

### **BRIEF**

# Digital Health Citizenship

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### **KEY MESSAGES**



- Equitable health benefits can only be gained from digital transformations when all people critically engage with digital ecosystems and actively participate in their governance.
- Through the promotion of digital health citizenship people are enabled to participate in the design and governance of digital transformations of health and to co-create digital environments that promote equitable health and well-being.
- To become effective digital health citizens, individuals require a combination of digital, health and civic literacy and skills.
- Many young people feel that they lack the skills, resources and opportunities to fulfill their potential roles as digital health citizens.
- Urgent, multi stakeholder action is required to strengthen digital health citizenship, including for young people.

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### Introduction

The digital ecosystem offers new spaces for political participation and civic debate, including on health and well-being issues. However, equitable health benefits can only be realized when citizens can:

- Critically engage with digital ecosystems;
- Have access to safe spaces and protect themselves and others from misinformation and abuse; and
- Make informed choices in respect to their data. (Kickbusch, 2022)

The Lancet and Financial Times Commission on Governing health futures 2030's report highlights the interconnections between digital literacy, health literacy and broader democratic and civic literacy skills, arguing that none of these skill sets can be expressed effectively without the other in a digital age. (Kickbusch et al., 2021)

Bringing these three areas together, digital health citizenship provides a frame through which to pursue governance approaches that increase health equity, enfranchise communities and advance public participation in health and well-being, particularly among young people. This brief seeks to define digital health citizenship and make a case for supporting a new generation of digital health citizens. It concludes with recommendations for greater investment in digital health citizenship as a key strategy for individuals and communities to harness the benefits of digital transformations for health.

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### What is digital health citizenship?

Digital health citizenship extends the notions of citizenship and digital citizenship to the health domain (see Figure 1). Each level represents an evolution of the previous level, incorporating nuanced ideas that have emerged as a result of the increasing integration of digital innovations in our health and everyday lives.

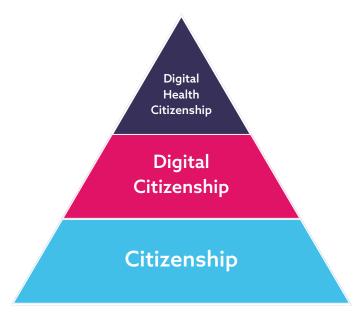


Figure 1. Evolution of digital health citizenship

Citizenship: Our use of the term 'citizen' does not imply any form of nationality or legal status but rather refers to members of a particular community or group. (Lister, 1997)

Membership of a community can be defined in a variety of ways including shared values, a common set of rights and duties, or a sense of social solidarity. Citizenship can encompass broader notions of belonging, identity and participation in the social, cultural and economic life of a community or society. It can also involve active engagement in shaping the collective destiny of the group, advocating for social and political justice and contributing to common goods such as health.

Digital citizenship: The concept of a digital citizen or 'netizen' has existed since the mid 1990s as people began to use the internet to interact with each other and shape decision-making processes. Today, there are two dominant perspectives on digital citizenship. The first emphasizes the role of digital devices and platforms in helping us engage with our

social and political surroundings. As these tools facilitate our participation in society, they make us digital citizens in the process. (Hintz, 2019) A second interpretation of digital citizenship focuses on the norms of technology use, conduct in the digital realm, and online safety, with education and digital literacy playing a vital role cultivating responsible digital citizenship. (Cortesi et al., 2020)

However, digital citizenship is not just limited to those who actively participate in the digital world. It also encompasses people's existence in a datafied environment where every action leaves digital traces and where digital economies depend on user participation. These data, generated both online and offline, are ollected, stored and used by various entities, contributing to the phenomenon known as surveillance capitalism. (Zuboff, 2019) Thus, digital citizenship involves navigating the complexities of the data-driven society to which we all now belong.

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Digital citizenship challenges traditional notions of citizenship and exemplifies a shift in the way civic and political interactions can take place. Digital tools offer more empowerment and visibility to communities traditionally excluded or underrepresented in politics and civic life, as well as offering new tools for building agency and resilience. (Holly et al., 2021) For example, digital tools are facilitating increased youth participation in civics and politics through enabling information seeking, content production and engagement with online communities. (Middaugh et al., 2017)

The notion of digital citizenship is more flexible and inclusive than traditional citizenship, which establishes certain prerequisites for how one can contribute as a citizen, such as legal voting age. (Cortesi et al., 2020)
Additionally, digital citizenship is a more holistic idea than digital literacy when debating important areas of life related to the digital landscape, as well as the corresponding skills needed to be successful within those areas.

**Digital health citizenship:** Digital technologies are creating new spaces for health to be promoted or harmed and new ways for

healthcare to be delivered. (Kickbusch et al., 2021) In this context, digital health citizenship examines how citizen engagement can shape the digitalization of health systems, the design and use of digital health technologies, as well as the broader impacts of digital transformations on health and well-being.

Citizen engagement is an important component of effective health policy-making processes. (World Health Organization, 2022) Digital tools can facilitate greater stakeholder involvement in health policymaking and the production and dissemination of health information. For this engagement to be meaningful and effective, individuals therefore require a combination of health, digital and civic literacy and skills (Figure 2).

Similarly, to counteract harmful and unethical digital practices in all sectors, citizens must be able to critically engage with digital ecosystems, protect against misinformation, and make informed choices about their data. As well as enhancing different forms of literacy, digital health citizenship requires collaborative and trustworthy governance models that address power imbalances and discrimination in digital ecosystems.

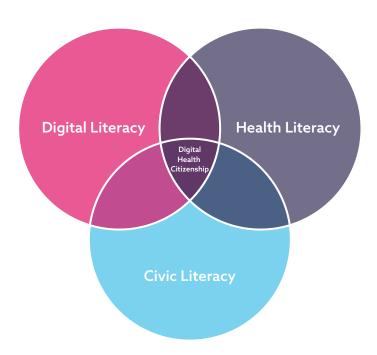


Figure 2. Three forms of literacy and skills required for effective digital health citizenship

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In summary, through the promotion of digital health citizenship:

- Individuals and communities can effectively use digital tools and platforms to engage in their healthcare choices, advocate for their rights and hold healthcare providers, policymakers and technology developers to account for ensuring that all people have access to quality healthcare resources, information and services, regardless of socio-economic status or location.
- More people can realize their right to participate in the design and governance of digital transformations of health and to co-create digital environments that promote equitable health and well-being.
- All stakeholders take collective responsibility in establishing ethical digital and data governance structures to promote equitable health outcomes.

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# Supporting a new generation of digital health citizens

Today's young people are the first generation to have their lifelong relationships with health systems, government and other aspects of society at least partially mediated through digital tools. They are also the first population group to be digitally monitored from birth. (Barassi, 2019) Whilst everyone is vulnerable to online harms, this is especially true for children and adolescents. (WHO, 2024) Young people have expressed concerns about the reliability of online information and impact of digital transformations on their privacy and other rights. Governing Health Futures 2030, 2021a) They are frustrated about the lack of control that they have over their data and the limited opportunities available to shape, design, or monitor digital technology to ensure it meets their health and well-being needs. (Governing Health Futures 2030, 2021b)

Digital health citizenship can play a crucial role in addressing the lack of enfranchisement experienced by young people in relation to digital transformations of health and to realize their rights both on and offline. Digital tools can support children's and youth's civic engagement and offer ways for marginalized and underrepresented groups to participate in decision-making as well as to advocate for their rights. (Committee on the Rights of the Child, 2021) Digital health citizenship provides avenues for young people to actively take part

in their own healthcare decisions, co-design digital first health systems and advocate for their recommendations, needs and rights to be central to health policies. Promoting digital health citizenship among children and youth therefore increases their ability to thrive in the digital age and equips them with essential skills to shape their health futures.

# Time to invest in digital health citizenship

Digital health citizenship is not a new phenomenon. Since the birth of the internet, people have used digital tools to support health goals. However, the rapid evolution and adoption of digital technologies over recent years has given rise to significant opportunities and risks for individual, community and planetary health. The profound influence of digital transformations in all aspects of our lives warrants urgent action to enhance digital health citizenship, particularly for young people.

The DTH-Lab is co-creating activities with youth to build young people's capacity as digital health citizens, including identifying—and producing where necessary—the information and tools that young people, including young health professionals, need to become confident digital health citizens. Multi-sectoral and intergenerational collaboration is required to strengthen digital health citizenship.

To enable all young people to become enfranchised digital health citizens, governments, international organizations and other actors must:

- **1.** Adopt a human rights and child rights approach to digital and data governance so that all young people can enjoy the benefits of digital connectivity and are protected from digital harms;
- 2. Invest in young people's combined digital, health and civic literacy so they can safely navigate digital environments and participate in decision-making processes;
- **3.** Meaningfully engage diverse youth in all governance processes related to health and digital transformations at local, regional and national levels; and
- **4.** Incorporate digital health citizenship into digital citizenship education and activities.

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