

Digital Health Transformation: Ethical and Social Implications

Extended abstract

Sanchez Nieminen Giovanna ¹[ORCID], and Miettinen Janika¹[ORCID]

¹VTT Oy

giovanna.sanchez@vtt.fi, janika.miettinen@vtt.fi

Digital health is seen as a promising tool for increasing health equity in a global level, with its potential to extend the coverage and access of healthcare services. Health care services are no longer bound to time and place as strictly as before, making health care more available to greater amount of people. This aspect of digital health is particularly important in low and middle-income countries, where new health technologies are seen as a necessity for solving critical societal problems and to reduce health inequities at low cost. Efficacy and cost-effectiveness are at the core of the development and implementation of digital health, but important aspects such as health equity and accountability often seem to be overlooked. Without proper implementation and evaluation of digital health programs and solutions, unexpected and negative impacts can emerge, further increasing the vulnerabilities of already marginalised groups.

While new health technologies are continuously developed and implemented, their social and ethical impacts have not been properly assessed yet, by neither the industry nor the academia. The present research is a contribution to the on-going EU Horizon 2020 VOGAS and A-patch projects, and it investigates how new point-of-care triage test technologies can affect health equity among different groups of population. VOGAS is focused on developing a non-invasive gastric cancer screening tool, and A-Patch on developing non-invasive diagnostics technology for detecting and monitoring tuberculosis. In addition to focus on the development of point-of-care technologies, both projects share the common framework of Responsible Research and Innovation (RRI) that targets at producing socially acceptable solutions that include real value for users and for society. As a framework, RRI connects different aspects of the relation between society and R&I through its focus on ethics, gender equality, governance, open access, science education and public engagement (European Commission, 2014).

Research findings indicate a critical lack of scientific research on the social and ethical impacts of new point-of-care technologies for early diagnosis and monitoring, particularly on how these technologies can affect health equity among various populations. This is particularly worrying when considering that healthcare inequity are systemic and closely intertwined with social inequities (WHO, 2018). The lack of literature considering social and ethical aspects of new digital health technologies is recognised by the academia (George et al., 2018; Hankivsky, 2012; Morgan et al., 2018; Robards, 2018). Thus, the present study aims to delineate and analyse the impacts, both positive

Copyright © 2019 for this paper by its authors. Use permitted under Creative Commons License Attribution 4.0 International (CC BY 4.0).

and negative, of digital health technologies for increasing health equity, especially concerning the potential risks of such technologies exacerbating existing inequities surrounding public health.

In the present study, intersectionality is adopted for the analysis of the relationship and interaction among various socio-economic factors of health inequity (e.g. social-economic status, ethnicity, gender and disability). Although the intersectionality approach has been used prior in health studies, evidence of its usage in studies combining health and technology cannot be found in the literature. As a part of the research, a literature review was conducted by using key words intersectionality, digital health and e-health. These keywords were selected to assess the existent literature that combines the intersectionality approach in digital health. The search clauses “(intersectionality) AND digital health” and “(intersectionality) AND e-health” were used in SCOPUS, PubMed, Web of Science Core Collection, Korean Journal Database, MEDLINE, Russian Science Citation Index and SciELO databases. The given selection criteria produced 22 hits in total, considering all databases. From these search results 10 were overlapping, meaning that the search produced a total of 12 hits. Within these 12 hits, four were out of the research scope, as they did not include either health or technology related aspects. The remaining eight hits which were relevant for the research scope were further studied. First by conducting content analysis of the abstracts and then by analysing the articles to their fully extent.

At this initial stage of the research, our findings revealed that the need for an intersectionality perspective in research and development of healthcare technologies and services is recognized by the academia. Since often only a single social category is analysed (e.g. gender, age, race), when trying to understand how health is shaped in different population groups and what impact healthcare technologies can have across these different groups. Furthermore, in most cases the focus of the articles was on health related information sharing and awareness raising through technology including themes such as access to internet, social media campaigns and the use of mobile phones within different population groups. As a result, the information did not include screening and monitoring technologies used by healthcare professionals, but technology that is used to transmit health information among citizens.

As an analytical approach, intersectionality can help us to unravel and understand the complex effects that digital health care solutions can bring for individuals, in particular those belonging to vulnerable groups. The intersectionality approach has been widely used in health studies making it possible to find research results from disease specific social factors at certain geographical contexts. This information can be used for recognizing vulnerable individuals who are at most risk of developing certain disease at a certain location. In our future work for VOGAS and A-Patch, we will use this information to support ethical technology development to guarantee that the socio-cultural factors will be taken into account as a part of the technology design. To achieve this goal we will map social factors and create patient profiles based on already existing intersectionality research on gastric cancer and tuberculosis. These profiles will be then used at different phases of the projects’ technology development processes and stakeholder engagement activities to address issues related to vulnerable population groups whom the technology should serve. It is our understanding that the analysis and map of

relevant social markers are essential for reaching socially and ethically acceptable outcomes in digital health. These can only be achieved with proper understanding of complex social and geographical contexts, and the proper assessment of the root causes of inequities and marginalisation of certain groups and individuals.

References:

1. European Commission. (2014). *Responsible Research and Innovation: Europe's ability to respond to societal challenges*. Brussels: Publications Office of the European Union.
2. George et al. (2018). Gender dynamics in digital health: Overcoming blind spots and biases to seize opportunities and responsibilities for transformative health systems. *Journal of Public Health*, 40, ii1–ii5. <https://doi.org/10.1093/pubmed/fdy171>
3. Hankivsky, O. (2012). Women's health, men's health, and gender and health: implications of intersectionality. *Social Science & Medicine*, 74, 1712-1720. <https://doi.org/10.1016/j.socscimed.2011.11.029>.
4. Morgan et al. (2018). Gendered health systems: evidence from low- and middle-income countries. *Health Research Policy and Systems*, 58, 1-12. <https://doi.org/10.1186/s12961-018-0338-5>
5. Robards, F. (2018). How Marginalized Young People Access, Engage With, and Navigate Health-Care Systems in the Digital Age: Systematic Review. *Journal of Adolescent Health*, 62, 365-381. <https://doi.org/10.1016/j.jadohealth.2017.10.018>
6. WHO. (2018). *Global Tuberculosis Report 2018*. Universal health coverage, social protection and social determinants, 7, 131-147. Geneva: World Health Organization.

Giovanna Sanchez Nieminen (Research Scientist at VTT Oy) has worked with international cooperation and public health since 2013. She has been involved with research projects related to the socio-political and ethical aspects of new technologies and international cooperation, including the on-going Horizon 2020 YAKSHA and VOGAS. (e-mail: giovanna.sanchez@vtt.fi)

Janika Miettinen (Research Scientist at VTT Oy) has worked in both national and EU level research projects related to ethical and societal implications of innovation. The on-going Horizon 2020 projects include NewHoRRizon and A-Patch. (e-mail: janika.miettinen@vtt.fi)