

Caring together with digital technology

Citation for published version (APA):

Janssen, R. (2022). *Caring together with digital technology: Exploring HIV self-testing practices with an app called HIVSmart!* [Doctoral Thesis, Maastricht University]. Maastricht University. <https://doi.org/10.26481/dis.20221213rj>

Document status and date:

Published: 01/01/2022

DOI:

[10.26481/dis.20221213rj](https://doi.org/10.26481/dis.20221213rj)

Document Version:

Publisher's PDF, also known as Version of record

Please check the document version of this publication:

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Scientific and Social Relevance of this Research for Key Stakeholders

Digital Health Technology: Developers, Designers and Implementers

In their work on tuberculosis and HIV diagnostics, Engel and Krumeich (2020) show how simplicity, for example through minimal user steps or simple sample preparation, is a highly valued characteristic by Global Health funders and in the design standards that direct the development of these diagnostics. However, they also show how users, such as laboratory technicians and clinicians, draw on other value registers, such as workflow, when considering the advantages and disadvantages of a diagnostic in their particular setting (Engel & Krumeich, 2020). For example, they highlight that a point-of-care test (POCT) that provides a quick HIV test result, but a result which only remains stable for 20 minutes, does not align with the workflow of a healthcare worker in Bangalore where they do not have the time to wait and read the result within that 20 minute window. In line with the insights of Engel and Krumeich (2020), I would like to reflect on HIVSmart! to provide considerations for digital health technology developers, designers and implementers in two ways. I first draw attention to how the values of “easy to use” and “providing useful health information” are enacted throughout the research study and, second, I consider how other value registers are expressed and what this means for digital health technology developers and designers in practice.

In Chapter 5, I examined the value of making an app which is easy to use and which provides useful health information as I explored how ease of use and provision of useful health information come about in relation to HIVSmart!. Through Chapter 5, and reflecting on responses from participants in Chapter 2, I showed how elements of the app such as its clear instructions and HIV information, were enhanced through the ongoing work of study staff and their support of participants while using the app. The work of study staff contributed to an app that was easy to use and provided useful health information. The app was not necessarily easy to interact with for the study staff right away, but became easier to use and explain to participants over time as they got more experience using the app. Furthermore, the HIV information and counselling in the app, though perceived positively by participants and study staff, was also not considered perfectly comprehensive or aligned to the specific setting. This was not necessarily an issue however, as one of the medical officers highlighted that healthcare staff should subsequently give context and further explanation to patients after they receive HIV information from the app. In this way, we see that an app, which is easy to use or that provides useful health information is valued, but how

or why an app becomes easy or useful in practice differs based on varying users. This is an important point for those who are implementing digital health technologies. Even if different actors articulate similar notions of what makes a “good” digital health technology (e.g. easy to use, providing useful health information), how the technology and users enact these values in practice varies – the app isn’t just easy and good at providing information on its own, it also becomes these things through and with the people around it.

I recommend that those developing and designing digital health technology, as well as those designing the services or interventions in which these technologies are embedded, should be sensitive to multiple ways of enacting similar value registers, as well as different value registers, reflected by the various shifting users who interact with a digital health technology. A developer might aim to make an app simple or easy to use, by for example making the app small in size to simplify downloading the app onto phones which do not have a lot of space. A designer could make the steps or language within an app as simple or clear as possible based on feedback from the user(s) and knowledge about the user context. However, a nurse or healthcare worker may also care about the content of the health information presented to patients – not only in relation to whether this content is “easy” to understand or whether this information is complete and useful to a patient – but also because of how this information aligns with, or contributes to, their counselling and care practices. Perhaps a healthcare provider cares more about whether or how app content initiates dialogue in a way that enhances a subsequent healthcare appointment. In this way, by considering multiple value registers, design trade-offs can happen as an app can be designed to include information, which is important to encourage dialogue or further action, while also considering which content can be removed to make an app smaller or less cumbersome for people to use. However, values built into the app also need to reflect what is possible within the context of clinic services. Striving to initiate additional dialogue between patients and healthcare providers could require changes to the time allotted for healthcare providers during an appointment with a patient. Therefore, choices about design and app development require close dialogue with various kinds of users in addition to a nuanced understanding of health care practices within a particular setting, as well as how these practices change with the introduction of a new digital health technology.

(Digital) Health Policy Makers – Shifting Focus in Implementation, Monitoring and Evaluation

One of the most striking findings illustrated throughout my thesis is the amount of time and resources drawn upon by study staff and participants through the HIVST process using the app. The research study in which HIVSmart! was evaluated provided additional technical resources, physical spaces, human resources, and additional methods of HIV testing for confirmation purposes. The people involved, whether it was study staff, a study participant, a partner or a family member of a participant, all invested time in the HIVST process. With these findings in mind, global and national policy makers should be cautious of how they portray cost-effectiveness and efficiency of digital health technology, especially in the case of self-testing. The vision within the WHO's "Global strategy on digital health 2020-2025" considers investment into workforce and institutions as a means of enabling the digital health system to do the work of improving efficiency and cost-effectiveness. The policy states that:

“[...] digital health can radically change health outcomes if it is supported by sufficient investment in governance, institutional and workforce capacity to enable the changes in digital systems and data use training, planning, and management that are required as health systems and services are increasingly digitized. With this essential investment in people and processes, in line with national strategies that lay out a vision for the digitalization of the health sector, digital health can improve the efficiency and cost-effectiveness of care, allowing for new business models in the delivery of services.” (WHO, 2021, p. 10)

Yet, in my thesis, I reveal how the digital health technology, and the many actors around it, co-produce novel care practices. Building upon the claim by Montgomery (2017) from her work in clinical trials, I argue that the successes of HIVSmart! cannot only be attributed to the app, or even the additional resources put forward in the study in which it was evaluated, but also the novel practices of self-testing and support constructed between the participants, health care staff in the study, and the technologies made available through the intervention. I argue that quantifying or attributing a financial cost or value to these novel practices is a difficult task. Yet, it makes sense that government and health services would want to consider cost-effectiveness when making decisions about implementing new digital health technologies. By integrating the design, implementation and evaluation process with a more explicit emphasis on studying the alignment practices taken up within a digital health intervention it could provide further data upon which to

base cost-effectiveness measures. Therefore, I recommend further mixed-methods research should be carried out which takes a closer look at how to evaluate alignment work for digital health technology and self-testing in relation to cost-effectiveness.

In a review of telehealth interventions for heart failure management, Greenhalgh and colleagues point out that by evaluating digital health through the lens of efficiency and quantitative outcome measures, it emphasizes a much colder biomedical practice (Greenhalgh et al., 2017). They suggest that focusing on “a ‘warm’, relationship-based, adaptive practice that engages with the patient’s unique predicament, acknowledges his or her vulnerability and emotions, and seeks to provide continuity of personal care” (p.12) reveals a different logic regarding the role of digital health. Although these two focuses can be combined in evaluating the role of technology in healthcare, focusing on economic and technical aspects obscures “value-based choices about what kind of care patients deserve” (Greenhalgh et al., 2017, p.12). My research highlights the feelings evoked through HIVST, as well as the healthcare provision taken up by digital health technology. This goes beyond measures of technical aspects and efficiency of an intervention and reflect a need for “warmer” ways of evaluating how digital health technology works. Thus, guideline and policy makers involved in the development of evaluation methods for digital health technology should also consider how patient values around good care and relationships are reflected in the indicators used to monitor and evaluate these technologies in practice.

In my research, people emphasized that part of the allure of HIVST with an app was that they could do it alone – this was often cited in relation to fear of judgement, social visibility, lack of trust, convenience or previous experiences of feeling uncared for. Yet, what does this mean if the ultimate aim of intervening with digital health technology is to bring people back into care? From the lens of technical efficiency, digital health technology should strive to make interactions within health services quicker by reducing time for administrative tasks or the time taken to respond to adverse events (see for example, WHO, 2016, p. 41). Yet, efficiency can also be understood as a means for creating “reduced need to consult a facility-based health-care provider” (WHO, 2016, p. 41). In light of my findings, aiming for reduced contact between a healthcare provider and patient is problematic when we consider the role of digital health in relation to an ongoing process such as self-testing. To begin, a person who engages in diagnostic processes related to HIV or sexually transmitted infection (STI) testing would (hopefully) engage with services in an ongoing manner as they test regularly, and because testing services are often linked

to additional sexual and reproductive care that offers access to things such as PrEP and contraception. Furthermore, envisioning digital health as a solution to improving time-efficiency overlooks some of the benefits of digital health when it comes to relationship building and good care. Those looking for convenient testing methods often spoke about long wait-times and opening hours at the clinic, not the length of the interaction with the healthcare worker within an appointment. Explaining an app or discussing elements of a person's experience with the app, such as the results of a risk assessment or uncertainties about a result in relation to someone's personal situation, takes valuable time. However, this also creates moments for relationship building between people and their healthcare provider and space for dialogue around concerns or elements of HIV services that a person may not have discussed otherwise. Therefore, emphasis on making this type of intervention time-efficient may well undermine some of the potential benefits digital health can bring to patient care. More emphasis needs to be put on developing and maintaining good relationships between patients and clinic services through digital health interventions so that people come back into care. This requires strong clinic services that have the time and capacity to care for patients who need treatment or further support. A digital health technology that is carefully embedded into local health services can then act as a gateway through which to build future relationships for testing and various other health issues.

If policy focuses too heavily on the cost-effectiveness or efficiency of digital health interventions, it risks further alienating some of the very people it aims to bring into care. Remember that participants in the HIVSmart! study did not necessarily want to avoid healthcare services or providers completely; people value healthcare providers who have time to discuss their concerns and who can ease their anxieties – people tend to turn away from clinic services when healthcare staff are too busy or overburdened to provide these things. If health policy makers are serious about helping industry, healthcare providers and the public get the most out of digital health interventions over the long term, especially in relation to historically stigmatized conditions such as HIV, they must also put emphasis on investment into clinic services, including human resources, which work with these technologies to support continuity of care.

Contributing to Notions of Care in Digital Health and Diagnostic Practices

Through this thesis, I develop a conceptual approach for analyzing the role of digital health in diagnostic practice. I combine theoretical insights from Science and Technology Studies (STS),

medical anthropology and sociology, care ethics, and implementation science, which focus on topics including diagnostic/health technology, digital health, diagnosis and research design. As technologies travel from one place to another, various users, such as clinicians and program implementers, mobilize technology in different ways to address problems specific to their new settings (Anderson, 2020). Aligning diagnostic technology to a new setting takes work, as it is made to fit the needs and values of (multiple) shifting users (Engel, 2020). As I show in my research, the study staff work to align HIVSmart! to the needs of participants, the technical infrastructure and the built environment in the township context of Cape Town. Yet, attending to this alignment work does not show how it feels to work with the app-based self-testing and, importantly, what this means for how people work with the technology. I incorporate the concept of affect to the alignment work to account for the emergence of feelings and action within HIVST. To do this, I draw on the work of Lupton (2018) who explores how the intended uses inscribed in digital health technology come together with a user to evoke feelings and modes of action. Yet, affect is not only evoked by the digital technology alone, it also happens in relation to elements beyond the app and HIV self-test, as the technology works in relation to other actors in the broader HIV diagnostic process within a particular setting. Drawing on work by Manderson (2020) and Jutel (2009), I conceptualize the app and self-test as part of the larger network of people and things within the HIV diagnostic process. To summarize, I show how alignment work is necessary to make the app fit the setting, while also acknowledging the affective relations that emerge through, and contribute to, interactions between users, the app and various human and non-human actors which make up the diagnostic network around HIV.

Next, I define “being at risk” of HIV as a form of diagnostic label. I do this because the “at risk” label affects the kinds of collaborations that emerge between study participants and other actors through the self-testing process. I therefore conceptualize the app and self-test as elements that work in relation to a network of other tests, healthcare workers, public health messaging and protocols which are brought together within a community which is considered at risk of HIV. Finally, by linking these different concepts to reveal the situated, affective, collaborative and iterative nature of digital health technology in relation to self-testing and diagnosis, I contribute to critical literature on research design for digital health technology evaluation. In line with arguments by Montgomery (2017), Greenhalgh and Russell (2010), and Greenhalgh and Swinglehurst (2011) on clinical trials and the limitations of (quasi-)experimental designs, I show

how ethnographic methods can highlight novel practices and the complexity of integrating digital technology within healthcare settings. A complexity that is often hidden within strict research designs such as RCTs. I also add to literature on what evaluation should focus on when looking at digital health technology implementation by arguing that such evaluations should also focus on how the relationship between digital health technology and human healthcare providers develops over time while providing care to patients.

My research was conducted within the boundaries of a research study on a digital health technology, and use of the app and self-test were offered as temporary services provided in parallel to clinic services at each research site. Future social sciences research into digital health technology aimed at aiding diagnosis should use my conceptual approach to explore programs that have been implemented within existing health services beyond the research study setting. For example, Baraitser and Lupton (2022) have used my work as an example of how to approach analysis of digital health and diagnostic practices by looking at the more-than-human and affective aspects of using a digital photo-diagnosis service provided by an online sexual health service in the United Kingdom. My conceptual approach has the potential to improve the design, implementation and evaluation of digital health technology and diagnostic services. For example, rather than only asking questions about whether a technology is easy to use, provides the right kind of content, or whether it has been designed properly to fit within a particular technical environment, my conceptual approach asks: what kind of alignment work is necessary to make an app work as intended? How do different affective responses emerge through the self-testing process with the app and how does this impact how and whether a person uses the app and self-test? How do human and non-human actors collaborate to make the app and self-test work? How are the iterative aspects of implementation captured and evaluated in order to provoke reflection and improvement of how the app works within HIV testing services? In asking these kinds of questions, researchers, program managers and clinicians can get further insight into how digital health technology supports patients and healthcare providers as part of the self-testing and diagnostic process within a particular setting. This insight can be used to improve the way these technologies are embedded in health services to meet the needs of different users. Beyond digital health, this conceptual approach also has the potential to elucidate the situated, affective, collaborative and iterative manner through which other kinds of health technology, such as vaccines, come to work within new settings. For example, one should ask; what kind of alignment work is necessary to make a

vaccine work as intended? How do different affective responses emerge and impact vaccine uptake? How do human and non-human actors collaborate to make vaccine design and implementation work? How are the iterative aspects of implementation captured and evaluated in order to provoke reflection and improvement for the future?

Considering my research findings and conceptual approach, as a final theoretical reflection I would like to briefly discuss the term self-testing. In her research on telecare practices, Pols (2012) argues that “self-management” is a misleading term. Instead, she describes telecare practices and the various actors involved as forms of “together-management” (p. 150). Similarly, I would argue that self-testing is a misleading phrase – however, calling it “together-testing” is too far of a stretch. The word “self” in self-testing carries significance for those who are too afraid or too busy to access testing services at a healthcare facility – for those who value the ability to do certain aspects of the self-testing process on their own for important reasons. However, from a policy or healthcare services perspective, it is necessary to more explicitly conceptualize the collaborative nature of self-testing because of the important implications it has for the support systems and investments that need to be installed alongside self-testing initiatives. Self-testing can only happen successfully when embedded within an assemblage of people and things that make up a diagnostic process for a specific health condition in a particular setting. Furthermore, my thesis shows how the tester takes an active role in collaborating together with different elements through each new testing process. Policy makers and public health administrators need to think beyond the availability and use of self-tests alone, and should focus more explicitly on how care is provided during testing together with different (digital) technologies, human resources and services, in order to attend to the various needs and concerns of the public. What these additional resources look like is again dependent on the particular context, including the specific disease, built-environment, technical and healthcare infrastructure and historical, social and political context.

No matter how one tests, whether it be on one’s own, or with the support of an app, telephone call, telehealth service, family, friends, a partner, healthcare provider or through a mix of these people and things, it is crucial that people feel they are cared for in their testing journey.