

What Canadians Think 2022 – Privacy Edition Survey:

Canadians' Perspectives on
Digital Health Privacy



Canada Health Infoway
Inforoute Santé du Canada

AUGUST 2022

Leger

We know Canadians

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Executive Summary

- More than 70% of Canadians feel confident they can generally protect their privacy online.
- 3 in 10 respondents say their perception of privacy of their personal health information (PHI) does not have any impact on their willingness to use digital health tools.
- More than half of respondents (56%) believe their health care privacy rights are adequately protected by law. This is even higher among those who have a family doctor. However, only 3 in 10 respondents say they are aware of Canadian privacy laws that protect their personal health information.
- Respondents have a high level of trust in health care providers to keep their personal health information safe and secure.
- A majority of the respondents say they would be willing to share their personal health information for secondary purposes.
- In order to consent to use of their personal health information, nearly all participants indicated that they first would like to know *how* their PHI will be used, *who* will be using it or have access to it.

A close-up photograph of a person wearing a white lab coat over a light blue shirt and a dark tie. They are holding a silver tablet computer with both hands, looking at the screen. The background is a blurred laboratory or office environment with various pieces of equipment and shelves. A semi-transparent grey banner is overlaid at the bottom of the image, containing the text 'STUDY OBJECTIVES AND METHODOLOGY' in white, uppercase letters.

STUDY OBJECTIVES AND METHODOLOGY

Context and Study Objectives

Infoway has been tracking **attitudes, expectations and experiences in digital health privacy in Canada** every 5 years since 2007.

This study aims to update this public opinion research by further exploring **Canadians' attitudes, utilization, perceptions and expectations around digital health privacy.**

Specific objectives of the study are to assess:

- **Perceptions** of personal privacy and privacy of personal health information (PHI) in digital health;
- **Awareness** of oversight bodies (federal and provincial) and mechanisms and their role in protecting Canadians' privacy rights in relation to personal health information;
- **Concerns** and acceptability of secondary use of electronic health information for purposes such as research, public health surveillance, and analysis and management of the health system using identifiable and non-identifiable data;
- **Trust** and mediators of comfort with respect to access, utilization and notification of uses of personal health information, including timely access to one's own health information.
- Any **changes in Canadians' perceptions and expectations of privacy in digital health** that may have been caused as a result of the pandemic.

Methodology

20 MINUTE online survey conducted March 8th – 20th 2022 with **2,010** citizens in Canada

Regional Sample Size

CANADIANS 16+ YEARS OLD	ATL*	QC	ON	MB	SK	AB	BC	TERR**	TOTAL
<i>Weighted</i>	137	470	773	67	60	223	270	10	2,010
Unweighted	127	453	777	74	61	233	274	11	2,010

*NS, PEI, NB, NL

**NWT, YK, NU

About Canada Health Infoway

At Canada Health Infoway (Infoway) we believe a more connected and collaborative system is a healthier system, and we work with governments, health care organizations, clinicians and patients to make health care more digital. We're working to ensure that everyone is able to access their personal health information, book appointments, get prescriptions, view lab test results and access other health services, online. We're working with our partners to transform the health system because we know that digital in health can be as transformative as digital has been in other aspects of our lives. We're an independent, not-for-profit organization funded by the federal government. Visit us online at www.infoway-inforoute.ca.

Methodology And Notes For Interpretation of Data



Web survey of **2,010 citizens in Canada.**

The survey was made available in both English and French.



Data collection took place from **March 8th - 20th, 2022.**



Using Canadian Census data, weighting was applied according to region, age, and gender to render a representative sample of the Canadian population. Sample base sizes indicated are unweighted.

A margin of error cannot be associated with a non-probability sample in a panel survey. For comparison purposes, a probability sample of this size would have a margin of error **±2.19%, 19 times out of 20.**

NOTES FOR READERS

ROUNDING

The data presented have been rounded. As a result, totals may differ slightly from 100%.

TRENDING

The data is compared with previous waves wherever applicable. While Leger did not conduct previous waves, trending was applied based on 2007, 2012, & 2017 results where possible.

Methodology - Leger's LEO Panel

Leger – the largest Canadian-owned polling and marketing research firm – conducted this web survey with 2,010 Canadians over the age of 16, selected from LEO's (Leger Opinion) representative panel via Computer-Assisted Web Interviewing technology (CAWI).

The LEO panel is the largest Canadian panel with nearly 500,000 representative panelists from all regions of Canada. LEO was created by Leger based on a representative sample of Canadian citizens with Internet access. LEO's panelists were randomly selected (RDD), panelists from more hard-to-reach target groups were also added to the panel through targeted recruitment campaigns. The double-opt-in selection process, a model to detect fraud and the renewal of 25% of the panel each year ensures complete respondent quality. To ensure a higher response rate and to reach people on their mobile devices, Leger has also developed a high-performance Apple and Android application. In fact, Leger is the only Canadian research firm offering both the number and quality of panelists. Most competing polling firms in Canada also use the LEO panel.

The results presented in this study comply with the public opinion research standards and disclosure requirements of the Canadian Research and Insights Council (CRIC) and the global ESOMAR network.



A woman with long, dark, curly hair is sitting on a light-colored sofa, focused on a silver laptop in front of her. She is wearing a beige long-sleeved top and blue jeans. In the background, a young boy in a yellow shirt is sitting on the same sofa, looking at a tablet device. The scene is set in a bright, modern living room with large windows in the background. A white mug is visible on a table in the foreground.

PRIVACY PERSPECTIVES AND EXPERIENCES

PRIVACY PERSPECTIVES

More than 70% of **Canadians feel confident they can protect their privacy online.**

- Among nearly a **quarter who do not feel confident**, main concerns are around possibilities of data being hacked, not trusting companies in following privacy policies, not knowing what companies are doing with their data, being concerned that their personal data is already available online, or that they must accept how their data is used if they want a particular service.
- Fewer people relate their lack of confidence in ability to protect their privacy online to issues with privacy protections on their device or being unfamiliar with technology, though this is found more so among respondents who are 55 years or older.



Overall, **1 in 5** say they are **not comfortable** with their **personal health information (PHI) being used** under any circumstances.

- **Those willing to share** their data say they will do so based on a **variety of conditions**, with **more than a quarter** saying they would want their **DATA ANONYMIZED**. Very few (2%) say they don't mind who uses data about them.

While 1 in 5 are unsure, a **majority (56%) of respondents believe their health care privacy rights are adequately protected by law**. This is even higher among those who have a family doctor. Although most of these respondents felt their privacy rights are **only somewhat adequately protected**.



72%
CONFIDENT in
PROTECTING
ONLINE PRIVACY

Quebeckers are more likely to say they are **VERY confident** (24%).

Caregivers report **high confidence** overall (79%).

AMONG those who are **NOT CONFIDENT** THEY CAN PROTECT ONLINE PRIVACY (n=472)

Main REASONS for NOT BEING CONFIDENT in protecting online privacy:



Older respondents (55+ years) are more likely to not know how to use privacy protections/settings (24%) or require assistance using tech (27%).
Younger respondents (<35 years) more likely to say they have to accept how their data is used if they want a service (56%).

Base: Total respondents (n=2,010)

8. Do you feel confident that you are able to protect your online privacy?

9. Why do you not feel confident that you are able to protect your online privacy?

RECEIVED VIRTUAL CARE IN PAST 12 MONTHS (Net) **55%**

By telephone **47%**

By video **11%**

Text message / email / online chat **7%**

No 43% **AMONG THOSE WHO DID NOT RECEIVE ANY VIRTUAL CARE (n=866)**

I can't recall **2%**

MAIN REASONS for NOT RECEIVING VIRTUAL CARE (VC) in past 12 months

HAVEN'T HAD A HEALTH ISSUE / NEEDED CONSULT 47%

Overall quality of in-person visit is better **18%**

I feel a personal connection with HCP is missing **11%**

Not appropriate for the health concern(s) **11%**

Not offered by HCP **9%**

Uncomfortable discussing certain health topics through VC **8%**

Need more information about VC services available to me **7%**

Don't trust my PHI will be secure 6%

Don't trust my PHI will remain confidential 5%

8%
have concerns related to PHI PRIVACY

Not comfortable / familiar with tech **4%**

In-person visits allow me to include caregivers **4%**

Insurance does not cover VC visit **3%**

No access to a private space to use VC services **2%**

Physical barrier prevents me from using VC **2%**

No access to reliable / fast Internet **1%**

9% were unsure

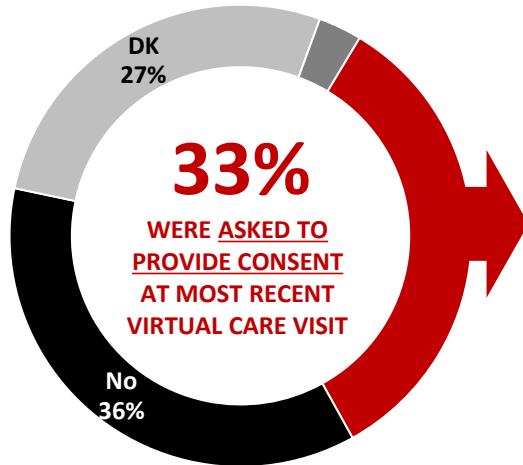
Base: Total respondents (n=2,010) / Respondents who say they did not have virtual care in past 12 months (n=866)

24. Have you used virtual care with a health care provider in the past 12 months?

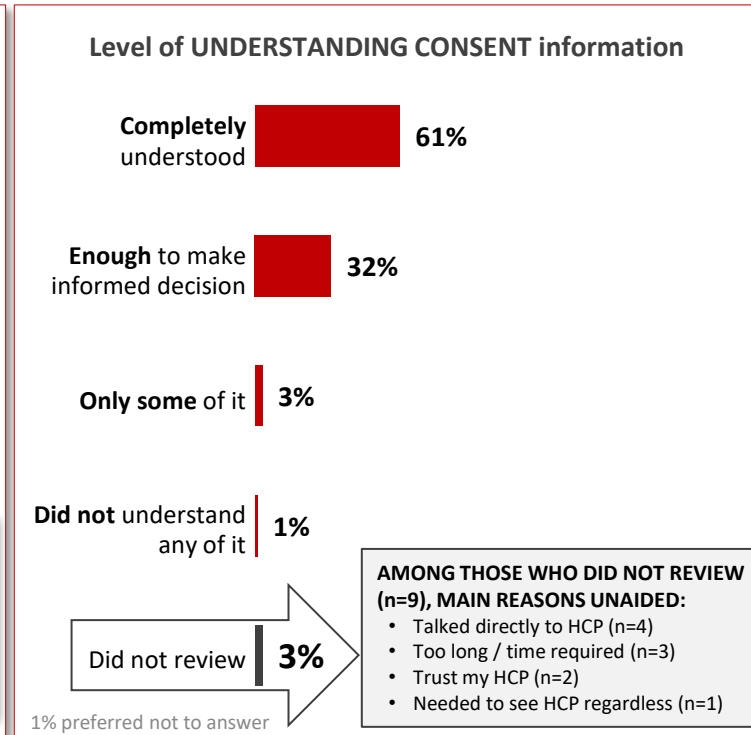
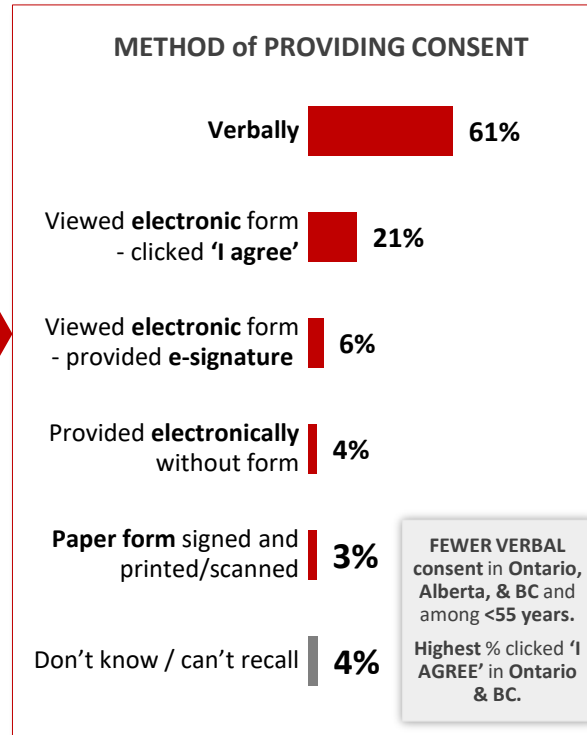
25. Which of the following reasons describes why you have not used virtual care in the past 12 months?

Consent Method Used During a Virtual Care Visit

Among those who have RECEIVED VIRTUAL CARE in the past 12 months, experience with PROVIDING CONSENT at the most recent visit



Highest recall of providing consent in Alberta (46%)



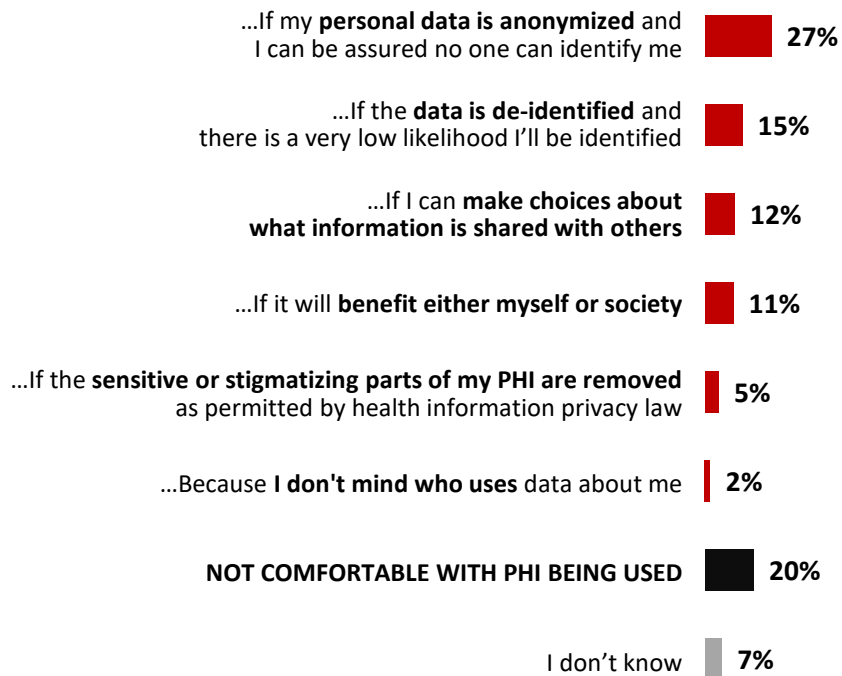
Base: Respondents who say they had virtual care in past 12 months (n=1,112) / Respondents who were asked to provide consent at most recent service (n=362) / who recall providing consent (n=348)

- | | |
|--|---|
| 27. Were you asked to provide consent to use virtual care for your most recent virtual care service? / | 28. Please describe how you gave your consent at your most recent virtual care consult. |
| 29. Did you understand what you were consenting to at your most recent virtual care consult? / | 30. Why did you not review the consent information? |

Attitudes Toward the Use of Personal Health Information

More than 70% respondents say they are **comfortable with their PHI being used** by others if certain conditions are met:

MY PERSONAL HEALTH INFORMATION CAN BE USED BY OTHERS...



Impact of Perception of Privacy on Willingness to Use Digital Health

3 in 10 respondents say their perception of privacy of their PHI does not have any impact on their willingness to use digital health tools. The impact overall does not appear to be particularly strong, especially in terms of avoiding digital health tools.

Extent that attitude toward privacy of personal health information IMPACTS WILLINGNESS to USE DIGITAL HEALTH tools:

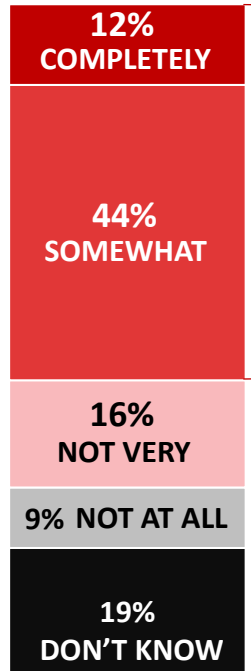


Base: Excludes respondents who say they don't mind who uses data about them (n=1,966)

11. How does your attitude toward the privacy of your personal health information (PHI) impact your willingness to use digital health tools?

Perception of Level of Protection of Health Care Privacy Rights

% of respondents who agree that their health care privacy rights are adequately protected by law:



56%
feel health care
privacy rights are
PROTECTED



A greater % with **FAMILY DOCTOR** believe health care privacy rights are **PROTECTED ADEQUATELY** (58% vs. 47% among those without)

CANADIANS' AWARENESS OF THEIR PRIVACY RIGHTS & HEALTH CARE PRIVACY LAWS

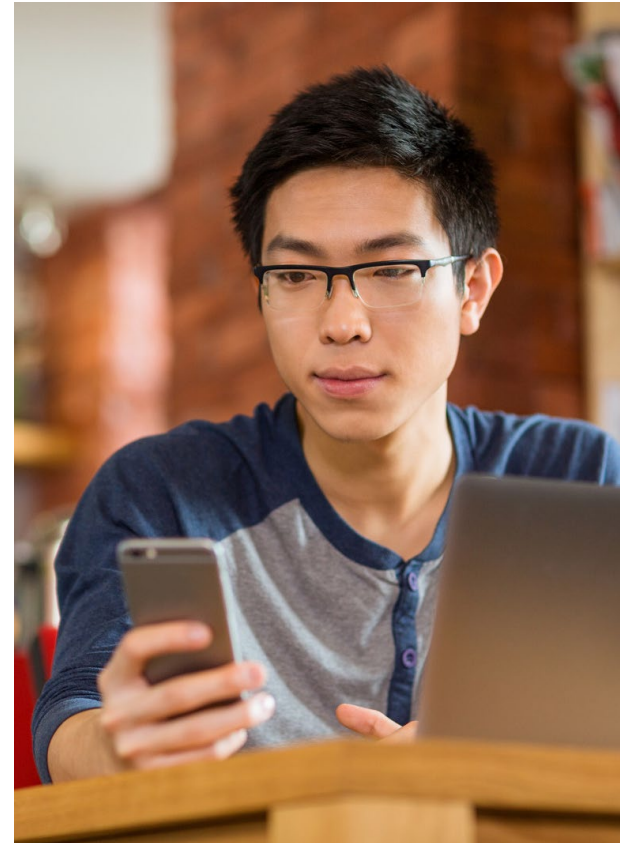
3 in 10 respondents say they are **aware of Canadian privacy laws** that protect their PHI.

- A majority of those aware say they know it's a serious offence for anyone to access their PHI without authorization and half are aware that they can request access to their PHI at any time.

Nearly half (44%) of Canadians say they looked for information about their **health care privacy rights** in various sources, such as places where they receive health care, online searches, and via federal/provincial/territorial government health agencies, among others.

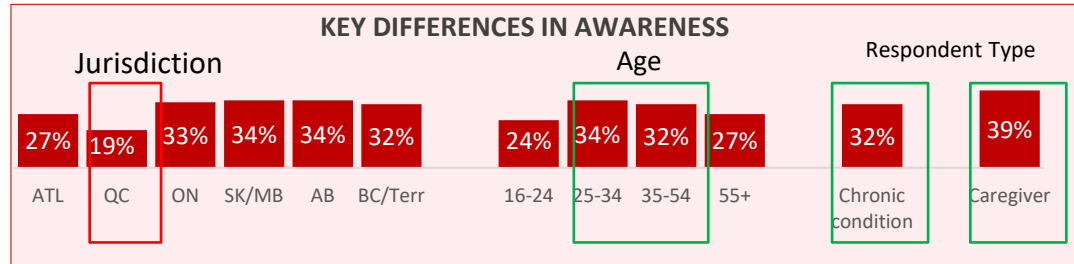
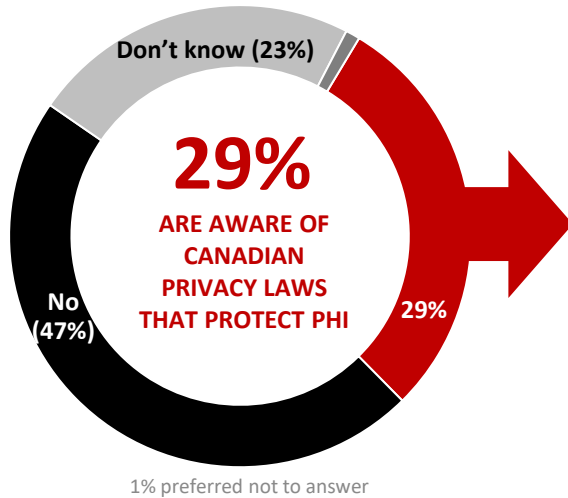
Nearly 3 in 10 say they have **exercised at least one or more patient privacy rights**. The most common privacy right exercised is **requesting access to their PHI** – reported by 17%.

Younger patients, those in urban areas, and those with chronic conditions or providing unpaid health care support are more likely to have exercised any patient privacy rights.



Awareness of Canadian Health Information Privacy Laws

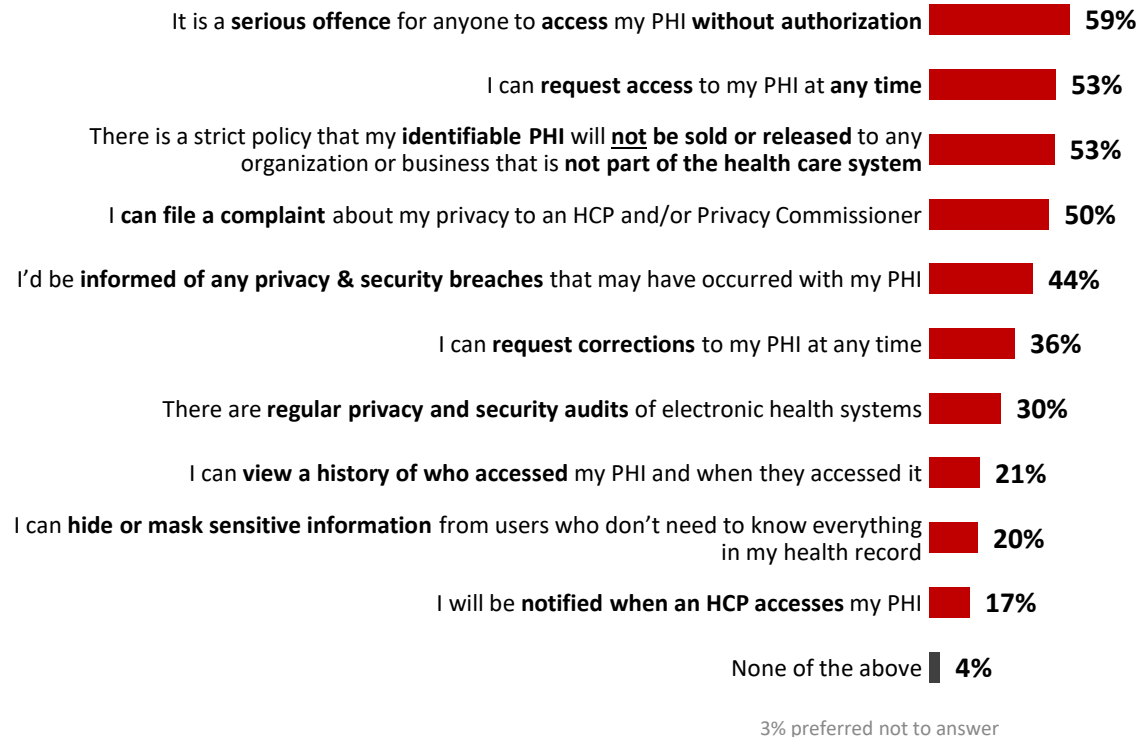
Awareness of (any) Canadian privacy laws that protect personal health information (PHI):



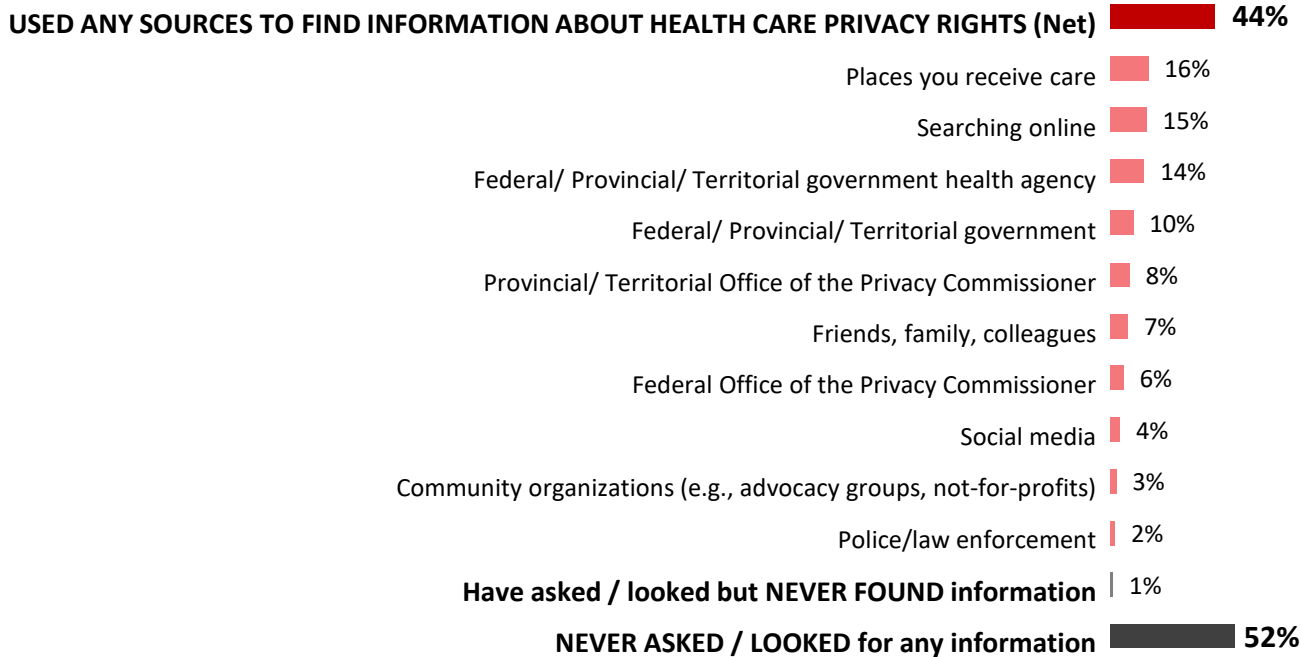
***Trend with caution – asked about clear / vague awareness in previous years:**
2017: 37%; 2012: 44%; 2007: 39%

Awareness of Canadian Health Information Privacy Laws

Among those who say they are aware of Canadian privacy laws, respondents state they know the following privacy rights:



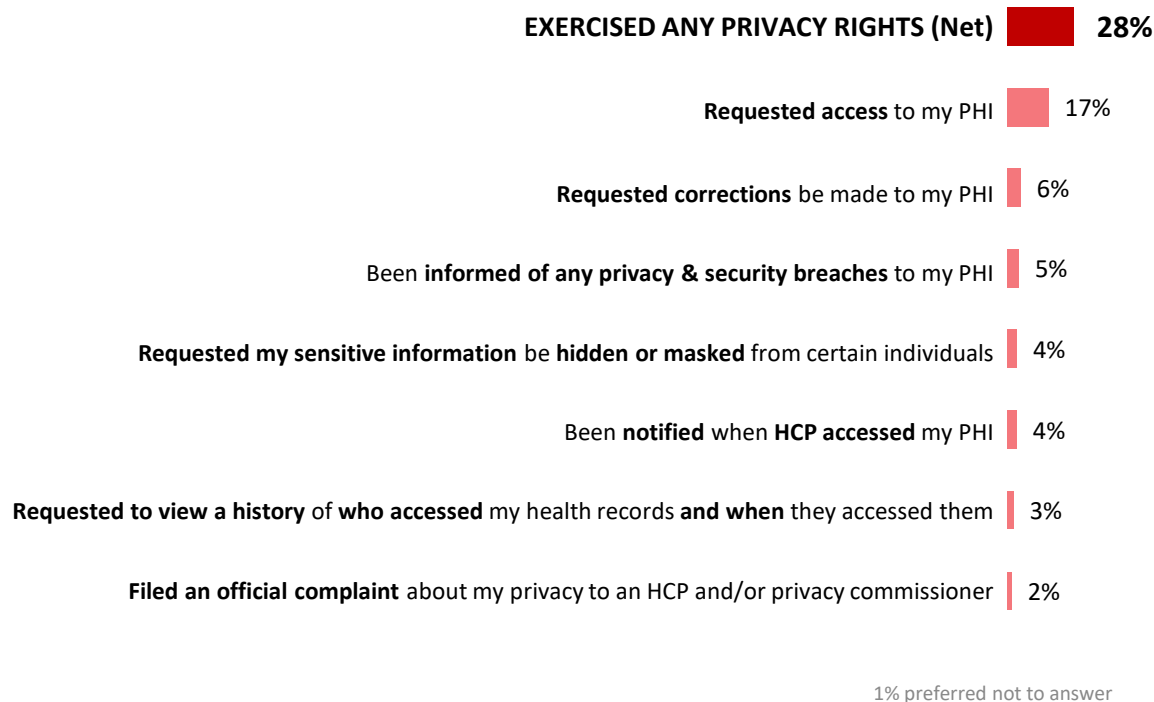
Sources of Information For Health Care Privacy Rights (Online or in Person)



2% preferred not to answer

Experience in Exercising Patient Privacy Rights

% of Canadians who have exercised any of the following patient privacy rights:



Base: Total respondents (n=2,010)

15. Have you ever exercised the following patient privacy rights?



LEVEL OF TRUST
IN PRIVACY OF HEALTH INFORMATION

LEVEL OF TRUST IN THE PROTECTION OF PERSONAL HEALTH INFORMATION

LEVEL OF TRUST IN PHI PROTECTION IN THE PUBLIC SECTOR

In general, respondents report a **high level of trust in health care providers** to keep their **PHI safe and secure**, among such providers as doctors, pharmacists, nurses and nurse practitioners (with a majority rating high trust for each of these health care providers on average).

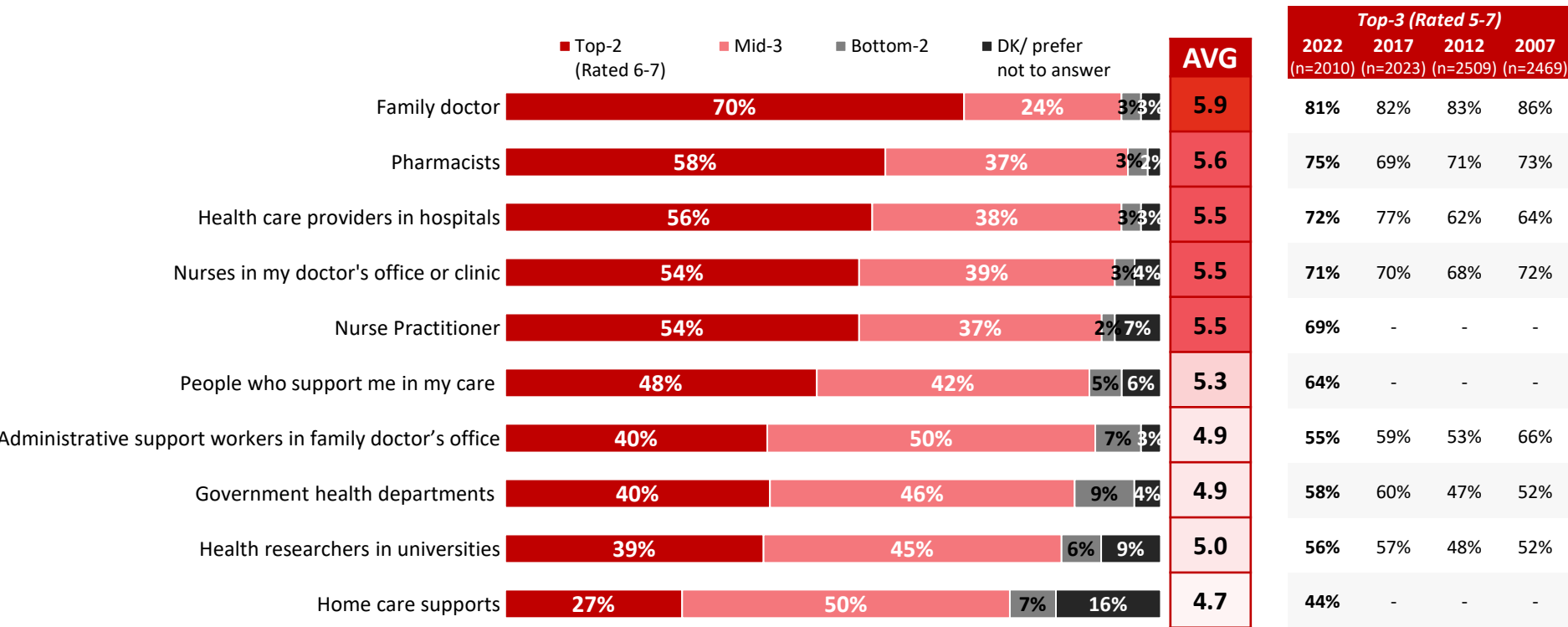
- While still fairly trusting, **somewhat lower trust** is reported when it comes to those **working in health care who do not necessarily provide direct patient care**: such as administrative workers in a doctor's office, government health departments, health researchers in universities.
- While some are unsure, there appears to be **lower trust in home care supports**.
- In general, those **who have a family doctor** appear to **trust health care workers more**.
- **No major changes** in level of trust of health workers **since 2017** in this regard.

LEVEL OF TRUST IN PHI PROTECTION IN THE PRIVATE SECTOR

Trust is lower when it comes to the **private sector** (e.g., health care providers in private sector, virtual care service providers, digital health tools / services, companies not directly involved in health care).



Level of Trust in Health Care Workers to Keep PHI Safe/Secure



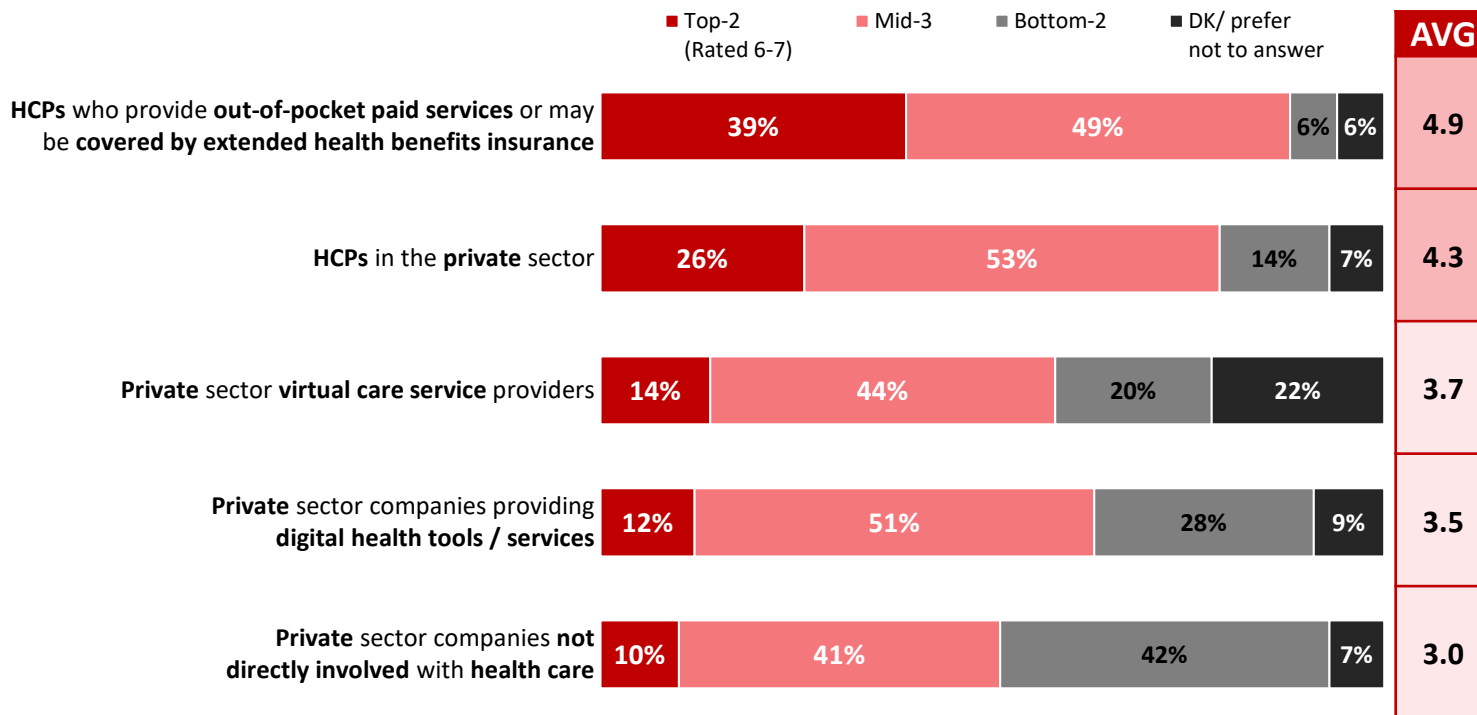
NOTE: Started asking about NPs, people who support in care, and home care supports this year – no trending

Base: Total respondents (n=2,010)

21. How much trust do you have in the following groups to keep your personal health information safe and secure?

*On a 7-pt scale, with
1 = no trust at all and
7 = great deal of trust

Level of Trust in Other Groups to Keep PHI Safe / Secure

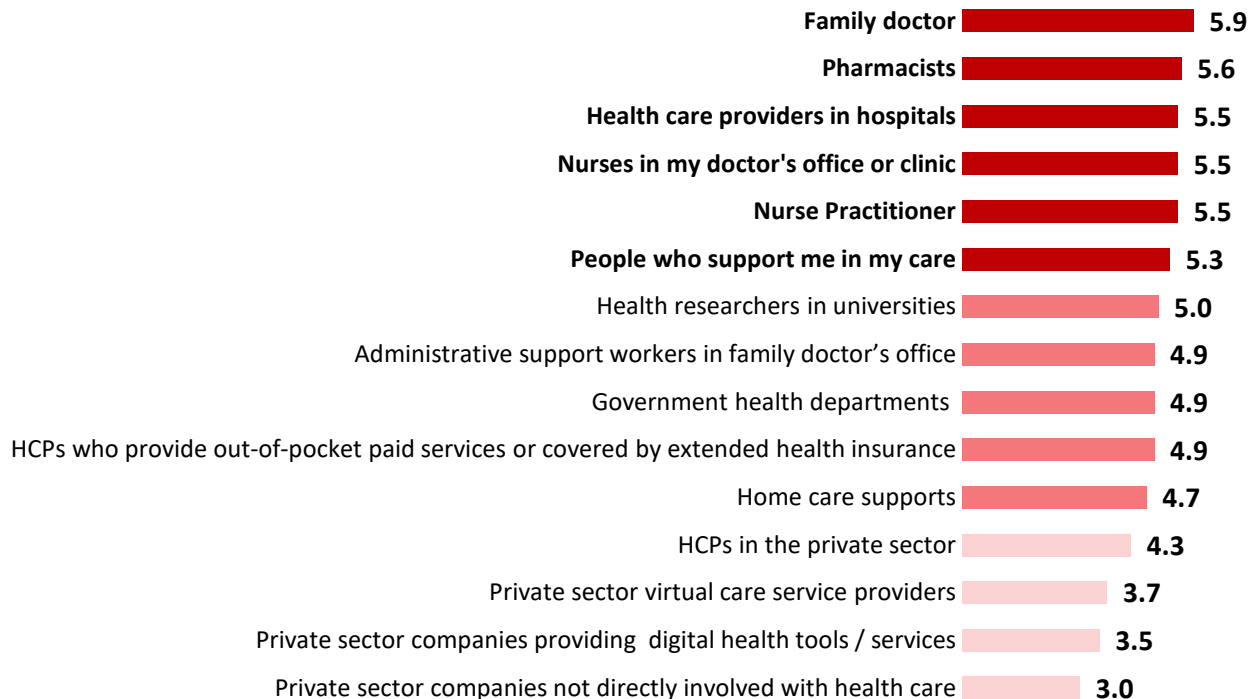


Base: Total respondents (n=2,010)

21/23. How much trust do you have in the following groups to keep your personal health information safe and secure?

*On a 7-pt scale, with 1 = no trust at all and 7 = great deal of trust

Level of Trust in Other Groups to Keep PHI Safe / Secure



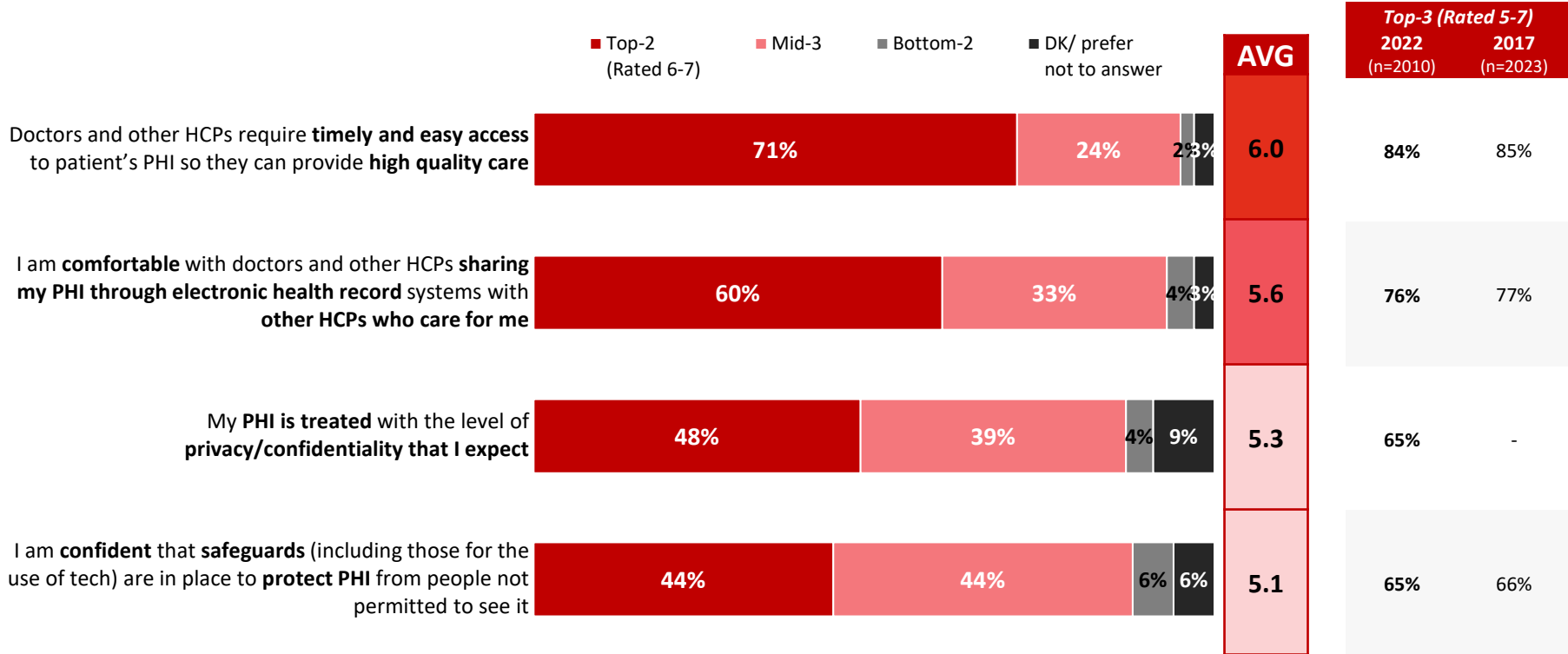
Base: Total respondents (n=2,010)

23. How much trust do you have in the following groups to keep your personal health information safe and secure?

*On a 7-pt scale, with
1 = no trust at all and
7 = great deal of trust

Perceptions of How PHI is Treated

Level of AGREEMENT with the following statements:



NOTE: Some statements not asked in previous years – trending where possible

Base: Total respondents (n=2,010)

22. Please rate the degree to which you agree or disagree with the following statements.

*On a 7-pt scale, with 1 = strongly disagree and 7 = strongly agree



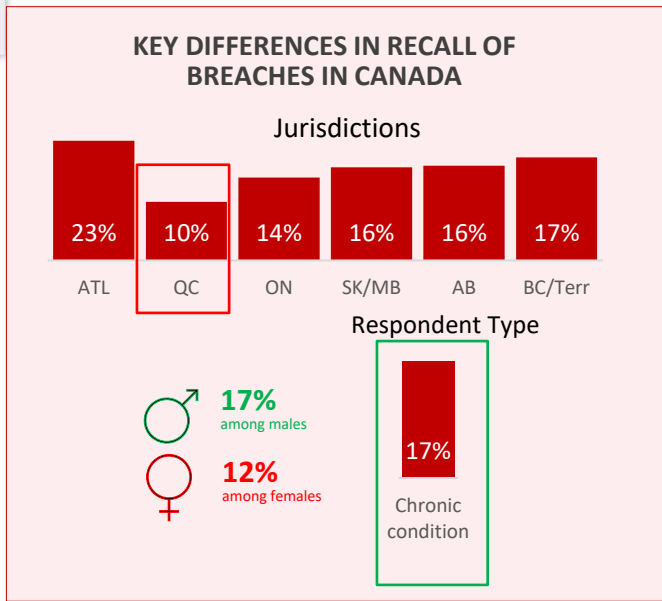
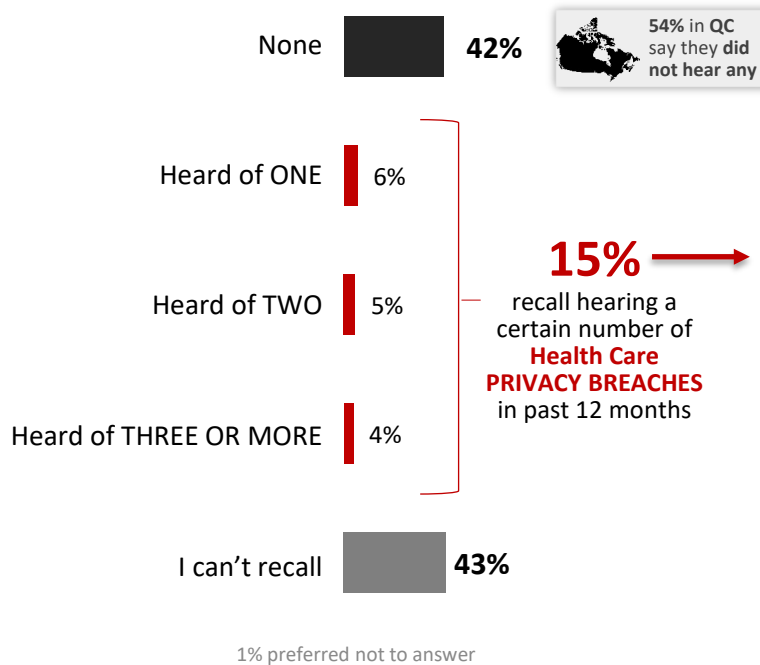
HEALTH CARE PRIVACY BREACHES
ATTITUDES AND EXPERIENCES

Experience with PHI Privacy Breach(es)

- **Most of the respondents surveyed report no awareness that they have personally experienced or know someone who experienced a privacy breach.**
- **Only 1 in 8 (12%)** respondents say they have **personally experienced or know someone who experienced a PHI breach**, with 5% personally experiencing one. Known breaches were reported by a greater proportion of respondents in Ontario, among people under 25 years old, those without a family doctor, with a chronic condition, and those providing unpaid health care support.
- **Hearing about privacy breaches** in Canada has a **mixed effect** on how respondents **perceive privacy of their own personal health information.**
- **Nearly 2 in 5** say it has a **strong or moderate negative impact**, while **1 in 5** say it has **NO impact** on them. Those without any negative impact mainly say it is not something that worries them, or they haven't heard of any breaches.
- Older respondents and unpaid caregivers report somewhat greater impact, while Quebecers report lowest impact. Interestingly, fewer Quebecers recalled hearing of any health care privacy breaches in the past 12 months.



Recall of Hearing about Health Care Privacy Breaches in Canada in Past Year

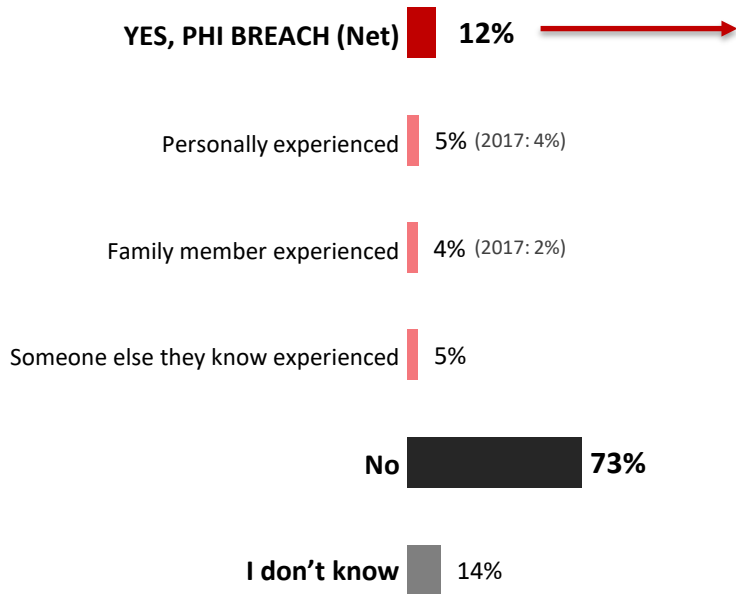


Base: Total respondents (n=2,010)

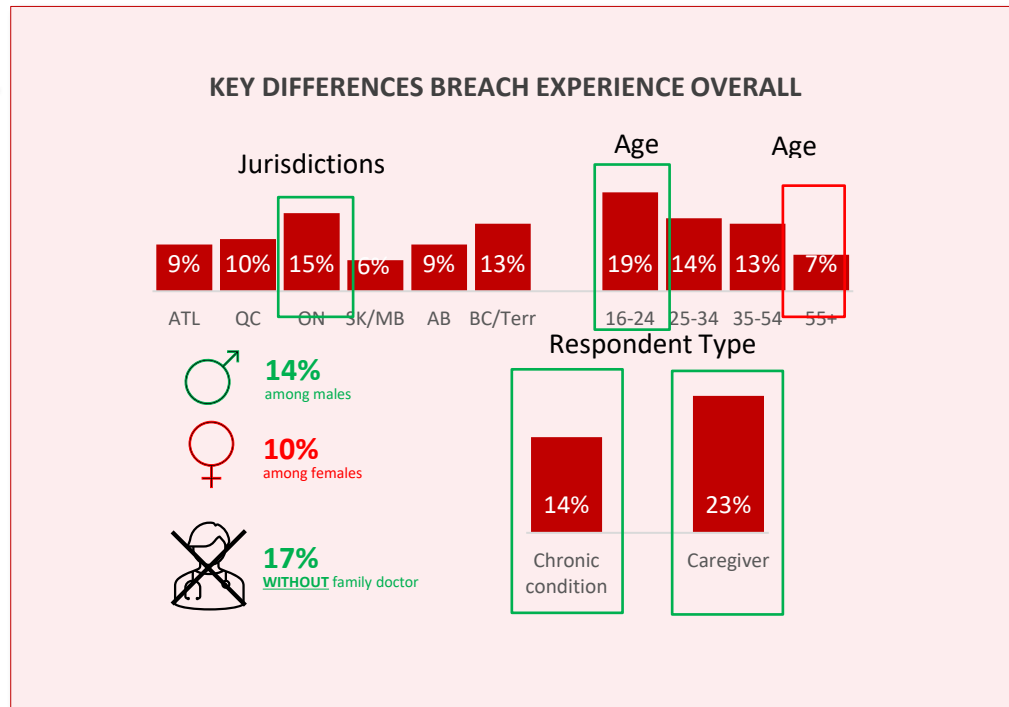
18. In the past 12 months, approximately how many times did you hear about health care privacy breaches in Canada as far as you can recall?

Experience with Privacy Breaches of PHI

% of respondents who have personally experienced or know someone who had a privacy breach of their PHI:



1% preferred not to answer



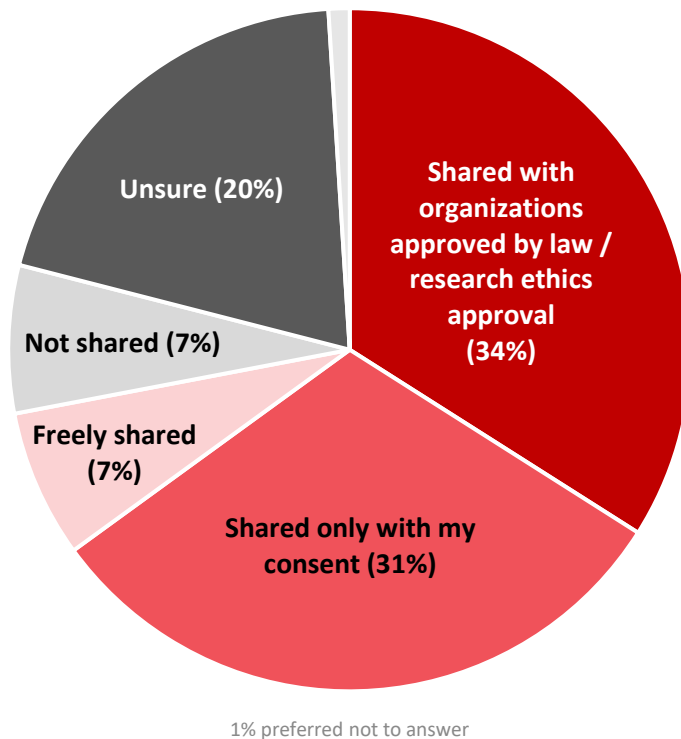
(#%) = 2017 data. Prior to 2017, question was asked overall if personally / family member experience breach

Base: Total respondents (n=2,010)

17. Have you, a member of your family, or someone you know ever experienced a breach where your/their personal health information was used inappropriately or released without your/their consent?



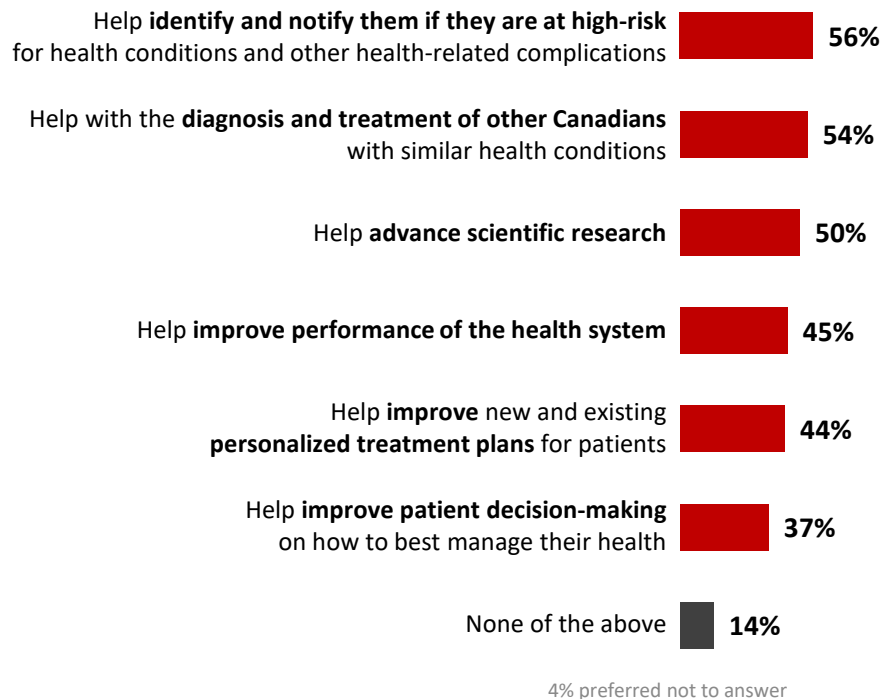
USE OF DATA
BEYOND PROVISION OF CARE



Base: Total respondents (n=2,010)

31. Which of the following best describes your belief about how personal health information is shared between health care organizations, government health agencies and university researchers for health research purposes?

Willingness to Share PHI Depending on the Purpose of Use





CONSENT PREFERENCES

CONSENT SCENARIOS (Preferences)

Participants were provided different scenarios and asked to select response options based on the context of the situation(s) presented.

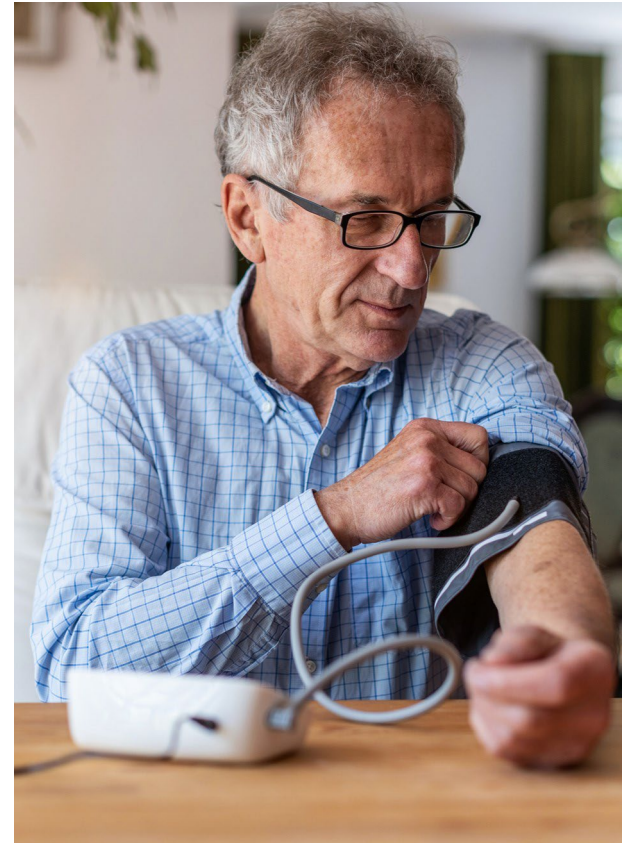
There were **no notable differences** when it comes to sharing PHI to be used by a **government public health** analyst vs. a **pharmaceutical company** researcher.

Nearly all participants indicated that certain conditions would have to be met for them to allow their PHI to be used:

- In particular, respondents said that for them to decide on whether to consent for their PHI to be used, they would like to know **how their PHI will be used and who will be using it or have access to it**, that their **PHI is stored in safe/secure place**, and that **strict rules prevent PHI disclosure** to others.
- Depending on the scenario, **9-16% would not want their PHI used at all.**

A majority (52-59%) of the respondents would want to be **asked for consent** to use their PHI **EVERY TIME** their data is used:

- **More than a quarter (26-31%)** would want to be asked the **first time and contacted periodically** to provide consent.
- Fewer (14-16%) would only want to be asked the first time PHI is used.



Consent Scenario #1: Government Public Health Scenario



Respondents were shown:

The health sector, which consists of a variety of organizations and individuals, often uses health data for public benefit. This data is a large pool of data, where it is not easy to identify a specific individual. The following scenarios are about a fictitious person named Alex. Please consider how Alex's situation relates to your experience.

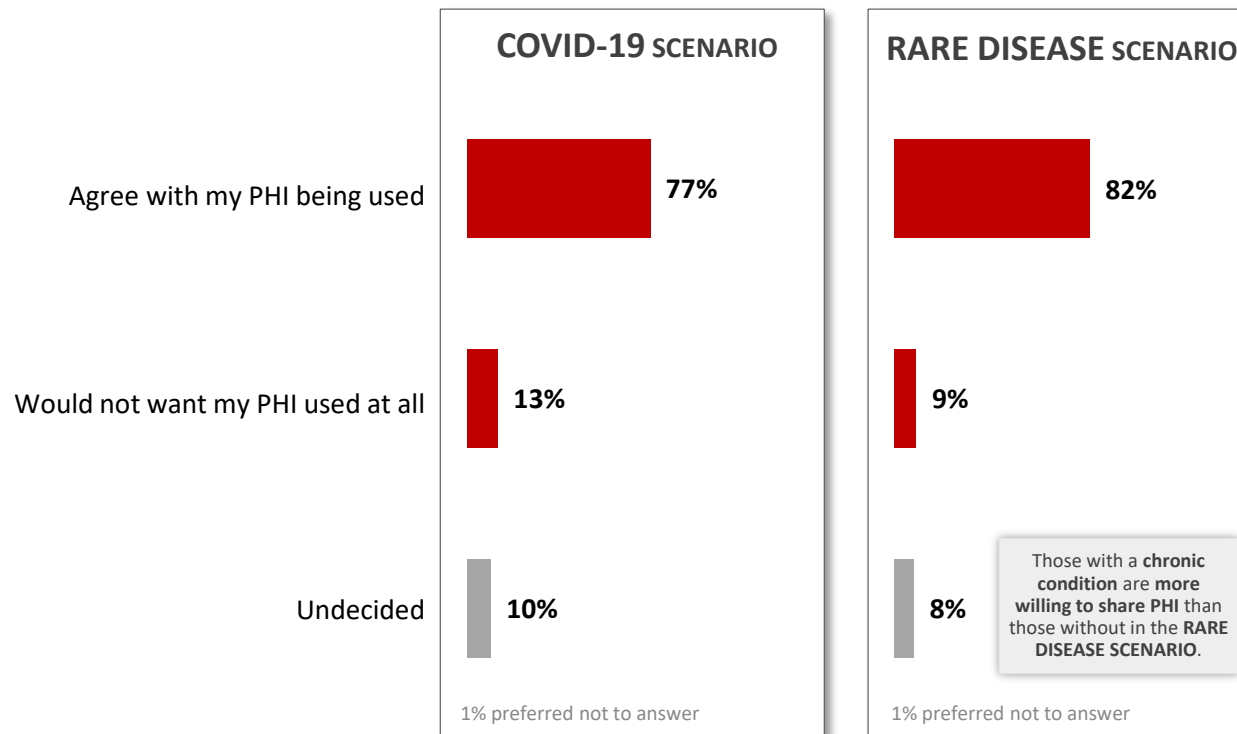
Respondents were then split randomly to be shown one of the following scenarios and answer a series of questions based on the situation/option shown.

COVID-19 Scenario (n=1,005 respondents shown)

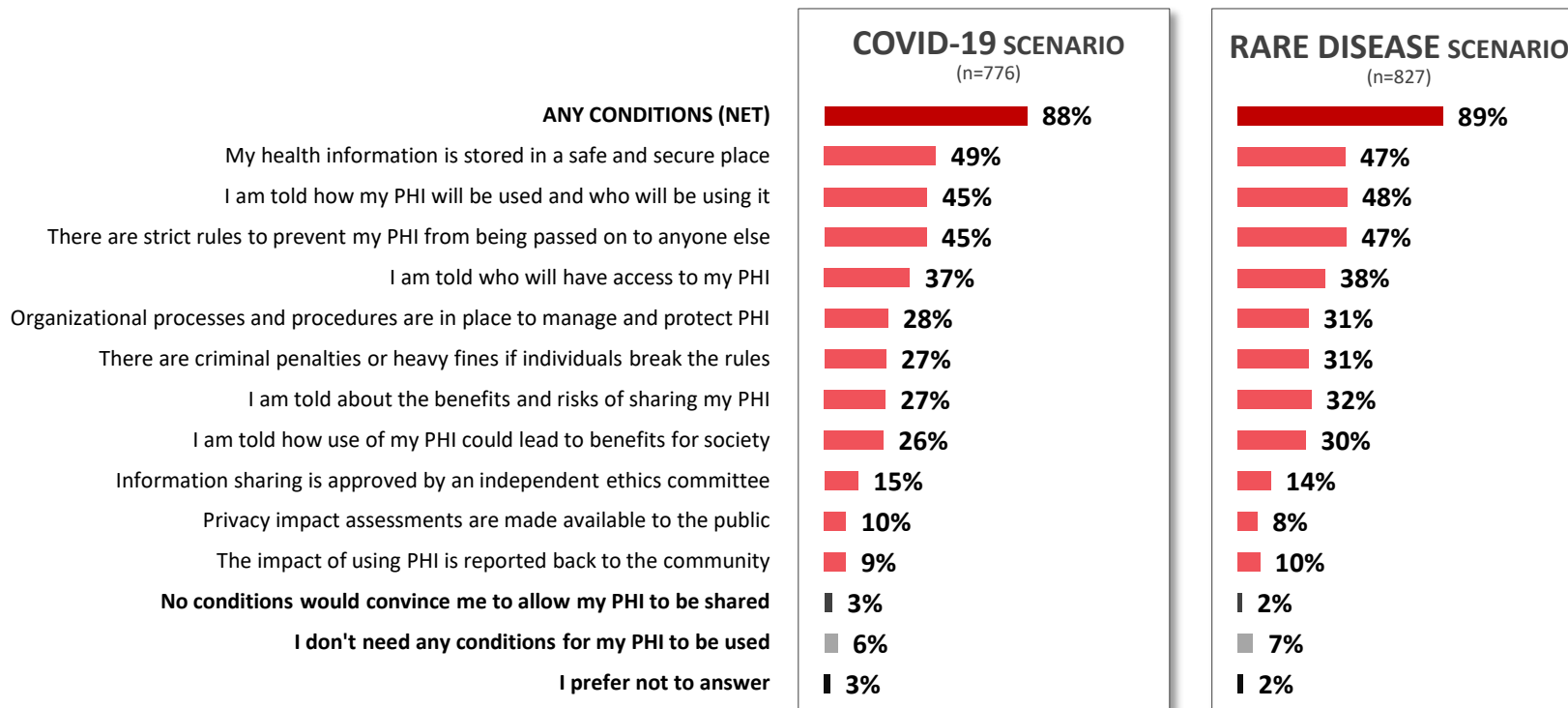
Alex has COVID-19. A government public health system analyst would like to use Alex's personal health information as part of a large pool of data to help with COVID-19 prevention and support efforts, including identifying at-risk populations and targeting vaccination clinics (e.g., identifying where to allocate more resources, etc.).

RARE DISEASE Scenario (n=1,005 respondents shown)

Alex has a rare disease (i.e., an illness that affects a small percentage of the population). A government public health system analyst would like to use Alex's personal health information to identify (and notify) people who have the same condition as Alex to get their regular eye exam, as people with the same condition are at higher risk for eye disease as well.



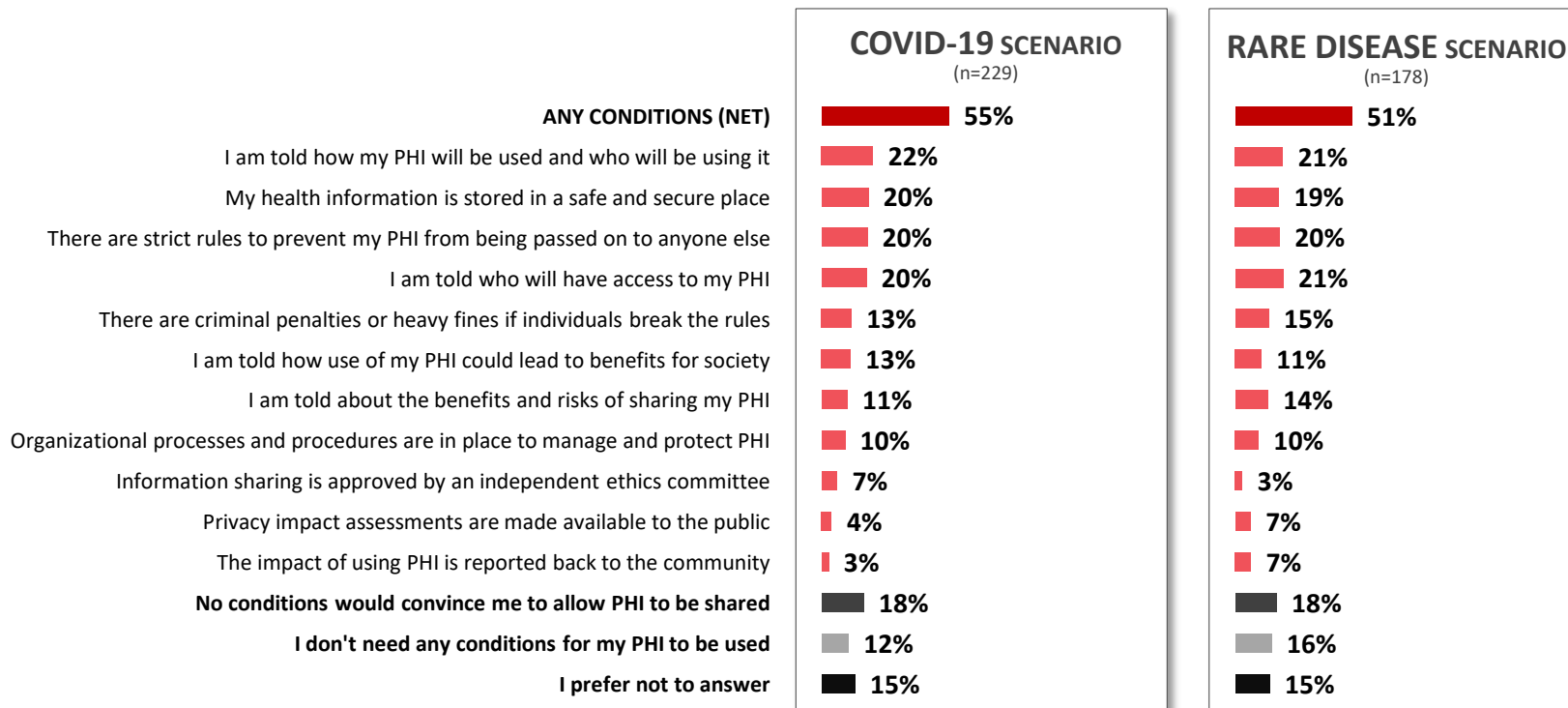
Government Public Health Scenario: Prerequisites for Consent Important to Canadians



Base: Respondents answering for COVID-19 scenario (n=776) / rare disease scenario (n=827)

34. Which of the following conditions are required for you to consent? / Which of the following conditions would convince you to allow your personal health information to be shared? Please select up to 5.


Government Public Health Scenario: Prerequisites for Consent Important to Canadians

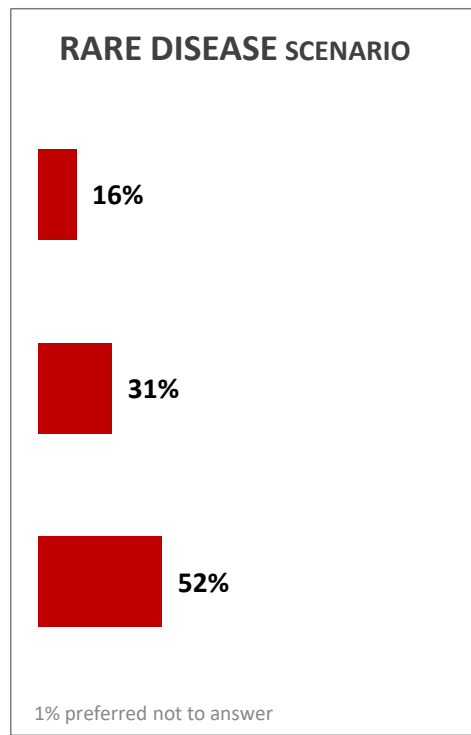
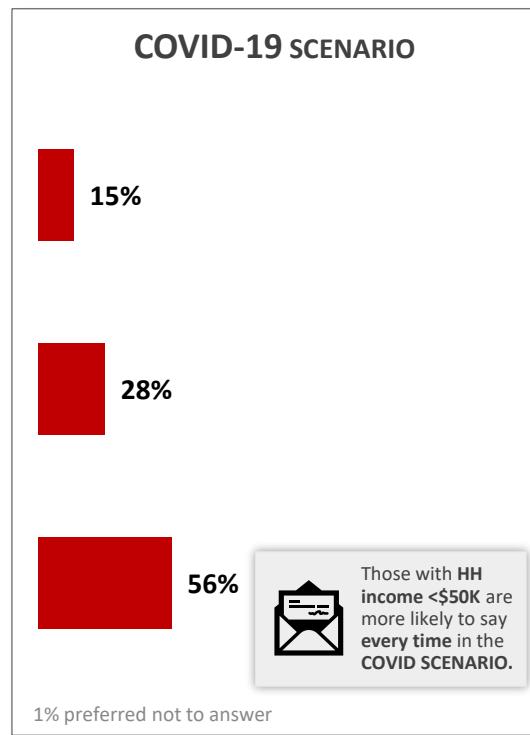



Base: Respondents answering for COVID-19 scenario (n=229) / rare disease scenario (n=178)

34. Which of the following conditions are required for you to consent? / Which of the following conditions would convince you to allow your personal health information to be shared? Please select up to 5.

Government Public Health Scenario: Preference for Frequency of Being Asked for Consent

 Females are more likely to say every time vs. males, while males are comparatively more likely to say the first time only.



 Those with HH income <\$50K are more likely to say every time in the COVID SCENARIO.

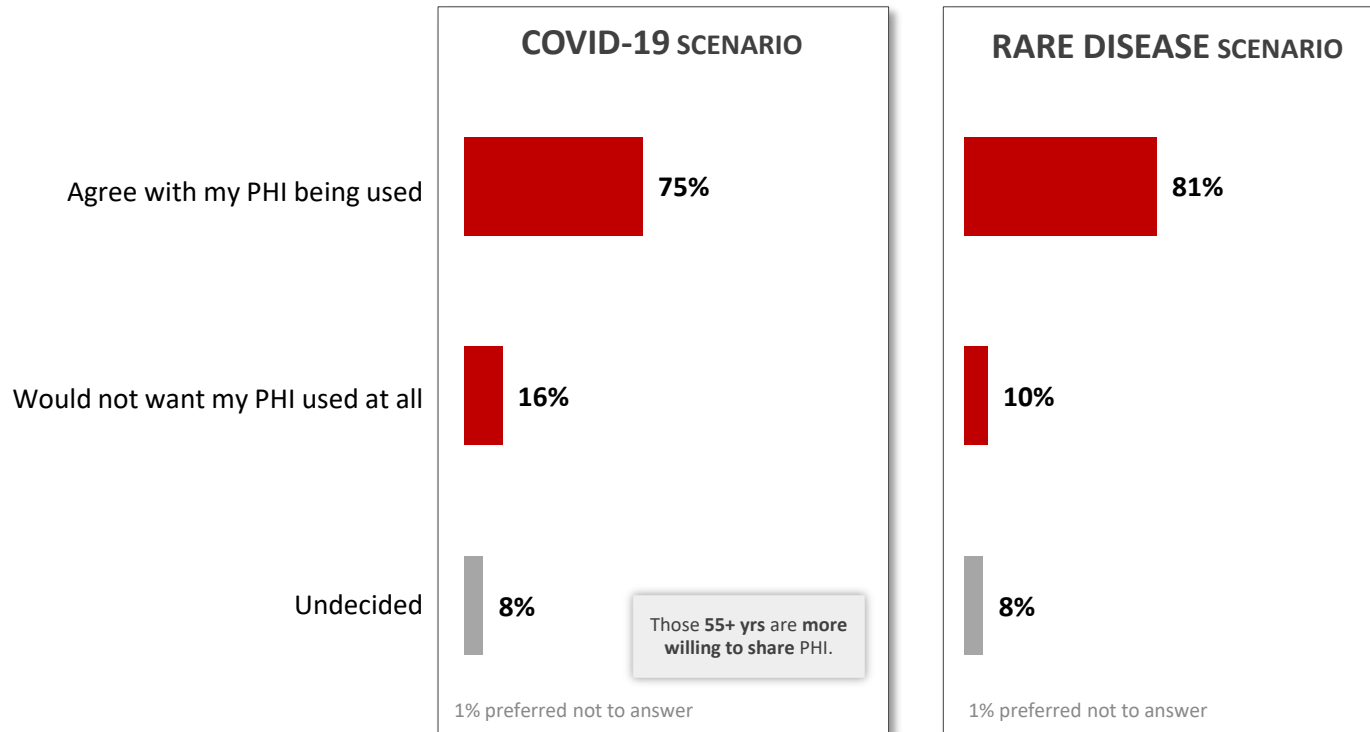
Respondents were presented with a second case/scenario within the same theme, and answered a series of questions based on that scenario.

COVID-19 Scenario (n=1,005 respondents shown)

A researcher affiliated with a pharmaceutical company would also like to use Alex's personal health information as a part of a pool of data for developing a treatment for COVID-19.

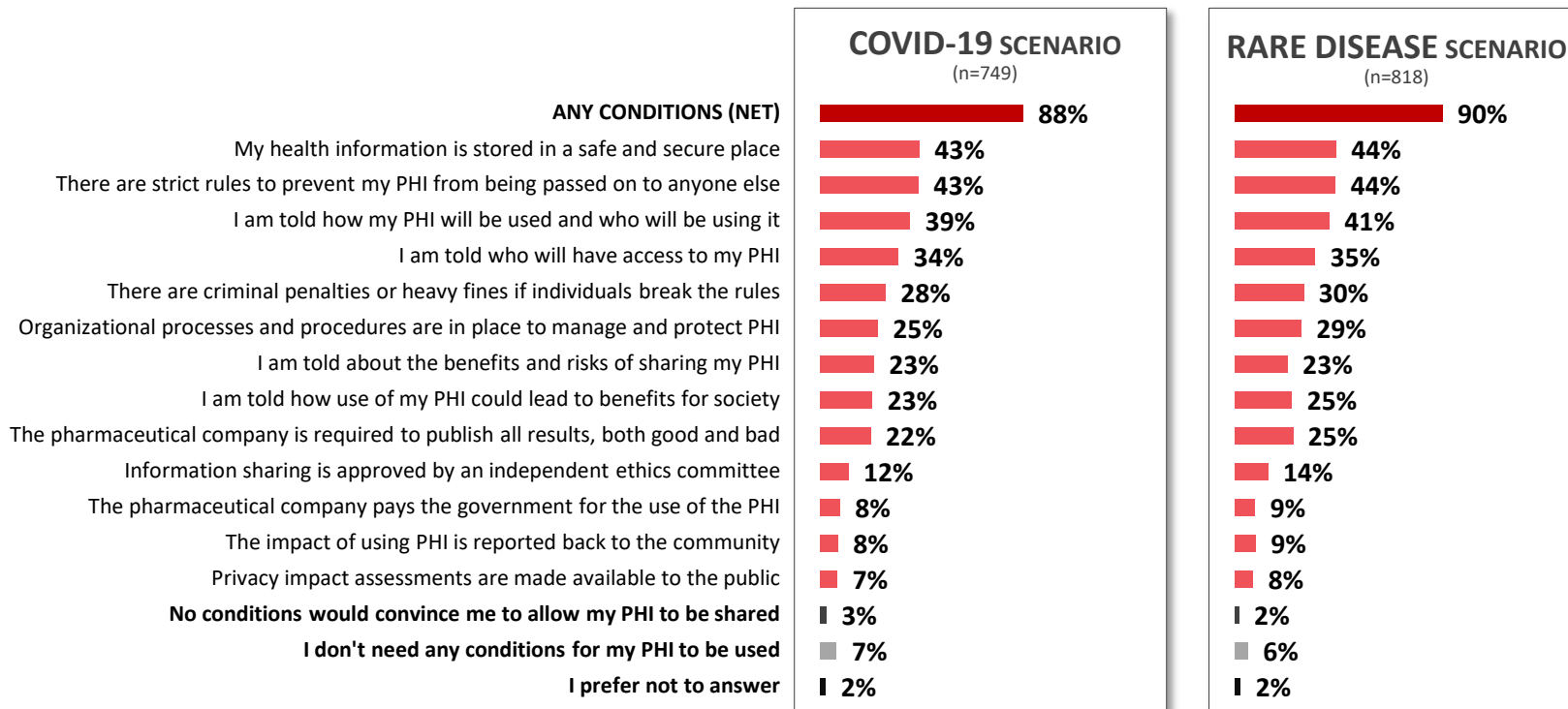
RARE DISEASE Scenario (n=1,005 respondents shown)

A researcher affiliated with a pharmaceutical company would also like to use Alex's personal health information as a part of a pool of data for developing a treatment for the rare disease.



Pharmaceutical Research Scenario:

Prerequisites for Consent Important to Canadians



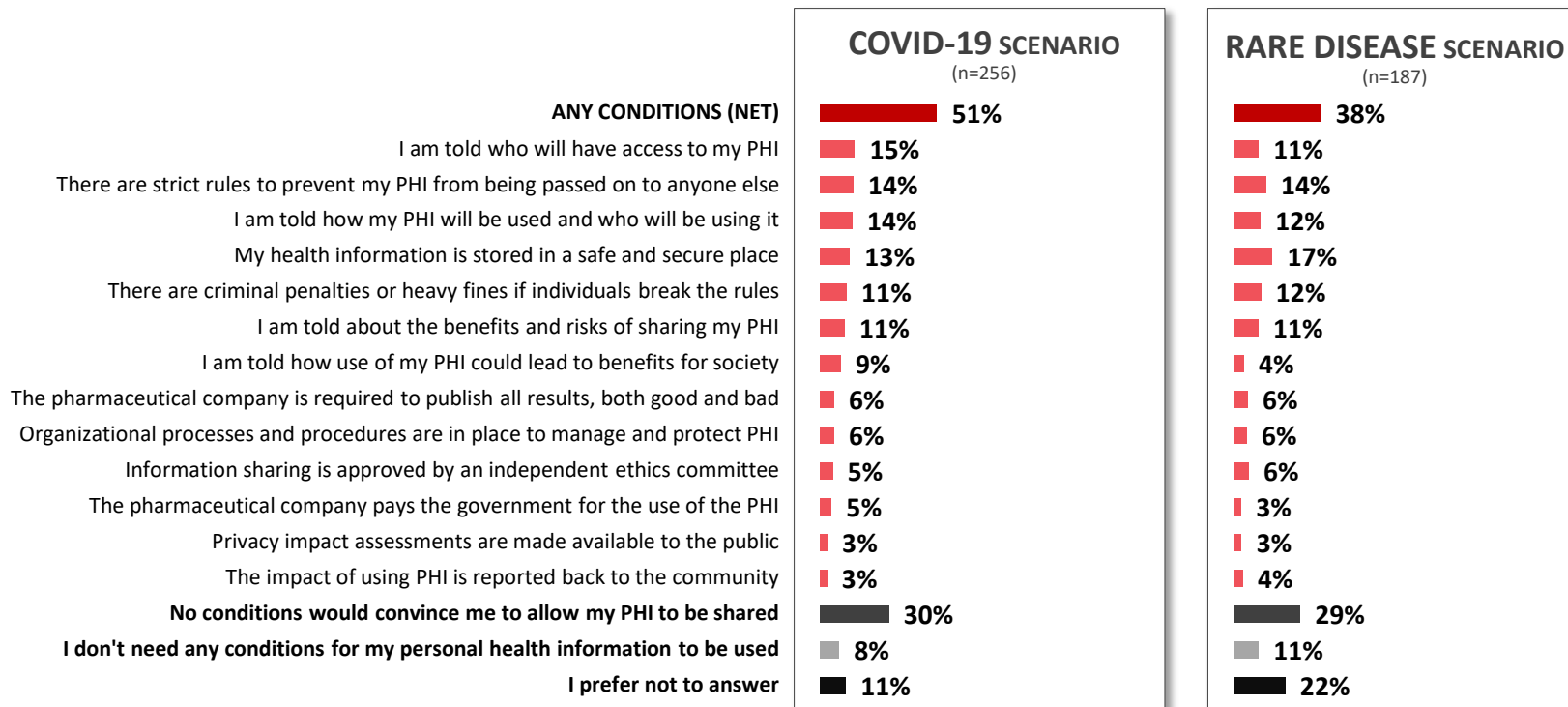
Base: Respondents answering for COVID-19 scenario (n=749) / rare disease scenario (n=818)

34. Which of the following conditions are required for you to consent? /

Which of the following conditions would convince you to allow your personal health information to be shared? Please select up to 5.

Pharmaceutical Research Scenario:

Prerequisites for Consent Important to Canadians

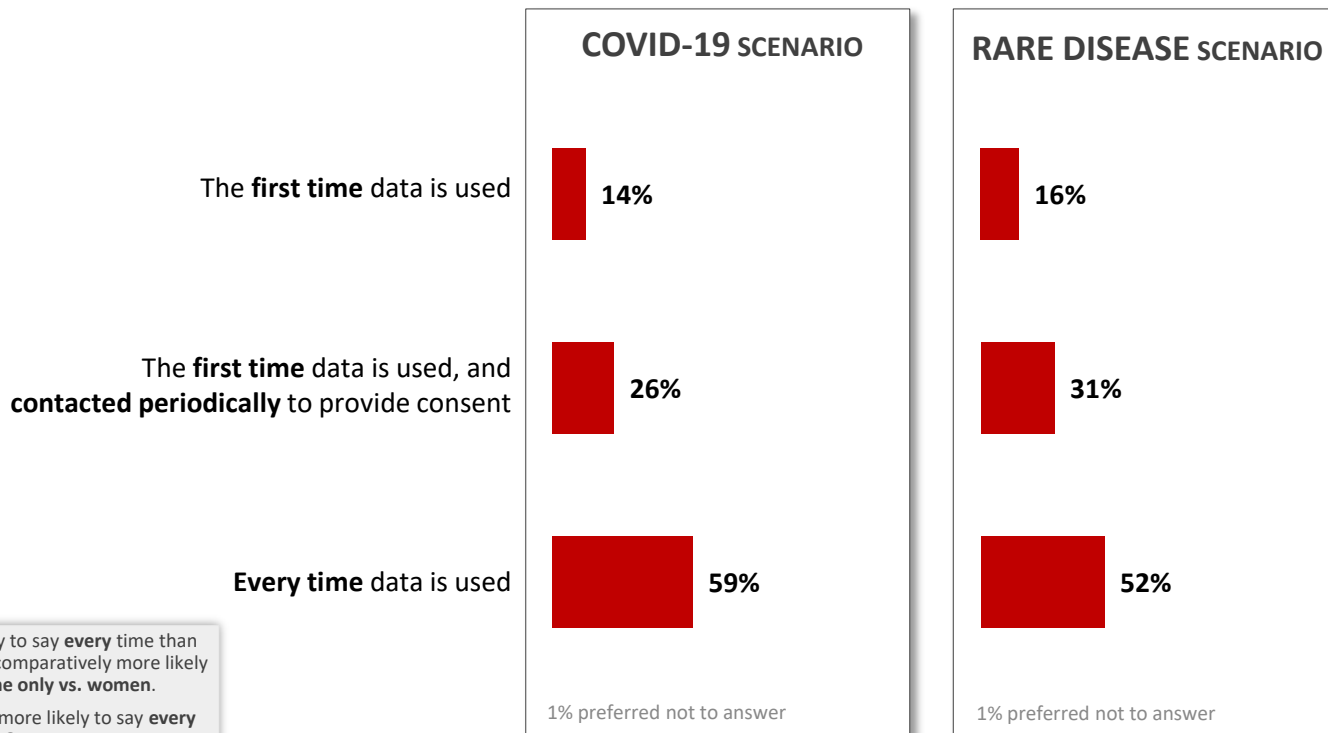


Base: Respondents answering for COVID-19 scenario (n=256) / rare disease scenario (n=187)

34. Which of the following conditions are required for you to consent? /

Which of the following conditions would convince you to allow your personal health information to be shared? Please select up to 5.

Pharmaceutical Research Scenario: Preference of Frequency Asked for Consent



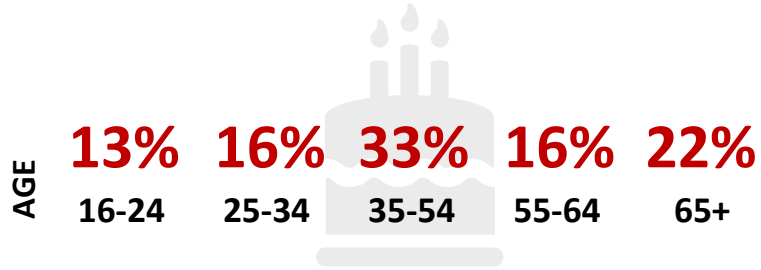
Females are more likely to say every time than males, while males are comparatively more likely to say the first time only vs. women.

Those 25-54 years are more likely to say every time, while those <25 & 55+ years are more likely to say periodically. Fewer 25-34 years want to be contacted periodically.

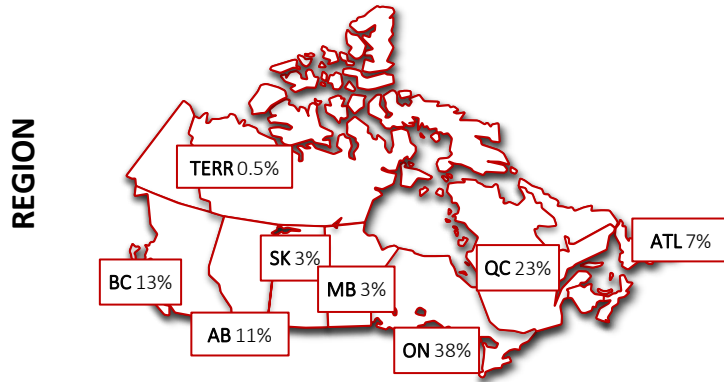
A crowd of people is silhouetted against a dramatic, sunset sky. They are holding up numerous Canadian flags, which are waving in the air. The scene conveys a sense of national pride and celebration.

SAMPLE COMPOSITION / DEMOGRAPHICS

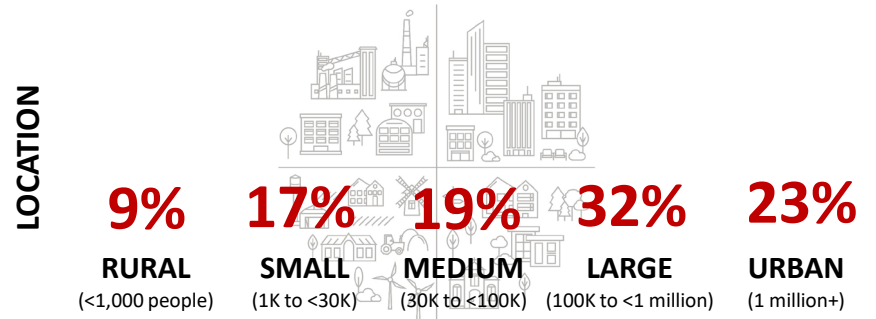
Respondent Profile (Weighted)



Average age: **47 years**



1% self-identified as gender diverse

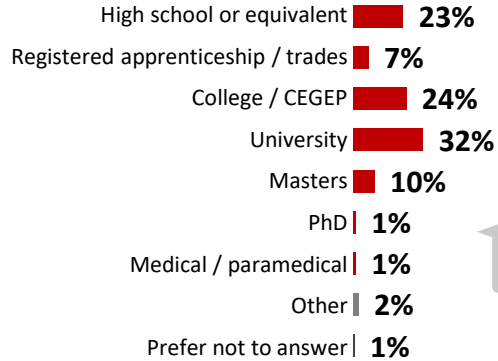


Base: Total respondents (n=2,010)

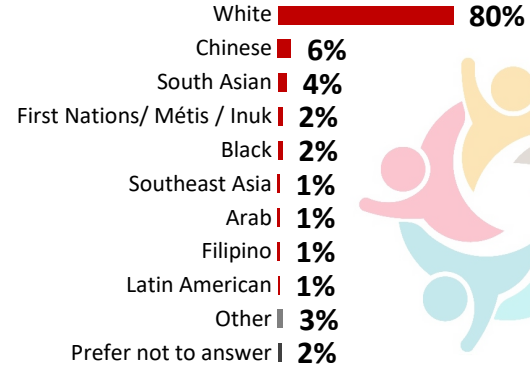
3. What is your age?
2. How would you describe your gender?
1. In which province/territory do you currently live?
49. How would you describe the community you live in?

Respondent Profile (Weighted)

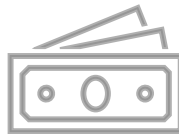
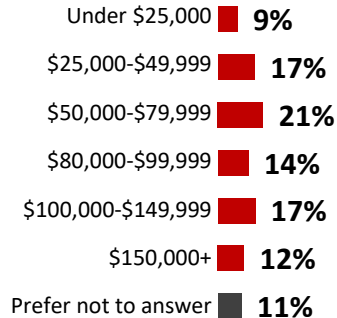
EDUCATION



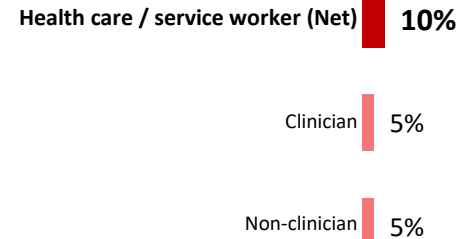
ANCESTRY / ETHNICITY



HOUSEHOLD INCOME



HEALTH CARE / SERVICES WORKERS



Base: Total respondents (n=2,010)

46. What is the highest level of education you have obtained?

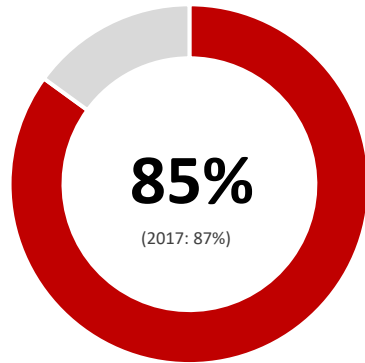
48. Which race category best describes you?

47. Please indicate your annual household income (e.g., total income including yourself and all individuals you live with) before taxes in the past year.

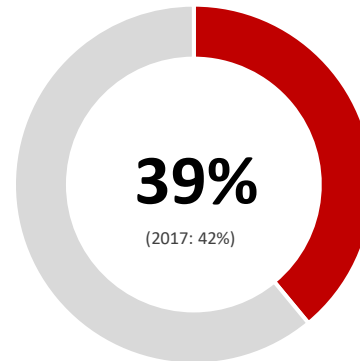
45. Are you employed in the health care or health services sector?

Health Care Profile

HAVE FAMILY DOCTOR / REGULAR PLACE OF CARE

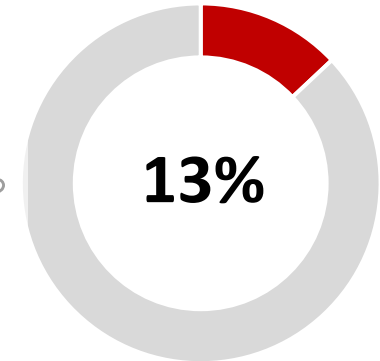


CHRONIC ILLNESS / CONDITION



A chronic illness is a physical or mental condition that has been diagnosed by a medical professional and persists or is expected to persist for six months or more.

PROVIDE UNPAID HEALTH SUPPORT



Base: Total respondents (n=2,010)

- 40. Do you have a family doctor or regular place of care, such as a health centre?
- 41. Do you have a chronic illness or condition at this time?
- 42. Do you provide unpaid support to someone with a diminishing physical ability, a debilitating cognitive or mental condition, or a chronic life-limiting health condition (e.g., taking to them to health care appointments, attending appointments, participating in treatment decisions, etc.)?