DIGITAL HEALTH LITERACY TOOLKIT

Module 1 - Introduction

GDHP Clinical and Human Engagement Work Stream

GDHP
Global Digital Health Partnership

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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 *carer* 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	The firsthand, direct experience, choices, and knowledge of a given individual. Lived/living experience is distinct from second-hand or mediated knowledge (e.g., having knowledge *about* a community, as opposed to having the knowledge of *being from* a community).
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 1- Introduction. Download the full Digital Health Literacy Toolkit at www.gdhp.health.

2.1. DEVELOPMENT OF THE DIGITAL HEALTH LITERACY CONCEPT AND THIS WORK

IN THIS SECTION

- Background to this Work
- Development of the Digital Health Literacy Concept
- Definition of Digital Health Literacy
- Objectives and Scope of Work

2.2. BACKGROUND TO THIS WORK

Health systems around the world are facing similar challenges relating to health human resources shortages, increased complexity and acuity of patients' health needs, and ongoing health system recovery from the COVID-19 pandemic. Data and digital transformation are key aspects of governments' response to these challenges and can support shared ambitions such as Universal Health Coverage and other health-related UN Sustainable Development Goals.

The Global Digital Health Partnership (GDHP) is an international collaboration formed to support the executive implementation of worldwide digital health services. It is comprised of 41 countries and territories, three international organisations, and five work streams:

- Clinical and Human Engagement (formerly Clinical and Consumer Engagement)
- Cybersecurity
- Evidence and Evaluation
- Interoperability
- Policy Environments

This toolkit builds upon a white paper released by the former Clinical and Consumer Engagement work stream (now the Clinical and Human Engagement work stream) in 2020. This previous white paper, *Citizen Access to Health Data,* discussed a survey about the state of citizen access to personal health information (PHI) in GDHP participant countries and territories. It found a trend of increasing access globally (Hagens et al, 2020).

Since the publication of *Citizen Access to Health Data,* digitization in health care has continued to advance. In particular, the COVID-19 pandemic spurred rapid adoption of digital health solutions such as virtual care/telehealth, digital immunization records, and electronic prescribing. Additionally, post-pandemic international efforts have focused on advancing the interoperability of health data through initiatives such as the International Patient Summary and the European Health Data Space.

However, the pandemic also demonstrated the need to prioritize digital inclusion. Individuals with limited access, abilities, and/or confidence to utilize digital health tools risk foregoing their benefits (World Health Organization, 2022). As digital care models continue to proliferate, digital health literacy skills are increasingly important to

managing one's own health information, making decisions about one's health, and accessing care.

This toolkit is a logical extension to *Citizen Access to Health Data* because while access to health information is a prerequisite for digital health literacy, it is not equivalent to it. Rather, access to health information must be supported with the skills to find, understand, appraise, and effectively apply that information. Individuals' engagement with digital tools and services is also contingent on trust, safety, and motivation.

2.3. DEVELOPMENT OF THE DIGITAL HEALTH LITERACY CONCEPT

A growing body of literature recognizes the significance of digital health literacy, but provides no universally accepted definition (Kim et al, 2023). While digital health literacy shares skills and competencies with health literacy and digital literacy, it also includes domains unique unto itself (van Kessel et al, 2022 | Monkman et al, 2017).

Norman and Skinner proposed "eHealth literacy" in 2006 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" (Norman & Skinner, 2006a). Their Lily Model of eHealth literacy integrated six core literacies:

- Traditional literacy
- Health literacy
- Information literacy
- Scientific literacy
- Media Literacy
- Computer literacy

This model emphasized the ability to find and appraise information online. While it recognizes inherent differences between paper-based and digital information seeking, it was not intended to cover the dynamic nature of a modern internet environment in which users both access and contribute information (e.g., social media, forums, and blogs), nor virtual delivery of care (e.g., virtual visits, remote patient monitoring platforms, etc.).

The eight-point eHEALS scale is based on Norman and Skinner's Lily Model. It remains the most widely used instrument to measure digital health literacy [CITATION?]. The scale centers information-seeking and appraising behaviours, and relies on self-reporting:

- Q1: I know how to find helpful health resources on the Internet
- Q2: I know how to use the Internet to answer my health questions
- Q3: I know what health resources are available on the Internet
- Q4: I know where to find helpful health resources on the Internet
- Q5: I know how to use the health information I find on the Internet to help me
- Q6: I have the skills I need to evaluate the health resources I find on the Internet
- Q7: I can tell high quality from low quality health resources on the Internet

- Q8: I feel confident in using information from the Internet to make health decisions
    - (Norman & Skinner, 2006b)

Some studies have questioned the validity of the eHEALS scale (Monkman et al. 2017), as digital health now comprises a broader spectrum of tools and services that require more, and more complex, skills to fully leverage.

Accordingly, alternative digital health literacy measures have been proposed. These subsequent models have sought to recognize more dynamic interactions between the individual and their digital environment. For example, the e-Health Literacy Framework proposed by Norgaard et al (2015) conducted a concept-mapping exercise with digital health users and health professionals to identify seven digital health literacy domains:

- Ability to process information
- Engagement in own health
- Ability to actively engage with digital services
- Feel safe and in control
- Motivated to engage with digital services
- Access to digital services that work
- Digital services that suit individual needs

Norgaard et al argue that some domains are dependent on the individual (e.g., ability to process information, engagement in own health), some on the broader digital/health ecosystem (e.g., access to digital services that work, digital services that suit individual needs) and some on the interaction between the individual and the system (e.g. ability to actively engage with digital services, feeling safe and in control, motivated to engage with digital services).

Similarly, the Digital Health Literacy Instrument (DHLI) proposed by van der Vaart and Drossaert "…aims to incorporate the diversity of skills to use both Health 1.0 and Health 2.0 tools" (van der Vaart & Drossaert, 2017). The DHLI also includes seven distinct skills:

- Operational skills
- Navigation skills
- Information searching
- Evaluating reliability
- Determining relevance
- Adding content

- Protecting privacy

The 2018 Transactional Model of eHealth Literacy defines digital health literacy as, "…the ability to locate, understand, exchange, and evaluate health information from the Internet in the presence of dynamic contextual factors, and to apply the knowledge gained for the purposes of maintaining or improving health" (Paige et al, 2018) and categorizes digital health literacy as "task-oriented" (e.g., message type, source, language) and "user-oriented" (e.g., personal, relational, and technological factors).

More recently, the World Health Organization has characterized digital health literacy as, "…whether people have access to the internet and digital devices and if they can use the information and knowledge obtained to assist them in dealing with health issues, in addition to basic understanding of health, risks and health services" (World Health Organization, 2022).

2.4. HOW THE CLINICAL AND HUMAN ENGAGEMENT WORK STREAM DEFINES "DIGITAL HEALTH LITERACY"

Building on the literature, the Clinical and Human Engagement Work Stream views digital health literacy as overlapping with — and distinct from — digital literacy and health literacy. An illustrative diagram was developed and disseminated in a GDHP member survey (refer to Module 3):

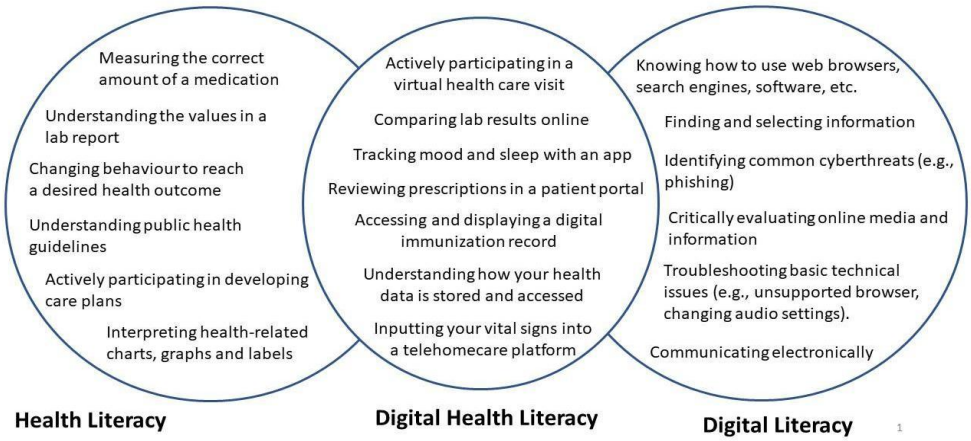

Figure 1: The Digital Health Literacy Venn Diagram disseminated to the GDHP.

The work stream's understanding of digital health literacy includes:

- Access, understanding, and use of one's electronic personal health information, as well as general health information found on the internet.
- Digitally participating in one's own health care; e.g., by inputting information in a consumer health app or portal, participating in a virtual visit, or sharing one's lived experiences and perspectives in an online community, exchanging secure electronic messages with a health care provider.
- Understanding privacy, consent, and an individual's rights and responsibilities relating to their electronic personal health information.
- Critically appraising the usefulness, credibility, and relevance of health information, tools, and sources found online.

The work stream's common understanding of digital health literacy thus encompasses:

- Multiple modes and channels
- Participation by a variety of actors (e.g., health care providers, patients, caregivers, other individuals)
- Defined rights, roles, and responsibilities
- Evaluation of information and information sources

The following definition of digital health literacy was provided to the GDHP membership via the Clinical and Human Engagement Work Stream survey:

"For our purposes, digital health literacy comprises 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."

Refinements to this definition may be undertaken in the course of future work.

2.5. DEVELOPMENT OF THIS WORK

2.5.1. Objectives

At the 9th GDHP Summit, held virtually in November 2021, the work stream recognized that:

- Increasing virtual care adoption as a result of COVID-19 [had] underscored the need to improve digital [health] literacy skills among citizens.
- There [was] an opportunity to collaborate and share best practices among GDHP countries.

Therefore, the work stream proposed the following objectives:

- Quantify information about digital health literacy capabilities and identify priority areas for education
- Compile digital health literacy resources from GDHP member countries
- Capture implementation experiences and develop case studies of results.

2.5.2. Scope and Evolution of Work

This work commenced with a survey disseminated to GDHP members to 1) determine their digital health literacy current state and future priorities, and 2) to capture examples of digital health literacy resources and programs already underway. To build on an opportunity for further work identified in Citizen Access to Health Data, the scope of this work included non-clinical audiences only; that is, patients, consumers, clients, caregivers, and the public.

In addition to the digital health literacy resources identified in the survey, a scan was conducted between May 2022 and January 2023 to capture additional examples. The scan was not intended to be exhaustive, and it was restricted to GDHP member countries and territories.

Some countries include digital health literacy under a broader concept of "digital citizenship." For this reason, some digital literacy resources were considered to be in scope if they included support for using digital health tools. Similarly, some health literacy resources were deemed in scope if they included accessing, using, and/or managing online information or tools.

Based on education priority areas identified in the GDHP Digital Health Literacy Survey, several digital health literacy resources were considered for "deep dive" interviews. Insights from these interviews guided the development of checklists and considerations for creating digital health literacy resources.

The learnings and considerations in this toolkit are not exhaustive and are presented "as is" for informative purposes only.

2.6. APPENDIX

Table 2: Summary of Digital Health Literacy Models

Framework	Authors	Date Developed	Description	Relevant Article
Lily Model	Norman & Skinner	2006	Six core literacies comprise eHealth literacy: • Traditional literacy • Health literacy • Information literacy • Scientific literacy • Media Literacy • Computer literacy	eHealth Literacy: Essential Skills for Consumer Health in a Networked World.
e-Health Literacy Framework	Norgaard et al	2015	Seven digital health literacy domains: • Ability to process information • Engagement in own health • Ability to actively engage with digital services • Feel safe and in control	The e-health literacy framework: A conceptual framework for characterizing e-health users and their interaction with e-health systems.

Framework	Authors	Date Developed	Description	Relevant Article
			• Motivated to engage with digital services • Access to digital services that work • Digital services that suit individual needs Some domains are dependent on the individual, some on the health system, and some on the interaction between the two.	
Digital Health Literacy Instrument	van der Vaart & Drossaert	2017	Includes seven distinct skills: • Operational skills • Navigation skills • Information searching • Evaluating reliability • Determining relevance • Adding content • Protecting privacy	Development of the Digital Health Literacy Instrument: Measuring a Broad Spectrum of Health 1.0 and Health 2.0 Skills
Transactional Model of e-Health Literacy	Paige et al	2018	Categorizes digital health literacy as "task-oriented" (e.g., message type, source, language) and "user-oriented" (e.g., personal, relational, and technological factors).	Proposing a Transactional Model of eHealth Literacy: Concept Analysis

2.7. MODULE REFERENCES

Hagens, S., Yu, E., & Maloney, S. Citizen Access to Health Data: An international review of country approaches to citizen access to health data. Prepared for the Global Digital Health Partnership; July 2020. Sydney, Australia. https://gdhp.health/wp-content/uploads/2022/03/GDHP-CCE_Final.pdf

Kim, J., Livingston, M. A., Jin, B., Watts, M., & Hwang, J. (2023). Fundamentals of Digital Health Literacy: A Scoping Review of Identifying Core Competencies to Use in Practice . *Adult Learning, 35*(3), 131-142. https://doi.org/10.1177/10451595231178298

Monkman, H., Kushniruk, A. W., Barnett, J., Borycki, E. M., Greiner, L. E., & Sheets, D. (2017). Are Health Literacy and eHealth Literacy the Same or Different?. *Studies in health technology and informatics*, *245*, 178–182.

Norgaard, O., Furstrand, D., Klokker, L., Knudsen, A., Batterham, R., & Kayser, L., & Osborne, R. (2015). The e-health literacy framework: A conceptual framework for characterizing e-health users and their interaction with e-health systems. *Knowledge Management and E-Learning, 7,* 522–40.

Norman, C. D., & Skinner, H. A. (2006a). eHealth Literacy: Essential Skills for Consumer Health in a Networked World. *Journal of medical Internet research*, *8*(2), e9. https://doi.org/10.2196/jmir.8.2.e9

---. (2006b). eHEALS: The eHealth Literacy Scale. Journal of medical Internet research, 8(4), e27. https://doi.org/10.2196/jmir.8.4.e27

Paige, S. R., Stellefson, M., Krieger, J. L., Anderson-Lewis, C., Cheong, J., & Stopka, C. (2018). Proposing a Transactional Model of eHealth Literacy: Concept Analysis. *Journal of medical Internet research*, *20*(10), e10175. https://doi.org/10.2196/10175

van Kessel, R., Wong, B. L. H., Clemens, T., & Brand, H. (2022). Digital health literacy as a super determinant of health: More than simply the sum of its parts. *Internet interventions*, *27*, 100500. https://doi.org/10.1016/j.invent.2022.100500

van der Vaart, R., & Drossaert, C. (2017). Development of the Digital Health Literacy Instrument: Measuring a Broad Spectrum of Health 1.0 and Health 2.0 Skills. *Journal of medical Internet research*, *19*(1), e27. https://doi.org/10.2196/jmir.6709

World Health Organization. (2022). Action area 4: Target priority groups that are not receiving or easily accessing health information or health care. In *Health literacy development for the prevention and control of noncommunicable diseases: Volume 3 Recommended actions* (pp. 43–47). World Health Organization. http://www.jstor.org/stable/resrep56503.12


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