitoba, Saskatchewan, Alberta), British Columbia/North (Yukon, Northwest Territories, Nunavut)
 - Five pan-Canadian groups with equity deserving populations
 - One group with visible minorities (Q7)
 - One group with Indigenous peoples (Q8)
 - One group with newcomers (Q9 & Q10)
 - One group with people living with a physical disability (Q11)
 - One group with members of the LGBTQ2IA+ community (Q5 & Q6)
 - Two pan-Canadian groups with informed patient advocates
- Ensure good mix of other demos (province within regions, age, gender, income, education, urban/suburban/rural etc.)

Group #	Audience	Region/Language	Time
Monday, August 28, 2023			
1	Adults 18+	Atlantic Canada (EN)	4:00 pm ET/5:00 pm AT/5:30 pm NT
2	Adults 18+	Prairies (EN)	7:00 pm ET/6:00 pm CT/5:00 pm MT
3	People living with a disability	National (EN)	6:00 pm ET/7:00 pm AT/7:30 pm NT/5:00 pm CT/4:00 pm MT/3:00 pm PT
4	Adults 18+	British Columbia/North (EN)	8:00 pm ET/7:00 pm CT/6:00 pm MT/5:00 pm PT
Tuesday, August 29, 2023			
5	Adults 18+	Quebec (FR)	5:00 pm ET
6	Adults 18+	Ontario (EN)	5:00 pm ET
7	Newcomers	National (EN)	7:00 pm ET/8:00 pm AT/8:30 pm NT/6:00 pm CT/5:00 pm MT/4:00 pm PT

8	Visible minorities	National (EN)	7:00 pm ET/8:00 pm AT/8:30 pm NT/6:00 pm CT/5:00 pm MT/4:00 pm PT
Wednesday, August 30, 2023			
9	Indigenous	National (EN)	7:00 pm ET/8:00 pm AT/8:30 pm NT/6:00 pm CT/5:00 pm MT/4:00 pm PT
10	Members of the LGBTQ2IA+ community	National (EN)	7:00 pm ET/8:00 pm AT/8:30 pm NT/6:00 pm CT/5:00 pm MT/4:00 pm PT
Wednesday, September 6, 2023			
11	Informed patient advocates	National (FR)	12:00 pm ET/1:00 pm AT/1:30 pm NT
12	Informed patient advocates	National (EN)	2:00 pm ET/1:00 pm CT/12:00 pm MT/11:00 am PT

Respondent’s name:	Interviewer:
Respondent’s phone number: (work)	Date:
Respondent’s phone number: (cell)	Validated:
Respondent’s email:	Quality
Sample source: panel random client referral	Central:
	On list:
	On quotas:

Hello/Bonjour, this is _____ calling on behalf of Earnscliffe, a national public opinion research firm. Would you prefer that I continue in English or French? Préférez-vous continuer en français ou en anglais ?

NOTE: If at this point the respondent prefers to respond in French, then the interviewer must be able to either proceed with the interview in French or read the following statement: « Je vous remercie. Quelqu’un vous rappellera bientôt pour mener le sondage/ le questionnaire/ la preselection en français. »

We are organizing a series of discussion groups on issues of importance on behalf of the Government of Canada, specifically the Public Health Agency of Canada. The Government would like to better understand Canadians’ views to help inform the development of future planning initiatives. We are looking for people who would be willing to participate in a 90-minute online discussion group. Up to 10 participants will be taking part and for their time, participants will receive an honorarium. May I continue?

Yes CONTINUE
No THANK AND TERMINATE

Participation is voluntary. We are interested in hearing your opinions; no attempt will be made to sell you anything or change your point of view. The format is a ‘round table’ discussion led by a research professional. All opinions expressed will remain anonymous and views will be grouped together to ensure no particular individual can be identified. The information you provide will be administered according to the requirements of the *Privacy Act*, the *Access to Information Act*, and any other pertinent legislation.

I would like to ask you a few questions to see if you or someone in your household qualify to participate. This will take about three minutes. May I continue?

Yes CONTINUE
 No THANK AND TERMINATE

Monitoring text:

READ TO ALL: “This call may be monitored or audio taped for quality control and evaluation purposes.

ADDITIONAL CLARIFICATION IF NEEDED:

To ensure that I (the interviewer) am reading the questions correctly and collecting your answers accurately;

To assess my (the interviewer) work for performance evaluation;

To ensure that the questionnaire is accurate/correct (i.e. evaluation of CATI programming and methodology – we’re asking the right questions to meet our clients’ research requirements – kind of like pre-testing)

If the call is audio taped, it is only for the purposes of playback to the interviewer for a performance evaluation immediately after the interview is conducted or it can be used by the Project Manager/client to evaluate the questionnaire if they are unavailable at the time of the interview – all audio tapes are destroyed after the evaluation.

26. Do you or does anyone in your immediate family or household work in any of the following areas?

	Yes	No
A marketing research firm	1	2
A magazine or newspaper, online or print	1	2
A radio or television station	1	2
A public relations company	1	2
An advertising agency or graphic design firm	1	2
An online media company or as a blog writer	1	2
The government, whether federal, provincial or municipal	1	2

IF “YES” TO ANY OF THE ABOVE, THANK AND TERMINATE

27. Are you a member of a local, provincial, territorial or federal patient advocacy organization?

Yes	1	CONTINUE
No	2	THANK AND TERMINATE
Don't know/Prefer not to say	9	THANK AND TERMINATE

28. What is your role in that organization? [ENSURE GOOD MIX]

Patient member	1
Board member	2
Executive member	3
Operational Staff (client service, marketing, admin, etc.)	4
Lobbyist	5
Fundraiser	6
Don't know/Prefer not to say	9

29. How many years have you been advocating for patients? [ENSURE GOOD MIX]

Less than a year	1
Two to five years	2
Six to ten years	3
More than 10 years	4
Don't know/Prefer not to say	9

30. Which of the following age categories do you fall in to? Are you...? [ENSURE GOOD MIX]

Under 18 years	1	THANK AND TERMINATE
18-24 years	2	
25-29 years	3	
30-34 years	4	
35-39 years	5	
40-49 years	6	
50-59 years	7	
60-64 years	8	
65+ years	9	

31. In which province or territory do you live?

ATLANTIC CANADA	
Newfoundland and Labrador	1
Nova Scotia	2
New Brunswick	3
Prince Edward Island	4
QUEBEC	5
ONTARIO	6

PRAIRIES	
Manitoba	7
Saskatchewan	8
Alberta	9
BRITISH COLUMBIA/NORTH	
British-Columbia	10
Nunavut	11
Northwest Territories	12
Yukon	13

32. How would you describe the area in which you live? [ENSURE GOOD MIX]

Large urban population centre, that is, it has a population 100,000 or greater	1
Medium urban population centre, that is, it has a population of 30,000 to 99,999	2
Small urban population centre, that is, it has a population of 1,000 to 29,999	3
Rural area, that is, it has a population of less than 1,000	4
Remote area, that is, it has a population of less than 1,000 and you are isolated from other communities	5
Don't know/Prefer not to say	9

33. What gender do you identify with? [ENSURE GOOD MIX]

Male	1	
Female	2	
Non-binary person	3	ELIGIBLE FOR GROUP 11
Two spirit	4	ELIGIBLE FOR GROUP 11
Another gender identify	5	ELIGIBLE FOR GROUP 11
Prefer not to answer	9	

This research will require participating in a video call online.

34. Do you have access to a computer, smartphone or tablet with high-speed internet which will allow you to participate in an online discussion group?

Yes	CONTINUE
No	THANK AND TERMINATE

35. Does your computer/smartphone/tablet have a camera that will allow you to be visible to the moderator and other participants as part of an online discussion group?

Yes	CONTINUE
No	THANK AND TERMINATE

36. Do you have a personal email address that is currently active and available to you?

Yes	CONTINUE, PLEASE RECORD EMAIL
-----	-------------------------------

No THANK AND TERMINATE

INVITATION

37. Participants in discussion groups are asked to voice their opinions and thoughts. How comfortable are you in voicing your opinions in front of others? Are you...? (READ LIST)

Very comfortable	1	MINIMUM 4 PER GROUP
Fairly comfortable	2	CONTINUE
Comfortable	3	CONTINUE
Not very comfortable	4	THANK AND TERMINATE
Not at all comfortable	5	THANK AND TERMINATE
Don’t know/Prefer not to answer	9	THANK AND TERMINATE

38. Sometimes participants are asked to read text, review images, or type out answers during the discussion. Is there any reason why you could not participate?

Yes	1	ASK Q23
No	2	SKIP TO Q25
Don’t know/Prefer not to answer	9	THANK AND TERMINATE

39. Is there anything we could do to ensure that you can participate?

Yes	1	ASK Q22
No	2	THANK AND TERMINATE
Don’t know/Prefer not to answer	9	THANK AND TERMINATE

40. What specifically? [OPEN END] **INTERVIEWER TO NOTE FOR POTENTIAL ONE-ON-ONE INTERVIEW**

41. Based on your responses, it looks like you have the profile we are looking for. I would like to invite you to participate in a small group discussion, called an online focus group, we are conducting at [TIME], on [DATE]. As you may know, focus groups are used to gather information on a particular subject matter. The discussion will consist of up to 10 people and will be very informal.

It will last up to 90 minutes and you will receive an incentive of... [MEMBERS OF THE GENERAL PUBLIC] \$100; [EQUITY DESERVING GROUPS] \$125; [INFORMED PATIENT ADVOCATES] \$150.

...as a thank you for your time. Would you be willing to attend?

Yes	1	RECRUIT
No	2	THANK AND TERMINATE
Don't know/Prefer not to answer	9	THANK AND TERMINATE

PRIVACY QUESTIONS

Now I have a few questions that relate to privacy, your personal information and the research process. We will need your consent on a few issues that enable us to conduct our research. As I run through these questions, please feel free to ask me any questions you would like clarified.

P1) First, we will be providing a list of respondents’ first names and profiles (screener responses) to the moderator so that they can sign you into the group. Do we have your permission to do this? I assure you it will be kept strictly confidential.

Yes	1	GO TO P2
No	2	GO TO P1A

We need to provide the first names and background of the people attending the focus group because only the individuals invited are allowed in the session and this information is necessary for verification purposes. Please be assured that this information will be kept strictly confidential. GO TO P1A

P1a) Now that I’ve explained this, do I have your permission to provide your first name and profile?

Yes	1	GO TO P2
No	2	THANK & TERMINATE

P2) A recording of the group session will be produced for research purposes. The recordings will be used by the research professional to assist in preparing a report on the research

findings and may be used by the Government of Canada to inform their work in this subject area.

Do you agree to be recorded for research and reporting purposes only?

Yes	1	THANK & GO TO P3
No	2	READ RESPONDENT INFO BELOW & GO TO P2A

It is necessary for the research process for us to record the session as the researchers need this material to complete the report.

P2a) Now that I've explained this, do I have your permission for recording?

Yes	1	THANK & GO TO P3
No	2	THANK & TERMINATE

P3) Employees from the Government of Canada may also be online to observe the groups.

Do you agree to be observed by Government of Canada employees?

Yes	1	THANK & GO TO INVITATION
No	2	GO TO P3A

P3a) It is standard qualitative procedure to invite clients, in this case, Government of Canada employees, to observe the groups online. They will be there simply to hear your opinions firsthand although they may take their own notes and confer with the moderator on occasion to discuss whether there are any additional questions to ask the group.

Do you agree to be observed by Government of Canada employees and employees of the creative agency?

Yes	1	THANK & GO TO INVITATION
No	2	THANK & TERMINATE

INVITATION

Wonderful, you qualify to participate in one of our discussion sessions. As I mentioned earlier, the group discussion will take place on [DATE] at [TIME] for up to 90 minutes.

Group #	Audience	Region/Language	Time
Monday, August 28, 2023			
1	Adults 18+	Atlantic Canada (EN)	4:00 pm ET/5:00 pm AT/5:30 pm NT
2	Adults 18+	Prairies (EN)	7:00 pm ET/6:00 pm CT/5:00 pm MT
3	People living with a disability	National (EN)	6:00 pm ET/7:00 pm AT/7:30 pm NT/5:00 pm CT/4:00 pm MT/3:00 pm PT
4	Adults 18+	British Columbia/North (EN)	8:00 pm ET/7:00 pm CT/6:00 pm MT/5:00 pm PT
Tuesday, August 29, 2023			
4	Informed patient advocates	National (FR)	12:00 pm ET/1:00 pm AT/1:30 pm NT
5	Informed patient advocates	National (EN)	2:00 pm ET/1:00 pm CT/12:00 pm MT/11:00 am PT
6	Adults 18+	Quebec (FR)	5:00 pm ET
	Adults 18+	Ontario (EN)	5:00 pm ET
8	Newcomers	National (EN)	7:00 pm ET/8:00 pm AT/8:30 pm NT/6:00 pm CT/5:00 pm MT/4:00 pm PT
9	Visible minorities	National (EN)	7:00 pm ET/8:00 pm AT/8:30 pm NT/6:00 pm CT/5:00 pm MT/4:00 pm PT
Wednesday, August 30, 2023			
10	Indigenous	National (EN)	7:00 pm ET/8:00 pm AT/8:30 pm NT/6:00 pm CT/5:00 pm MT/4:00 pm PT
11	Members of the LGBTQ2IA+ community	National (EN)	7:00 pm ET/8:00 pm AT/8:30 pm NT/6:00 pm CT/5:00 pm MT/4:00 pm PT

Can I confirm your email address so that we can send you the link to the online discussion group?

We ask that you login a few minutes early to be sure you are able to connect and to test your sound (speaker and microphone). If you require glasses for reading, please make sure you have them handy as well.

As we are only inviting a small number of people, your participation is very important to us. If for some reason you are unable to attend, please call us so that we may get someone to replace you. You can reach us at [INSERT PHONE NUMBER] at our office. Please ask for [NAME]. Someone will call you in the days leading up to the discussion to remind you.

So that we can call you to remind you about the discussion group or contact you should there be any changes, can you please confirm your name and contact information for me?

First name
Last Name
email
Daytime phone number
Evening phone number

If the respondent refuses to give his/her first or last name, email or phone number please assure them that this information will be kept strictly confidential in accordance with the privacy law and that it is used strictly to contact them to confirm their attendance and to inform them of any changes to the discussion group. If they still refuse THANK & TERMINATE.

Appendix G: Discussion guide

Introduction

Section time: 10 min / Cumulative time: 10 min

- Moderator introduces themselves (including pronouns) her/his/their role, the name of the firm the moderator works for, and the type of firm that employs them (that is, an independent marketing research firm).
- Before we begin, I would like to acknowledge that I am joining from the traditional, unceded territory of the Algonquin Anishinaabe nation. I recognize that we are all joining from different places and encourage you to share the Indigenous traditional territory you are joining from as part of your introduction later.
- Role of moderator: to ask questions, make sure everyone has a chance to express themselves, keep track of the time, assures participants that moderator has no special interest in, or knowledge of, the issues discussed.
- Role of participants: speak openly and frankly about opinions, remember that there are no right or wrong answers and no need to agree with each other.
- Results are confidential and reported all together/individuals are not identified/participation is voluntary.
- The length of the session (1.5 hours).
- The presence of any observers, their role and purpose, and the means of observation (observers viewing and listening in remotely).
- The presence and purpose of any recording being made of the session.
- Confirm participants are comfortable with the platform and some of the specific settings such as: how to mute and unmute themselves; where the hand raise button is; and the chat box.

- As mentioned, when we invited you to participate in this discussion group, we're conducting research on behalf of the Government of Canada. These groups are being conducted for the Public Health Agency of Canada (PHAC), more specifically, to explore matters related to health care and health data.

[Moderator will ask participants to introduce themselves.]

- Introduction of participants: To get started, let us introduce ourselves.
- As you know, my name is Stephanie. I have been in public opinion research for 25 years and have a passion for qualitative research and getting to meet and speak with interesting people like yourselves. / As you know, my name is Doug. I became a researcher 30 years ago and I have come to truly love finding out what people think about all kind of different topics and issues.
- Now let us go around the virtual room. Please tell us what you feel comfortable sharing about yourself including your first name, where you're joining us from, what you do during the day, and your favourite hobby or past time.

General warm-up and context setting

Section time: 10 min / Cumulative time: 20 min

- What do you think of Canada's health care system today? What are the best and worst things about our health care system?
 - How much do these things matter to you?
- Would you describe Canada's health care system as modern or outdated? Why?
- Would you describe it as world-class? Why or why not?
- What would need to happen to make Canada's system world class? Why do you say that?
- How important is it for the government to modernize the health care system? Why?
- When you think of modernizing Canada's health care system or creating a world-class health care system, what needs to be done to achieve that? Why?

Familiarity and comfort with sharing health data

Section time: 20 min / Cumulative time: 40 min

- [hands up] How many of you are aware of the term 'health data'?
- [projective activity, chat box] To the best of your knowledge, what is it or what does it refer to...? Please use the chat box to record your answer. You can send your response to "everyone".

[if participants have difficulties recording their responses in the chat, they will be called upon to provide their response verbally.]

- [show on screen] Which of the following, if any, do you think are considered health data? Why or why not?
 - Illnesses, conditions, allergies, or prescribed medications a person has or has had
 - Lab results for any sort of diagnostic tests done on a person such as blood tests or X-rays
 - Basic metrics such as blood pressure, heart rate, blood sugar
 - Health care providers that have seen the person
 - History of visits to hospitals, clinics, or other types of health services such as surgeries
 - Vaccination rates for different communities or groups
 - Wait times for surgeries across different provinces and territories
- [keep same list on screen] And what is your personal level of comfort with your health data being shared with your health care providers? Why or why not?
 - Are you more or less comfortable sharing any of this particular data? Which data? Why?
 - [if participant says 'it depends'] What specifically does it depend on? Why?

- [keep same list on screen] When used for other purposes, like research or public health, are you comfortable sharing this information with provincial, territorial or federal governments? Why or why not?
 - Are you more or less comfortable sharing any of this particular data? Which data? Why?
 - [if participant says 'it depends'] What specifically does it depend on? Why?
 - Does the purpose for which the data is being used make a difference? Why?

For the purposes of our conversation here today/tonight, health data is any type of information about a person that is useful for diagnosing, monitoring, or treating a person. Health data also includes information about public health events, how our health systems are working and information about communities. Health data that has personal identifiers like name or health card number removed is called de-identified.

- How does this definition of health data differ from what you tend to think of when you hear the term health data?
 - What is different from what you expected?
 - Does this definition raise any questions in your mind? If so, what are they?
- Having heard that description, how, if at all, have your views/thoughts on this topic changed from where you started at the beginning of our conversation? Why?

Expectations and aspirations

Section time: 30 min / Cumulative time: 70 min

- To the best of your knowledge, how well or poorly do you think this sort of health data is currently being shared between health care providers? Why do you feel that way?
- How well or poorly do you think this data is being shared between provinces, territories, and the federal government?
- What would you like to see changed in terms of how data is/should be shared? Why?
- Are there potential changes that you fear? Why?

- How would you feel about your health data being shared across the system (i.e., with specialists, labs, etc.) to improve your care? Why do you feel that way?
- How do you feel about your health data being shared for other purposes, such as for health research? Why do you feel that way?
- How would you feel about your health data being shared with public health officials to better understand the health of the Canadian population?
- Would you be more comfortable sharing your health data if it was de-identified (the information that could identify you was removed)?

- Are there circumstances in which you WANT your health data to be shared or HOPE IT IS being shared? If so, what kinds of circumstances are you thinking about and why those?
 - What kind of controls do you assume should be in place to make sure that your health data is appropriately shared and protected by all who handle it?
 - In these cases, are you concerned about the protection of your health data? What are you concerned about?
 - What would you need to hear in order to feel completely comfortable with how your health data was being shared or stored in those cases?

- Are there circumstances in which you DO NOT WANT your health data to be shared or HOPE IT IS NOT being shared? If so, what kinds of circumstances are you thinking about and why those?
 - PROBE: In these cases, what are you worried might happen as a result of that?
 - PROBE: Is there anything that would make you comfortable with your health data being shared in those circumstances?

Let's talk about different people or organizations who typically use health data in their work.

- Are there any people or organizations with whom you would feel more or less comfortable sharing any of your health data? Why?
- How would you feel about the following having access to your personal health data? Why?
Probe:
 - Health care providers such as doctors, surgeons, nurses, specialists
 - Lab technicians
 - Pharmacists
 - Health system administrators
 - Medical researchers
 - The Government of Canada
 - Provincial and Territorial governments
 - Local public health authorities
 - [For patient advocates]
 - Canada Health Infoway
 - Canadian Institute for Health data

In the case of medical researchers

- Do you feel they need access to health data to do their jobs? Why or why not?
 - What kind of information do you think they need?
 - How would you feel if they didn't get access to that kind of information?
 - If they need health data that would include yours with thousands, maybe even millions of other people, but without any information that identifies any of the people whose data it is, how do you feel about that?
 - Is there anything you would need to hear or any people or organization you'd need to hear from in order to feel comfortable with this?
- And what about public health officials in provincial, territorial or federal governments? Do you feel the same or differently? Why?
- Of all the groups considered, who are you most comfortable sharing your health data with? Who are you least comfortable with? Why?

Safeguards

Section time: 15 min / Cumulative time: 85 min

I am going to read you a statement, please with a show of hands, let me know who agrees with this statement.

- [hands up] I am confident that safeguards are in place to protect my medical records and other health data from being seen by people who aren't allowed to see them.
 - [for those who agree] What is it you think is in place or what gives you that confidence? Why?
 - [for those who do not agree] Why do you disagree?
 - Are you thinking of something specific that is missing or is it a general concern?
 - What would need to change or happen to make you agree with this statement – or is that never possible? Why?

[show on screen] The Government of Canada is currently working with the provinces and territories to improve health care for Canadians by modernizing health systems. High-performing performing health systems with modern digital and health data systems will:

- make sure people in Canada have access to, and control over, their own health data;
 - make sure health data are readily accessible and can be readily shared by to those authorized to support a person's care
 - enable secure access to health data by authorized users who need health data to conduct medical research (cures for diseases or causes of cancer), improve the health care system (ER or surgery wait times), or make decisions affecting public health in a community (social determinants of health, such as how poverty impacts access to health care) and at the population level (public health events like COVID).
- How strongly do you support or oppose governments focussing on each of those priorities? Why?
 - If progress occurred in all three of those areas focussing on how your health data is shared, generally speaking, how comfortable would you be with your health data being shared in this way, or would you say your level of comfort depends upon something else?
 - [if comfortable] Why?
 - [if 'it depends'] On what? Why?
 - What do you need to hear depending on the circumstances?
 - [everyone else] Is this "good but not enough" or not even of any comfort at all? Why?
 - What else does it need to say?

Conclusions

Section time: 5 min / Cumulative time: 90 min

[MODERATOR TO REQUEST ADDITIONAL QUESTIONS ARE SENT VIA THE CHAT BOX DIRECTLY TO THE MODERATOR AND PROBE ON ANY ADDITIONAL AREAS OF INTEREST]

This concludes what we wanted to cover tonight.

- Do you have any final thoughts or any advice for the Government of Canada?

Thank you very much for your participation. We really appreciate you taking the time to share your views. Your input is very important.