

DIGITAL HEALTH LITERACY TOOLKIT

Module 2 – GDHP Digital Health Literacy Survey Results

GDHP Clinical and Human Engagement Work Stream



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- Current and former chairs of the GDHP work streams
- Individual GDHP members and their colleagues who contributed materials, survey responses, and feedback
- Case example interview informants:
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 - Hong Kong: Dr. NT Cheung

Please note that the information presented in this document does not necessarily represent the views of the individuals or organisations mentioned.

ABOUT THE GLOBAL DIGITAL HEALTH PARTNERSHIP

The Global Digital Health Partnership (GDHP) is a collaboration of governments and territories, government agencies and the World Health Organization, formed to support the effective implementation of digital health services.

Established in February 2018, the GDHP provides an opportunity for transformational engagement between its participants, who are striving to learn and share best practice and policy that can support their digital health systems. In addition, the GDHP provides an international platform for global collaboration and sharing of evidence to guide the delivery of better digital health services within participant countries.



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1 GLOSSARY

Table 1: Terms Used in This Toolkit

Term	Definition
Caregiver	Individuals who provide support to another individual, including interacting with health care delivery services on their behalf (in some countries, the term <i>carer</i> may be used more frequently).
Digital health	The use of electronic information and technologies to manage health and deliver care.
Digital health literacy	The ability to find, understand, and apply health information, and to manage one's own health, by using electronic tools and information sources such as apps, video conferencing platforms, online portals and web sites.
Digital inclusion	The activities necessary to ensure that all individuals and communities have access to and use of technology.
Global Digital Health Partnership	A collaboration of country governments and global partner organisations formed to support the executive implementation of worldwide digital health services.
Interoperability	The ability for information systems and software to exchange mutually comprehensible and usable data.
Lived/living experience	<p>The firsthand, direct experience, choices, and knowledge of a given individual.</p> <p>Lived/living experience is distinct from second-hand or mediated knowledge (e.g., having knowledge <i>about</i> a community, as opposed to having the knowledge of <i>being from</i> a community).</p>
Patients	Individuals who are actively engaging with health care delivery services to manage or improve their own health.
Person-centered care	An approach to care which prioritizes the individual health needs, goals, and values of the person receiving care.
Personal health information	Any identifying information about a person's health or health care.
The public	The general population, beyond a health care context.
Virtual care	Health care delivered via technology, whether synchronously or asynchronously.

2 EXECUTIVE SUMMARY

Digital health literacy is a foundational element of successful health care transformation. The ability to independently and safely access, understand, and apply health information, and to manage one's own health by using electronic tools and information sources such as apps, video conferencing platforms, and online portals is now essential. As digital tools increasingly support the delivery and management of care, digital health literacy supports patients' autonomy, agency, and participation within the health system, enabling them to:

- Access, manage, and use their own health data to make informed decisions about their health and health care
- Use technology to actively participate in their care
- Use technology to self-manage their health as appropriate
- To the extent possible, choose the modality of care best suited to their individual health needs, goals, and preferences.

This toolkit compiles international learnings and practices to support the advancement of public digital health literacy. Developed by the Clinical and Human Engagement work stream of the Global Digital Health Partnership (GDHP), it is intended for use by anyone seeking to:

- Develop or procure resources to build digital health literacy skills among the general public
- Contextualize their existing digital health literacy work within the international landscape
- Understand the evolving definitions, impacts, and implications of digital health literacy.

The GDHP was founded in 2018 to facilitate cooperation and knowledge exchange in digital health. This toolkit integrates its membership's collective expertise through a members' survey, semi-structured interviews, and consultation at bi-annual summits. Member insights are complemented with a collection of international digital health resources and considerations for developing digital health literacy resources.

This document contains Module 2 – GDHP Survey Results. Download the full Digital Health Literacy Toolkit at www.gdhp.health.

3 GDHP DIGITAL HEALTH LITERACY SURVEY: OVERVIEW, FINDINGS, AND IMPLICATIONS

IN THIS SECTION

- Survey Overview
- Survey Findings
- Discussion
- Implications for the Clinical and Human Engagement Work Stream
- Copy of the Digital Health Literacy Survey

3.1. SURVEY OVERVIEW

3.1.1. Context

In early 2022, the Clinical and Consumer Engagement work stream surveyed GDHP members to understand the international digital health literacy landscape and identify priority areas for action. This survey built on a previous environmental scan of digital health literacy resources conducted in January 2022.

Survey responses were received from:

- Australia
- Canada
- I-DAIR ¹
- Hong Kong, China
- Italy
- Nigeria
- New Zealand
- Poland
- Portugal
- South Korea
- Sweden
- Switzerland
- United Kingdom
- Uruguay
- Zambia

¹ The International Digital Health and AI Research Collaborative (I-DAIR) became HealthAI in 2023.

3.1.2. Problem Statement

The survey's guiding problem statement was: What is the current state of digital health literacy across the international community, and what best practices and common priorities can help to shape ongoing citizen education?

3.1.3. Methodology

Four authors contributed to an initial draft of the survey, which was refined through a review by work stream members. The final survey was disseminated to all GDHP members in March - May 2022, with findings reported to the GDHP membership in October 2022.

Appendix A presents a copy of the survey, which consisted of open- and close-ended questions. These responses were synthesized to identify common themes. An additional environmental scan of digital health literacy resources and programs in GDHP member countries² was conducted from May to October 2022 to identify examples omitted in the survey process.

3.1.4. Limitations

The GDHP is an international collaboration with members at varying levels of digital health adoption and digital health literacy. Digital health literacy is an emerging concept which may have multiple understandings, though a definition was provided in the survey to support consistency.

Development of the survey was conducted primarily by three individuals from Canada Health Infoway and may thus have been disproportionately influenced by the perspective of a single organisation within a single country. The survey authors' primary language is English, with fluency in French. The survey was developed, distributed, and completed in English only. Examples of digital health literacy resources and programs not available in English or French were translated into English for high-level comprehension via an artificial intelligence tool.

The survey response rate was approximately 50 per cent of GDHP membership at time of dissemination. While the survey respondents were diverse in geography, digital health maturity, and health system structures, governance, and funding, this sample size may not capture the full breadth of experience across the GDHP.

3.2. SURVEY FINDINGS

3.2.1. Proportion of Population Able to Find and Use Online Health Tools

Eight respondents reported that most (i.e., more than half) of their citizens or the populations they serve are able to find and use online health tools. Three respondents reported that some are able to do so, while three reported that almost all are able to do so. No responses were received indicating "few or none."

² At the time of the scan, the GDHP was comprised of 30 member countries and territories.

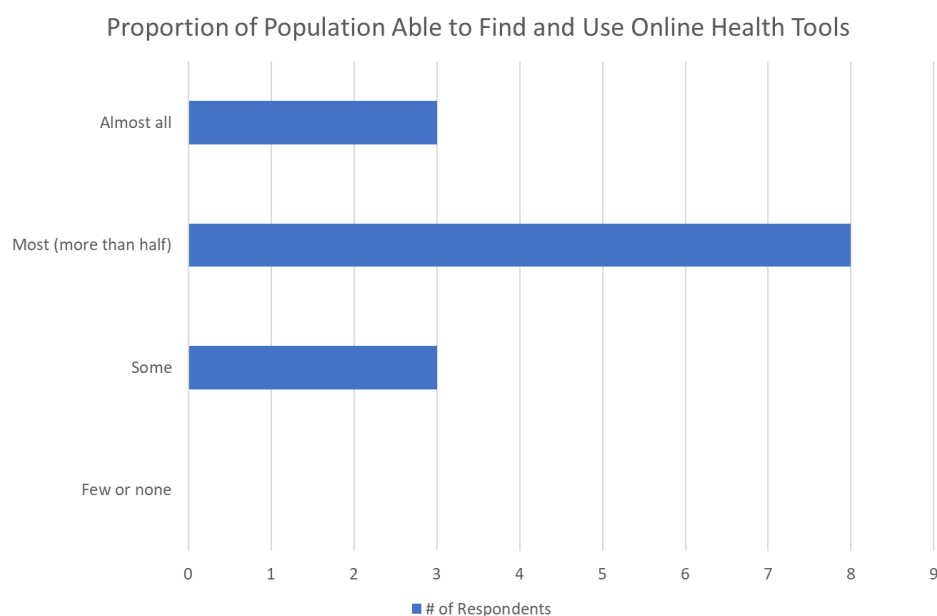


Figure 2: Responses to the question, “Please estimate what proportion of your country’s citizens (or the populations you serve) are able to find and use online health tools?” [n = 14]

3.2.2. Current State of Digital Health Literacy Tools and Programs

Six respondents indicated that digital health literacy tools and programs are available in limited circumstances. Three respondents reported that digital health literacy tools and programs are available/in use for some citizens; four respondents reported that they are widely available and in use. One respondent indicated that such tools and programs are not available.

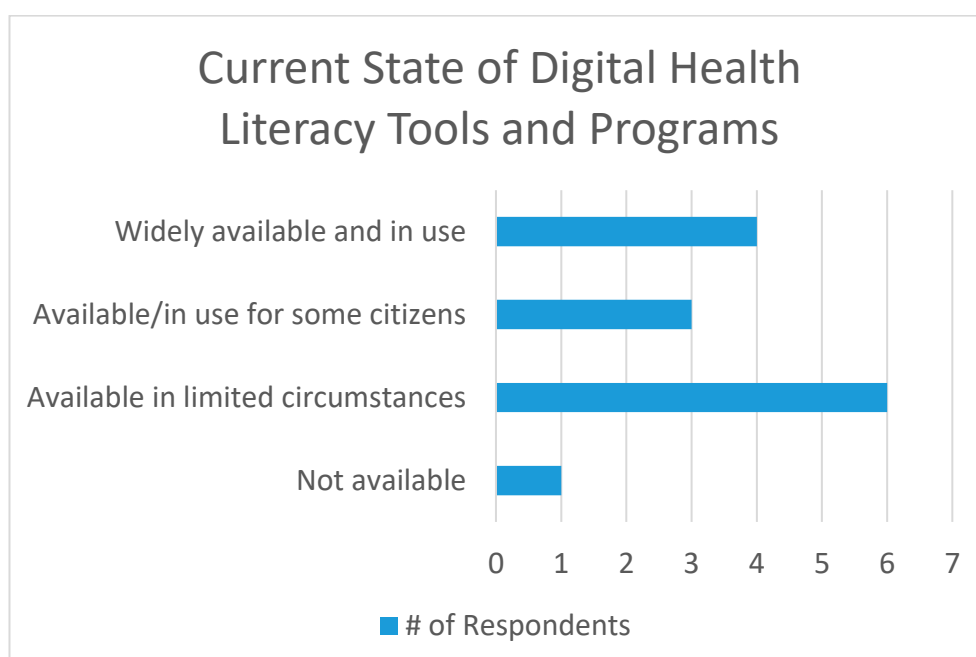


Figure 3: Responses to the question, “Which statement most accurately describes the current state of digital health literacy tools and programs in your country?” [n = 14]

3.2.3. Education Priority Areas

The survey presented a list of digital health literacy education priority areas. Respondents were asked to indicate all areas that were priorities for their country and/or organisation (some GDHP members do not represent governments). The most highly selected priorities were furthering individuals' understanding of how they can use health data to manage their health, and furthering their understanding of the digital health tools available to them. Practical tips on preparing for a virtual visit and understanding how to use the internet and related technologies were the least selected priorities.

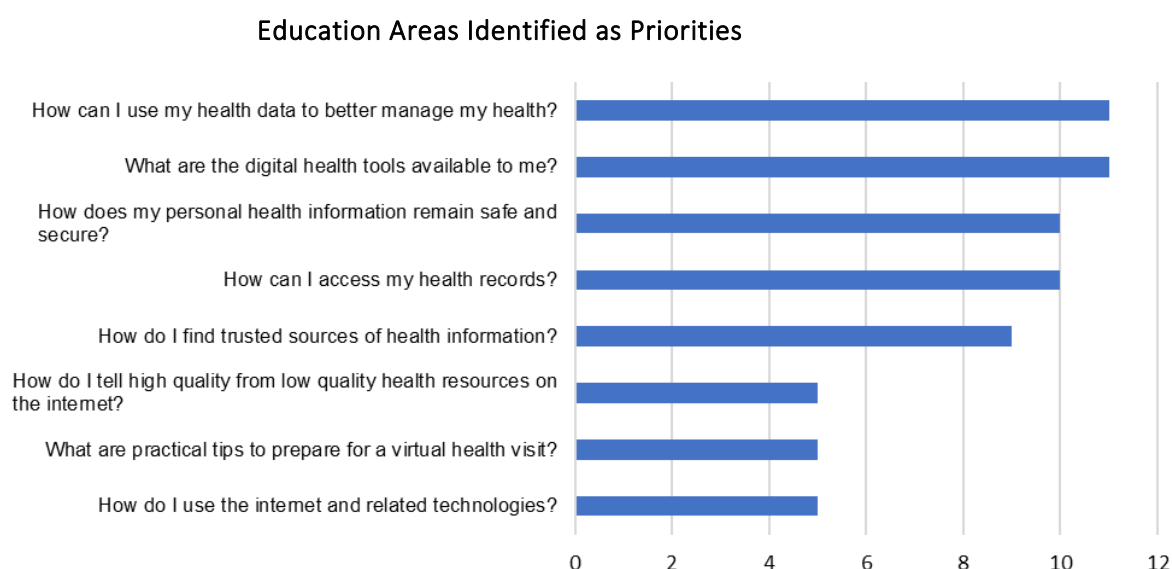


Figure 4: Responses to the question, “What digital health literacy education areas are priorities for your country and/or organisation?”

3.2.4. Digital Health Literacy Tools and Programs Implemented or in Development

Nine respondents identified 26 digital health tools/programs implemented or in development in their country or organisation. Alongside the resources identified through an additional scan, these resources were categorized by audience, tool type (e.g., e-learning modules, website articles, infographic, videos), and topic focus area.

Some resources were intended to support digital literacy and/or health literacy, rather than digital health literacy. These resources were included for illustrative purposes, but flagged as not being specific to digital health.

Finally, some resources were not available online (e.g., educational programming in communities). Descriptions of these resources were included in the scan.

3.2.5. Content Desired in a GDHP Digital Health Literacy Repository

Respondents were instructed to select all answers that applied. An open text field was included to capture content not otherwise listed.

All respondents desired examples and case studies of digital health resources and programs, and nine respondents reported a desire for best practice/implementation guides. Glossaries/taxonomies were the least selected type of content.

Content Desired in a GDHP Digital Health Literacy Repository

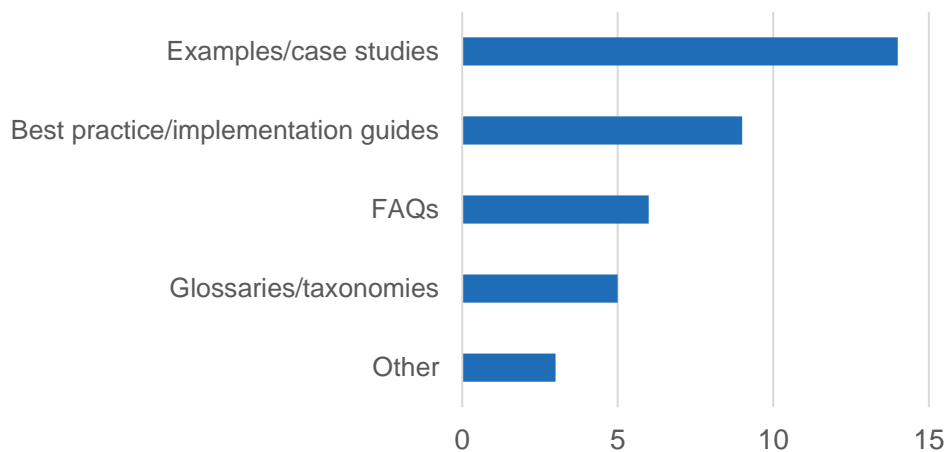


Figure 5: Responses to the question, “What content would you most like to see in a GDHP repository for digital health literacy resources?”

Additional desired content identified in the open text field included:

- Lessons learned
- Approaches for different population groups
- Evidence of evaluation on change impact assessments, integration/uptake, and engagement/effect on organisational outcomes
- Architecture, laws, regulations and policies
- Conceptual framework with examples from educational programs, guides and guidelines
- Academic collaborations

3.3. DISCUSSION

Respondents reported that their populations are generally able to find and use online health tools. While respondents were not asked about their populations’ level of proficiency or confidence in using digital health tools, “How do I use the internet and related technologies?” and “What are practical tips to prepare for a virtual health visit” were the least likely to be selected as priority education areas. These results suggest that basic internet skills are perceived to be prevalent among respondents’ populations.

Nonetheless, the survey findings indicate relatively limited implementation of resources to support digital health literacy, as half of respondents reported that they were “available in limited circumstances” or “not available.”

With respect to the digital health literacy resources desired and in use among respondents, this survey should be considered within the context of a modern internet environment. Among respondent countries, support for basic digital literacy/internet

skills may be undertaken through existing initiatives and/or educational settings, perhaps explaining the relatively low interest afforded to them in this survey.

In addition, the COVID-19 pandemic catalysed the use of video conferencing, messaging, and related technologies beyond health care, including for socialization, entertainment, and work. Virtual care technologies deployed in the urgency of the early pandemic shared similarities with, or were built upon, existing consumer technologies – e.g., Zoom, Facetime, email, and telephone. Thus, respondents may have felt their populations are already proficient in using virtual care tools.

Respondents demonstrated stronger interest in resources relating to individuals' use of their personal health information, including:

- How to use their personal health information (PHI) to better manage their health
- The privacy and security implications of accessing and sharing PHI
- How to access their PHI

This interest aligns with international efforts to improve individuals' access to their PHI; e.g., the [International Patient Summary](#) and [European Health Data Space](#). As health data becomes more readily accessible across care settings, patients' understanding of how to access their data and attendant privacy and security implications is increasingly important to supporting their agency and encouraging adoption of patient-facing technologies.

3.4. IMPLICATIONS FOR THE CLINICAL AND HUMAN ENGAGEMENT WORK STREAM

Members of the work stream discussed the survey findings at the 11th GDHP Summit in October 2022. While the digital health literacy repository was initially envisioned as a curation of existing material, the work stream determined that there was value in conducting “deep dive interviews” with selected countries.

These semi-structured interviews were intended to gain insight into:

- Time, effort, and resources involved in creating the digital health literacy resource(s)
- Development processes, challenges, and outcomes
- Leading practices and lessons learned.

The interviews formed the basis of the case examples and checklists and considerations presented elsewhere in this toolkit.

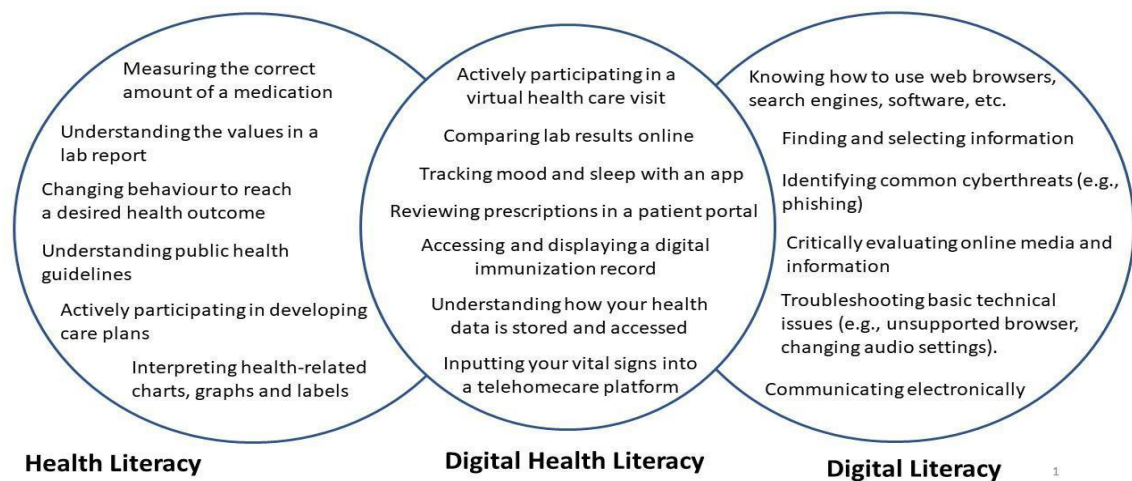
3.5. APPENDIX: COPY OF CLINICAL AND CONSUMER ENGAGEMENT³ DIGITAL HEALTH LITERACY SURVEY

Context:

As virtualization of health care accelerates as a result of the COVID-19 pandemic, digital health literacy skills are becoming increasingly important to citizens seeking to navigate their health systems and/or take a more active role in managing their health. The Clinical and Consumer Engagement Work Stream is currently building upon strategies to improve digital health literacy; this survey will help to leverage and refine a previous environment scan of digital health literacy progress across member nations.

While there are many interpretations and definitions of digital health literacy, the World Health Organization defines it as, “...the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem.” Digital health literacy combines aspects of health literacy and digital literacy, as illustrated by the examples in the diagram below; it is expected that there may be overlap between digital health literacy resources and more general digital citizenship and/or digital literacy initiatives.

For our purposes, digital health literacy comprises the ability to find and understand health information, and to manage one’s own health, using electronic tools and information sources such as apps, videoconferencing platforms, online portals and web sites.



Focus to November 2022:

- To quantify digital health literacy across the international community
- Identify priority areas for further education
- Begin developing a central repository of digital health literacy resources.

³ Survey predates the work stream’s name change from “Clinical and Consumer Engagement” to “Clinical and Human Engagement.”

Problem Statement:

What is the current state of digital health literacy across the international community, and what best practices and common priorities can help to shape ongoing citizen education?

Purpose of Survey:

The purpose of this survey is threefold:

To understand digital health literacy progress globally

To identify existing digital health literacy tools, programs and best practices

To determine what should be included in a shared GDHP repository of digital health literacy resources

Survey Instructions:

Please fill out the following survey to the best of your knowledge. You may choose to **bold** your answers, or to indicate your answers by typing/pasting an “X” or ✓ symbol. Where indicated, you may also type responses directly into this document.

All submitted surveys will be analyzed, reviewed with the Work Stream, and used to inform next steps. Thank you in advance for your contribution to, and support of, the Clinical and Consumer Engagement Work Stream.

Please complete your survey by May 6, 2022 and submit to Katie Bryski (kbryski@infoway-inforoute.ca).

General Information

Below, please write the name, role and organisation of the respondent(s) to this survey.

Survey Questions

Q1. What digital health literacy education areas are priorities for your country and/or organisation? [Select all that apply]

- ☐ How do I find trusted online sources of health information?
- ☐ How do I tell high quality from low quality health resources on the internet?
- ☐ How does my personal health information remain safe and secure?
- ☐ How can I access my health records?
- ☐ How can I use my health data to better manage my health?
- ☐ What are the digital health tools available to me?
- ☐ What are practical tips to prepare for a virtual health visit?
- ☐ How do I use the internet and related technologies?
- ☐ Other [Please describe below]

Q2. Please estimate what proportion of your country's citizens (or the populations you serve) are able to find and use online health tools? [Select one]

Examples may include the ability to access a patient portal, have a virtual health visit, retrieve/display a digital immunization record, use an app to track vital signs, etc.

- ☐ Almost all citizens
- ☐ Most citizens (more than half)
- ☐ Some citizens
- ☐ Few or no citizens

Q3. To your knowledge, which statement most accurately describes the current state of digital health literacy tools and programs in your country and/or among the populations you serve? [Select one]

Tools and programs can be government and/or community-led, and may include local, regional and/or national initiatives.

- ☐ Digital health literacy tools/programs are widely available and in use.
- ☐ Digital health literacy tools/programs are available and in use for some citizens.
- ☐ Digital health literacy tools/programs are available in limited circumstances.
- ☐ Digital health literacy tools/programs are not available.

Q4. If your country and/or organisation has one or more digital health literacy tools/programs implemented or in development, please provide a short description, and if possible, a link:

Q5. What content would you most like to see in a central GDHP repository for digital health literacy resources? [Select all that apply]

- ☐ Examples and case studies from other countries
- ☐ Best practice and implementation guides
- ☐ Glossaries/taxonomies
- ☐ Frequently Asked Questions (FAQs)
- ☐ Other [Please write below]

Q6. If you are not a member of the GDHP Clinical and Consumer Engagement Work Stream, would you like to stay updated about - or get involved with - the development of a central repository for digital health literacy resources? [Select one]

- ☐ Yes, please – I would like to be involved.
- ☐ Yes, please – updates only.
- ☐ No, thank you – please do not send me further emails.

Q7. Do you have colleagues knowledgeable about digital health literacy who would be interested in receiving this survey? [Select one]

- No
- Yes – their contact information is... [Please write below]

Q8: Are you aware of any digital health literacy tools/programs implemented or in development in countries who are not GDHP members? If so, please provide a short description, and if possible, a link. [Please write below]

Q9: OPTIONAL: If your organisation's activities span multiple countries, do you have additional digital health literacy best practices, resources or insights to share? [Please write below]

Q10. OPTIONAL: Do you have any other comments about digital health literacy in your country, or about a shared GDHP repository of digital health literacy resources? [Please write below]

3.6. MODULE REFERENCES

Canada Health Infoway. (2020). Canadian Digital Health Survey: What Canadians Think. <https://www.infoway-inforoute.ca/en/component/edocman/3856-canadian-digital-health-survey-what-canadians-think/view-document?Itemid=101>

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