

Editorial

Health literacy—politically reloaded

In the last 20 years, HPI published about 100 papers with health literacy as a keyword. Three—each about 10 years apart—are particularly helpful to understand where health literacy stands at this point. Twenty years ago, Don Nutbeam proposed three levels of health literacy: functional health literacy, interactive health literacy and critical health literacy (Nutbeam, 2000). I have found them helpful to analyze health literacy in the context of COVID-19 and to consider actions that need to be taken from a health promotion perspective. Many of these are in the political sphere and require interventions beyond the health system and even at the global level. This reinforces Evelyne de Leeuw's analysis (de Leeuw, 2012) of 10 years ago that a third wave of health literacy is beginning to address a broader ecosystem and the political determinants of health. There is of course also a growing recognition of health literacy as a crucial concept to address the COVID-19 crisis (Van den Broecke, 2020).

The disconcerting development of the nature and overwhelming quantity of (health) information in the first decades of the 21st century allows us to speak of a fourth wave. I suggest four action areas for health promotion in response to this development: improve scientific literacy, address the infodemic, address health data extraction and address the political dimension of health literacy.

ACTION 1: IMPROVE SCIENTIFIC LITERACY

The 2020 coronavirus pandemic has made clear, how much health literacy depends on other literacies and basic skills. Numeracy combined with the ability to understand abstract concepts has become particularly important: how to understand the numbers that now dominate the news and define how we can live our life and assess the risks to ourselves and to others: incidence, mortality rate, exponential growth? How can we grasp

the comparisons within and between countries—for example of vaccination rates—by which we judge our politicians? Even in normal times, it is difficult for people to realistically assess probabilities and risks to health and understand the difference and interface between personal risk and population health; under pandemic conditions it becomes even more important (Shilton, 2020).

The pandemic has reinforced the lack of understanding and appreciation of public health in the general population, and most of the world's societies are now paying the price for this neglect. If there is one key public health issue that every person should understand it is the importance of preparedness and prevention: this might help address the constant questioning by people (and politicians and the media) of steps to prevent the spread of the pandemic because the prophesied spread did not occur. Indeed, the lack of health literacy (especially in understanding public health interventions and how they both protect the individual and the community) of key decision makers has been one of the determining factors of the COVID-19 pandemic (Paton Walsh *et al.*, 2020).

The importance of scientific literacy has become even more evident through the pandemic and has linked the health literacy discussions back to questions about what basic knowledge and skills are required in modern societies to understand health and to be able to participate in and act on health matters, both with respect to individual and community health (Zen, 1990). An example beyond COVID-19 is the complexity of navigating the rapid development of medical research combined with digital access. Users now have access to individual genetic risk profiles through companies like '23andMe' which offer to find out 'what your DNA says about you and your family'. (23andMe, n.d.). Only there is no support at hand when the test delivers bad news (Pomerantz, 2019). The access to self-testing for COVID-19 can also be problematic if there is no health

system to which a person who tests positive can turn. The intensive discussion about the role of schools for children's health must be expanded to include a curriculum that increases their scientific literacy and numeracy.

ACTION 2: ADDRESS THE INFODEMIC

The original definition of interactive health literacy refers to the social skills required for the exchange of health information and the participation in discussions about health. But that is no longer sufficient—this has changed so radically with the intensified use of social media. Of course, there are many positive dimensions: health information has become much more accessible and there are many online tools to support health decision-making, provide online mental health support and engage discussions among patients. But for the pandemic response a new phenomenon—the ‘infodemic’—has become a major determinant of health. The WHO defines it as ‘... too much information including false or misleading information in digital and physical environments during a disease outbreak. It causes confusion and risk-taking behaviours that can harm health. It also leads to mistrust in health authorities and undermines the public health response.’ (World Health Organization, n.d.)

We know that false information is spread with malicious political intent to destabilize societies and sow distrust in political decision-making, also across borders (Cross, 2017; BBC News, 2021). An important part of this is the activity by anti-vaccination groups, many of which are now well organized internationally. Their message is amplified on the web through the attention reinforcing (‘echo chamber’) algorithms by which social media function (Cinelli *et al.*, 2021). ‘People are shown things that appeal most to them, they click, they read, they watch, they fall into rabbit holes that reinforce their thoughts and ideas, they connect with like-minded people. They end up in their own personalized version of reality.’ (Stern, 2021)

This is reinforced by the fact that official sources of health information—from state agencies for example—are no longer trusted by some parts of the public. For example, surveys done among a representative group of Americans in May and October of 2020 show about a 10% decline in trust of the CDC (US Centers for Disease Control and Prevention) over that period (Pollard and Davis, 2021). The spreading of false information often goes hand in hand with destructive forms of communication: hate speech, threats, trolling and mobbing. Democratic discourse is becoming difficult to uphold and health has been politicized in new ways during the pandemic. This also reflects a deterioration in civic

literacy—a truly dangerous development as democracy is threatened world-wide (ABC Life Literacy Canada, n.d.; Somer and McCoy 2019). WHO has developed a set of tools to address the infodemic but many national health promotion agencies still lag far behind.

ACTION 3: ADDRESS HEALTH DATA EXTRACTION

There is another new dimension of digital health literacy which also indicates additional aspects of critical health literacy. It is great to have access to enormous amounts of health information on the web, communicate with others about health, access health services and advice and have the help of a wide variety of Apps to monitor health, yet in most cases, the data generated through a person's health activities on the web are extracted for profit by the social media platforms with no privacy rules to stop them. Health data are progressively more valuable and their value increases when they can be linked to other data sets (Hughes, 2019). Indeed, countries have made deals with private companies in relation to health data: In order to have early access to COVID-19 vaccines, Israel struck a unique deal with Pfizer: vaccines for data to study herd immunity (Estrin, 2021).

I have written before about the dark side of digital health (Kickbusch, 2020). Because of the value proposition this extraction is practiced not only in relation to health data but though the combination with what is called the ‘shadow health record’ (Price *et al.*, 2019). This can include credit scores, court documents, smartphone locations, sub-prime auto loans, search histories, app activity and social media posts (Beebe, 2019). This means that knowledge about a user's rights in relation to health data is a very important component of digital health literacy. This goes deeper than having the skills to use digital media to search for health information—it requires the understanding of what information we generate for others in the process and how we can protect ourselves and our right to privacy. There is a clear need for legislative action on the one hand to protect the public, on the other hand school curricula can no longer neglect teaching pupils how to navigate the digital world.

ACTION 4: ADDRESS THE POLITICAL DIMENSIONS OF HEALTH LITERACY

Of course, health literacy has always had a political dimension, we need only think of the immense industry lobbying in response to a sugar tax or better food labelling. The women's health movement was deeply political in empowering women to understand their bodies and

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