



Canada Health Infoway Inforoute Santé du Canada

Distribution of Electronic Access to Personal Health Information (PHI) across Sociodemographic and Socioeconomic Strata in Canada

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ABSTRACT

Using data from the 2023 Digital Health Equity Analysis conducted by Canada Health Infoway, we examine the current landscape of access to electronic personal health information across several population groups in Canada. We explore the concept of digital health equity and discuss its importance in facilitating improved health outcomes and experiences through increased access to electronic personal health information across the health system. Furthermore, we present examples of current initiatives and work taking place to support equitable access to personal health information online.

BACKGROUND AND CONTEXT

The spread of COVID-19 required expeditious and innovative solutions to facilitate continued access to health services and personal health information while supporting physical distancing measures (Health Canada 2021). These solutions took the form of virtual care platforms, patient portals, clinical decision support tools and more. Many of the solutions that were rapidly deployed at this time have remained in place and gone on to support improved access to personal health information across the Canadian healthcare system.

For instance, Canada Health Infoway (Infoway) has committed to improving connectivity among all care sectors, organizations, and providers through the [Shared pan-Canadian Interoperability Roadmap](#) (Canada Health Infoway 2023). Within the Roadmap, it is highlighted that a connected Canadian healthcare system relies on all persons in Canada being able to access, manage, and share their personal health records (Canada Health Infoway 2023). Electronic access to personal health information, a key component of

personal health records, is an integral to enhance connectivity (Canada Health Infoway 2023). Additionally, the “*Connected Care for Canadians Act*” (Bill C-72), proposed by the federal government, reflects a significant step forward in strengthening Canada’s healthcare ecosystem by prioritizing data sharing and interoperability (Health Canada 2024).

Ideally, through these initiatives, all patients should be able to effectively use technology to access their personal health information regardless of their socioeconomic, sociodemographic, cultural, linguistic, racial, or ethnic group, enabling every person in Canada to remain informed and engaged in all aspects of their care (Health Canada 2021; Canada Health Infoway 2023). In turn, this equitable access should translate into more positive health outcomes and behaviours through increased patient involvement (Health Canada 2024).

However, this is currently not the case. Instead, it has been revealed that digital health solutions, implemented during the pandemic, may have unintentionally exacerbated pre-existing health inequities across several population groups, hindering action towards improved access to online personal health information and a more connected healthcare system (Public Health Ontario 2023; Crawford, A. & Serhal, E. 2020). This is concerning as delayed access to personal health information has been found to impact access to care and lead to negative health outcomes, particularly for those in marginalized and vulnerable populations (Health Canada 2024).

As a result, work to adequately interpret and evaluate dimensions of digital health equity has progressed significantly since the onset of the pandemic. Virtual care experts have consulted and defined digital health equity as *“the provision of equitable health service using digital communication or information tools for the collection, exchange and use of health-related information for purposes of promoting quality care (Health Canada 2021).”* A digital health supplement to the Health Equity Impact Assessment has been developed as a tool to support equitable design considerations for digital health solutions prior to and during development and delivery (CAMH 2022). Additionally, frameworks, such as the Digital Health Equity Framework (DHEF), have been proposed to define the scope of digital health equity and the factors that impact it (Crawford, A. & Serhal, E. 2020). Resources for more information on the Health Equity Impact Assessment and Digital Health Equity Framework (DHEF) are provided in the Appendix sections [2] & [3].

In each case, the complexity of digital health equity is emphasized. There are numerous perspectives and factors to consider when assessing digital health equity due to the interactive and overlapping nature of individual identity (Crawford, A. & Serhal, E. 2020; Public Health Agency of Canada 2022). Nonetheless, it is necessary to develop a current state picture of access to electronic personal health information. This analysis hopes to identify how digital health solutions can be improved to adequately support initiatives related to health system connectivity and access to electronic personal health information for all population groups in Canada.

METHODS

The purpose behind our analysis was to generate insights into potential variations in access to online personal health information across equity stratifiers. Here, equity stratifiers are considered factors, determinants, and drivers of access to electronic personal health information (Canada Health Infoway 2024). Data used to facilitate our analysis was collected from the 2023 Canadian Digital Health Survey, conducted between November 28th and December 28th, 2023. This survey is online, cross-sectional, and bilingual in nature, capturing person-based data on awareness, use and perceptions regarding digital health technologies and services. A sample of 10,130 patients in Canada aged 16 years and over was achieved using an online panel of over 400,000 representative panelists from all regions of the country (Canada Health Infoway 2024). Full sample description is available in the survey report.

We evaluated equitable access to electronic personal health information, the dependent variable of interest, by:

- 1) Identifying and defining equity stratifiers.
- 2) Operationalizing equity stratifiers and key variables in the 2023 Canadian Digital Health Survey dataset.
- 3) Performing disparity metric assessments with an odds ratio and relative terms.
- 4) Completing graphical, bivariate and trend analysis to track metrics.

The equity stratifiers that were part of the analysis include:

- Access to a Regular Health Care Provider (HCP) or Place of Care
- Chronic conditions

- Healthcare Encounters- Healthcare Users
- Age Categories
- Gender Identity
- Rurality
- Education Level
- Household Income
- Virtual Care Users
- Digital Health Literacy (DHL)

For more information on the data source and analysis methods, review the Appendix and survey report.

ANALYSIS

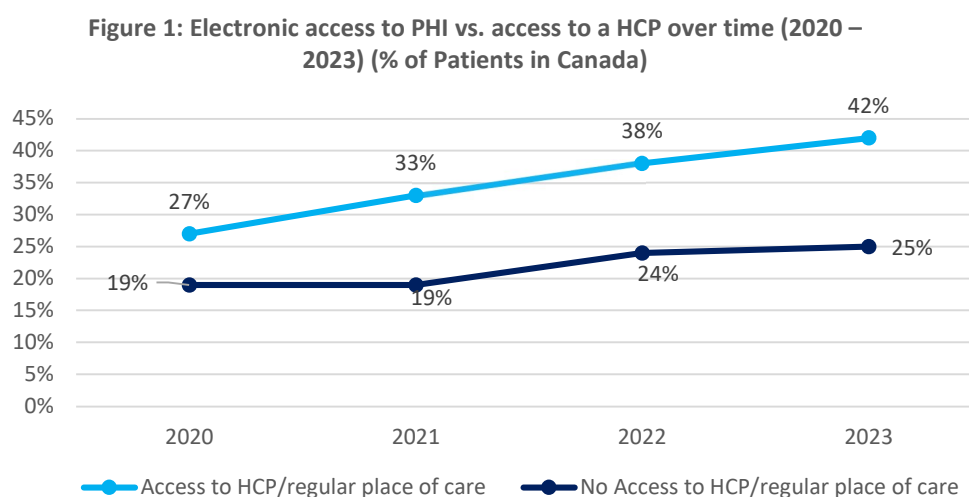
While most Canadians are interested in accessing their personal health information (PHI) online, not all have been able to do so yet, highlighting the need for continued efforts to meet patient care needs.

Overall, people in Canada reported high interest in accessing their personal health information online (81%). However, when surveyed on having ever accessed their personal health information online, less than half (39%) reported to have done so (Canada Health Infoway 2024).

The difference in these values highlights an existing gap (42%) between interest and access to electronic personal health information.

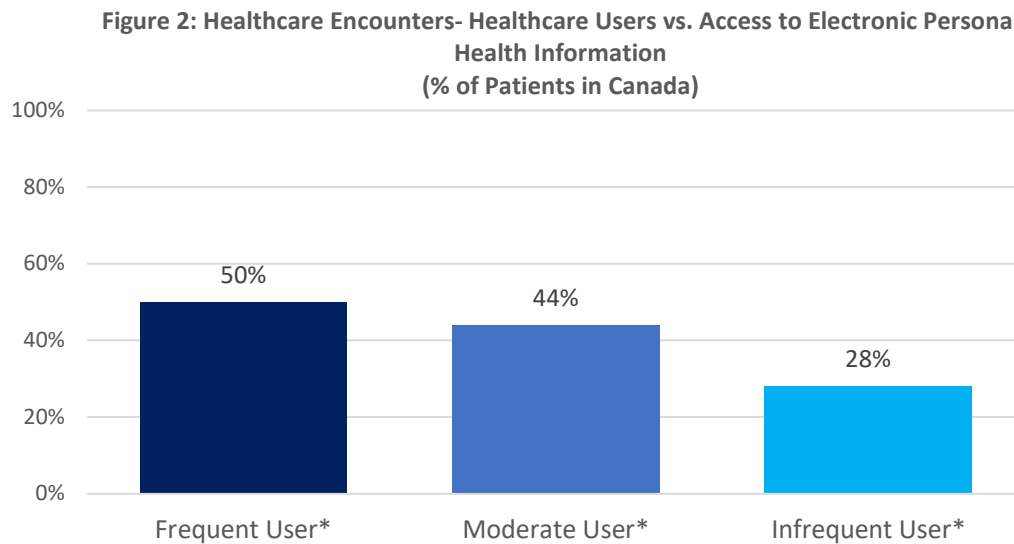
Access to electronic PHI is driven by several health-related factors.

Those with access to a regular healthcare provider (HCP) or place of care are more likely to access their electronic personal health information than those who do not (42% vs. 25%) (Canada Health Infoway 2024). Tracking of this stratifier demonstrates that the difference between these population groups has continued to increase since 2020 (Figure 1) (Canada Health Infoway 2024).



Similarly, patients with chronic conditions accessed their personal health information online more than those without a chronic condition (45% vs. 33%) (Canada Health Infoway 2024).

The factors described were thought to prompt increased utilization and familiarity with the health system. Therefore, the number of healthcare encounters were evaluated and access to electronic personal health information was determined to increase with usage (Figure 2) (Canada Health Infoway 2024).



*Infrequent user (<5): Less than five healthcare encounters/visits in the past 12 months, either in-person or virtual;

*Moderate user (5-10): between five and ten healthcare encounters/visits in the past 12 months, either in-person or virtual;

*Frequent user (>10): more than ten healthcare encounters/visits in the past 12 months, either in-person or virtual [8].

Access to electronic PHI is driven by several sociodemographic factors.

Senior Canadians (aged 65 years or over) are reported to have the highest access to their personal health information compared to all other age categories (16 to 24 years- 29%; 25 to 34 years- 36%; 35 to 54 years- 38%; 55 to 64 years- 40%; 65 years and over - 48%) (Canada Health Infoway 2024). Additionally, female respondents and those living in non-rural areas have higher access to their electronic personal health information than male respondents (43% vs. 35%) and those living in rural areas (40% vs. 32%), respectively (Canada Health Infoway 2024).

Increased education level is also positively associated with electronic personal health information access as higher access is measured among those with university-level education (Figure 3) (Canada Health Infoway 2024).

Figure 3: Education Level vs. Access to Electronic Personal Health Information
(% of Patients in Canada)



In addition to the sociodemographic factors mentioned above, it must be noted that historical data has indicated that there are Indigenous-specific barriers to accessing electronic personal health information (Canada Health Infoway 2021). However, Indigenous, and all other racial data, was omitted from the 2023 Digital Health Equity Analysis as Infoway has prioritized working with Indigenous partners to review data collection and evaluation methodologies within Indigenous communities.

Higher household income is associated with higher electronic access to PHI.

Respondents with \$100,000 or more in annual household income are more likely (48%) to report access to their electronic personal health information than those with \$50,000 to \$99,000 (39%) or less than \$50,000 in household income (33%) (Canada Health Infoway 2024).

Access to electronic PHI is driven by a couple of digital factors.

Virtual care users are more than twice as likely to have access to their personal health information than those who are not (52% vs. 24%) (Canada Health Infoway 2024).

Furthermore, respondents who scored 28 or more on the eHEALS scale were more likely to have access to their personal health information than those who scored less than 28 (40%

vs. 32%) (Canada Health Infoway 2024). The eHEALS is an 8-item scale designed to assess consumers' perceived skills at using information technology for health and measure consumers' combined knowledge, comfort, and perceived skills at finding, evaluating, and applying electronic health information to health problem (Norman, C. & Skinner, H. 2006).

DISCUSSION

Results indicate that there is much work to be done to ensure equitable access to electronic health information across all population groups. All stratifiers included in this analysis were determined to have a statistically significant relationship with access to online personal health information at the 0.01 level of significance (Table 1, Appendix). This finding exhibits the multi-faceted and compounded nature of digital health equity that is remarked in existing literature (Crawford, A. & Serhal, E. 2020).

Moreover, interest in accessing personal health information is high among patients in Canada, demonstrating that there is appetite for solutions that facilitate access. The difference that exists between interest and access highlights an important gap that requires effort to mend (81% vs. 39%). Patients may lack awareness on how their personal health information can be accessed digitally, meaning increased promotion and accessibility of these solutions is necessary. Likewise, current digital health solutions may be difficult to use due to data silos and aggregation issues that fragments personal health information across different platforms and portals (Canada Health Infoway 2023). Finally, patients may know they can access their personal health information electronically, but not have the skills, resources, or training to be able to so (Richardson, S. et al. 2022).

Lack of training, resources, and skill could also explain why lower income and education

level individuals access personal health information online less than higher income (33% vs. 48%) and education communities (College/Apprenticeship- 39%; University- 44%; H.S. or less- 31%). These variables may be related to knowledge and awareness which support our findings that increased digital health literacy and experience with virtual care are able to access their personal health information online more than those with lower literacy skills (40%vs. 32%) and a lack of virtual care experience (52%vs. 24%). Both digital factors as well as education and income level would provide patients with increase knowledge, comfortability, and expertise in navigating digital health technologies (CAMH 2022; Richardson, S. et al. 2022). Infoway's Digital Health Learning Program is an example of how individuals can be made aware of and provided with the necessary knowledge to understand and access their personal health information electronically (Canada Health Infoway 2021)

Other factors, such as chronic condition status (with- 45% vs. without- 33%), the presence of a regular healthcare provider or place of care (with- 42% vs. without- 24%), the number of healthcare encounters (frequent- 50% vs. infrequent- 28%) and age (65 years and older- 48%) support the perception that increased experience and interaction with the healthcare system enables increased access to electronic personal health information through greater awareness of and engagement in their health (Crawford, A. & Serhal, E. 2020; CAMH 2022).

For rural, access to health services has historically been limited due to infrastructure and funding constraints (Public Health Agency Canada 2022). Digital health technologies that would enable electronic access to personal health information are hindered by existing barriers, such as limited internet and/or cellular service (Health Canada 2021). Our findings

support these perspectives with rural communities experiencing reduced access to electronic personal health information compared to non-rural communities (40% vs. 32%).

As demonstrated, access to electronic health information is integral. Improved access enables patients to be empowered and engaged. Heightened engagement and awareness of health status with digital access to their personal health information allows for better management of one's health by way of access to diagnostic imaging and lab results, educational material, medication lists, secure provider messaging, and more (Sieck, C. et al. 2018). Improved care as well as health outcomes can only become possible when patients are provided the information and tools to be in active partnership with healthcare providers (Health Canada 2024; Canada Health Infoway 2023).

Future studies should focus on the type and amount of health data patients contribute, their awareness and involvement in the activities that require usage of their health data and their perceptions of health data stewardship and governance. These topics would support the development of the current state of access to electronic personal health information by evaluating specific measures of patient contributions and involvement.

CONCLUSION

To conclude, the COVID-19 pandemic was a catalyst for digital health technology growth and deployment. Canada's healthcare system is the most digitized it has ever been and plans to continue along the path of modernization through action and strategy, like the Shared Pan-Canadian Interoperability Roadmap and the proposition of Bill C-72. For the objective of fulsome access to electronic personal health information to be achieved, stakeholder investment in promotion, education, training, adoption, and funding must occur.

Infoway is bringing together key stakeholders—including jurisdictions, clinicians, industry partners, Indigenous communities, and federal representatives—to develop and implement interoperable solutions that drive forward the Shared Pan-Canadian Interoperability Roadmap (Canada Health Infoway 2023). Interoperability is the essential foundation for a connected care system, enabling patients to access and share their personal health information, providing clinicians with timely and comprehensive patient data, and transforming digital health systems to work together rather than in silos (Canada Health Infoway 2023). By fostering collaboration and creating standards that support seamless data sharing, Infoway and our partners are paving the way for a more integrated healthcare ecosystem that ultimately empowers patients, enhances clinical decision-making, and improves health outcomes for *all* Canadians (Canada Health Infoway 2023).

Altogether, the key to a more connected Canadian healthcare system relies on the prioritization of equity in digital health solution design, deployment, and use to support electronic access to personal health information across all population groups.

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