

Ethical, legal and social aspects of mHealth technologies: Navigating the field

THE META RESEARCH GROUP

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mHealth blurs health sector boundaries, challenging health ethics research: a dynamic approach and curiosity for tech innovation is needed.

Keywords: mobile health technologies, ELSA research, complexity, responsible innovation, interdisciplinarity

INTRODUCTION

Mobile health (mHealth) technologies, such as apps, smartwatches, sensors or technology built into shoes or fabrics, are increasingly becoming an essential part of healthy lifestyles, disease prevention and management. The hope is that mHealth can revolutionise and transform healthcare (European Commission 2014, 2018; WHO 2011).

Given the ground-breaking importance for health and health care mHealth is assumed to have, our research team “META”¹ interrogates the ethical, legal and social aspects (ELSA) of mHealth. In this article, we identify some profound and potentially conflicting implications of mHealth for individuals and society. In our conclusion, we emphasise the importance of rethinking disciplinary and normative approaches to mHealth.

INCREASES IN SELF-EMPOWERMENT, HEALTH BENEFITS AND EFFICIENCY

A significant part of the transformative potential of mHealth is seen in its participatory and empowering effects, which will likely lead to increased user autonomy and a democratisation of healthcare. With the help of various digital technological features, the roles of users (i.e. healthy individuals and patients) are shifting towards more active participa-

¹ Acronym for: “mHealth: Ethical, legal and social aspects in the technological age”. The project is funded by the German Ministry of Education and Research, and runs from April 2018 to March 2024 (Grant number: 01GP1791). In an interdisciplinary team with expertise in philosophy, bioethics, public health ethics, sociology, law, gender studies, public health and medicine, we have undertaken empirical and conceptual research since April 2018.

tion in the maintenance and improvement of their own health, and away from oversight by health professionals or the healthcare system (Swan 2012). mHealth thus challenges conventional hierarchies in healthcare (Kingod 2018); patients are no longer “passive recipients of care” (Lewis & Leibrand 2016); they become “digitally engaged” (Lupton 2013d). Health-related knowledge is no longer concentrated within the boundaries of medical facilities or in the hands of medical experts. In this narrative, mHealth users are empowered to be in charge of their health and to personally improve it.

The hope is that mHealth can positively influence disease management, prevention and health promotion, as well as access to health care (Kreps & Neuhauser 2010, Ospina-Pinillos et al., 2018). There are demonstrable benefits of its use for example in areas of surveillance and mapping of malaria infection patterns (Brownstein 2009, Fornace 2018), prenatal care for asylum seekers (Borsari et al., 2018) or in relation to physical activity after prostatectomy (Agarwal et al. 2018). Some studies indicate that those who digitally track their own health are more likely to improve their health awareness and behaviour (Figueiredo et al. 2017). For example, one study has identified a positive short-term effect on smoking cessation (Uthman et al. 2019) and studies have shown that the use of mHealth increases individuals’ health awareness, e.g. with respect to chronic diseases (Griauzde et al. 2019).

It has been argued that helpful factors in mHealth-facilitated behavioural changes include immediate graphical representations of body data, the ability to share information and the feeling of being part of a social network of users with similar experiences (Rönkkö 2018). Hopes for reducing harmful hierarchies and exclusionary processes have been associated with the use of the internet (Tierney et al. 2018), to which mHealth is connected. Furthermore, situationally relevant data available at all times have been found to help users and healthcare professionals to obtain a more detailed understanding of health and illness, enabling better-informed health decisions (Steinhubl et al. 2015).

Advocates of mHealth promote these technologies as the most promising drivers of solutions to pressing organisational and financial challenges in the healthcare sector (PwC 2013; Swan 2012). In their view, these technologies will facilitate increased effectiveness in implementing healthcare and prevention initiatives, a promotion of healthy lifestyles, improvements in international communication by health professionals, reductions in health inequalities and a personalisation of healthcare.

CHALLENGES: DATA, POWER, HEALTH AND JUSTICE

Despite these promising effects, there are significant challenges connected to mHealth. On a systemic level the “datafication of everything” (Mayer-Schönberger & Cukier 2013) is a significant and challenging issue. Some argue that the seemingly complete descrip-

tion of the reality given by peta- and exabytes of data is, in fact, never neutral but always a selective capture of reality only (Chang et al. 2014; Kitchin 2014). Scholars point out that digital technologies create an illusion of a comprehensive representation of reality, signifying a possible paradigm shift in knowledge and knowledge production (Chang et al. 2014; Kitchin 2014). Moreover, the selective representation of “reality” is shaped by normative assumptions about healthy lifestyles and social roles, which are fundamentally impacted by categories of power, such as gender, race or class (Hendl et al. 2019).

Just like data, algorithms are also never neutral, but carry with them certain dominant norms, values or concepts. The training data used to feed algorithms and the past data and definitions of success utilised by them can all be skewed by selective bias in data as well as by developers’ personal values or prejudices (O’Neil 2016; AI NOW 2018). A resulting algorithmic bias can lead to misrepresentations of reality and have a negative impact on already structurally marginalised and disadvantaged groups (O’Neil 2016; Eubanks 2018; AI NOW 2018).

Further, data collection and control can bring about problematic power imbalances and increasingly asymmetric relationships between those who provide data and those who process and use it in large quantities (Ruckenstein & Schüll 2017; boyd & Crawford 2012, Lupton 2015b, Fangerau et al. 2016, Sharon 2016). For example, some point out that users of digital technologies do unpaid and invisible digital work (Ruckenstein & Schüll 2017), of which they might not be aware. By performing this work, users increasingly lose control over the data they create (Ruckenstein & Schüll 2017). Companies can monetise users’ data, which is highly valued in the “healthcare market”, which includes insurance companies (Nissenbaum & Patterson 2016: 98) along with other sectors such as marketing. Questions then arise as to how informed consent can be achieved or whether it is even possible to speak of informed consent when it is unclear how personal data will be processed, monetised or otherwise used (Fangerau et al. 2016).

Cyber-bullying or cyber-attacks (harmful hacking of devices) or data thievery are seen as additional risks (Belleken et al. 2016; Kotz 2011). Hacking and data misuse create new vulnerabilities within whole (sub)populations (Barnett et al., 2013). Malware and the intentional or unintentional manipulation of medical devices are also concerning and can cause e.g. unauthorised changes in the dosing of drugs (Khera 2017).

The increase in the self-tracking and “quantified self” movements are also being discussed critically. Such readings emphasise that potentially unrealistic body and health norms are being created, which can result in higher social pressures, disempowerment, exclusion or decreasing solidarity (Lupton 2014b; Sharon 2016, 2017). If mHealth generates constant surveillance, areas of human lives, such as nutrition, sexuality and (un-)healthy behaviour, can become associated with feelings of bad conscience, guilt and shame (Lupton 2015a). Kreitmair et al. (2017) argue that constant information updates can hinder productivity and have an addictive potential. Self-optimisation through

mHealth technologies could potentially cause depression in users, doing more harm than good (Fangerau et al. 2016; Hussain et al. 2017).

Technical difficulties can also jeopardise the necessary medical accuracy and reliability of mHealth data, for example, when instructions are not displayed correctly on a digital device by the patient or physician (Kreitmair et al. 2017). If mHealth applications misread body functions, such as heart rate, and give erroneous instructions, large groups of users may be misinformed (Coppetti et al. 2017) or distorted epidemiological records may arise.

Some individuals or population subgroups can also face inequalities in access to and use of mHealth. These can include individuals who have not been advised regarding the use of mHealth, who do not have a smartphone or access to internet or other relevant mHealth technology, do not know how to use mHealth technology, do not want to use it or do not use it for reasons of cost or battery capacity (Firth et al 2016, Malvey & Slovensky 2017). Others can be left behind or neglected by mHealth technologies that are not designed for diverse populations (AI NOW 2018).

Other considerations of justice are rarely discussed in the scholarly literature but they are highly relevant in our view. These include the tensions between social determinants of health (Marmot & Wilkinson 2006) and the resulting social gradient on the one hand and the emphasis on self-responsibility for health and healthy behaviour on the other (Voigt 2013; Wikler 2002). As discussed above, mHealth strongly encourages a shift towards self-responsibility for health, which is also supported by and even driven by economic interests, e.g. in the private IT and marketing sectors. Health insurance funds and private companies are increasingly using digital technologies to reward successful behavioural change or personal responsibility (AOK 2018; Barlyn 2018; Barmer, 2018). However, not everyone has the same living and working conditions that would enable them to make free, informed and well-balanced decisions in relation to their health (Voigt 2010). The shift towards self-responsibility could therefore lead to problematic finger pointing, especially towards the socially disadvantaged, and have serious implications for social values such as solidarity and social justice in health (Lupton 2016a).

ADVANCING MHEALTH WHILE UPHOLDING VALUES?

We have only briefly looked at a few aspects of mHealth here, but hope to have provided a glimpse into how profound the implications are for individuals and societies at large. mHealth technology is a tool that not only operates in the realm of health and well-being but that can also influence socio-politically relevant factors, such as knowledge production and social epistemology, and even democratic structures, economic interests and power patterns.

One area that has not been covered so far in this chapter pertains to the global implications of mHealth. Expectations are high that mHealth will be a crucial tool in reaching once difficult-to-reach populations, especially in remote communities in low- and middle-income countries (WHO 2011). It remains to be seen whether and how global health equity can be achieved through technology and which new ethical, legal and social implications will need to be discussed. For instance, can and should concepts of informed consent and data protection information be implemented and used universally? What are the implications of globally interacting IT companies and globally forming new patient collectives being connected through social media independent of national borders?

Altogether, unprecedented interest and power is being brought to bear by the IT and data sector, the private sector (including marketing) and users connecting on social media. The traditional boundaries of the health sector and expert knowledge are increasingly being blurred, if not left behind altogether. We are facing a “jumble” of overwhelmingly complex issues that overlap in ambiguous, contradictory and multi-dimensional ways. Implications on a societal and global level, which we are only beginning to unpack, are potentially dramatic. How should an analysis and interpretation of the implications of mHealth be undertaken and which values and norms should guide the various steps in relation to the technologies’ development, dissemination and use?

Bioethics and public health ethics have analysed emerging health technologies for decades and should be well placed to investigate the normative implications of mHealth, especially in an interdisciplinary ELSA format. However, these disciplines are limited in terms of their methods and frameworks. As mHealth transcends and blurs the boundaries between traditional fields of health and medicine as well as the national boundaries of health systems, traditional research and analytical approaches have to be questioned and adapted. What is needed is an even more interdisciplinary, dynamic, flexible and creative approach to research questions and methods and a curiosity and openness towards technological innovation and the involvement of new stakeholders in the field of health and medicine, e.g. the globally operating private IT sector.

Given the complex implications beyond areas of health and medicine, analyses and interpretations of the implications of mHealth will inevitably go beyond traditional frameworks of bioethics and public health ethics. For example, issues of feminist concerns; sociological inquiries into disadvantage and power; relevant insights from social epistemology and political philosophy; and norms and paradigms in economics, globalisation and technology will have to be investigated more prominently.

Of central concern is finding the appropriate balance between the laudable effects on health itself and empowerment, democratisation and procedural improvements in health and healthcare, while limiting potentially negative developments so that ethical values can be upheld. Exploring and applying values such as justice, wellbeing, human rights, freedom, democracy, solidarity and diversity should guide the way towards good policy

and practice. At the same time, a generalised evaluation of mHealth is challenging, as each type of technology, and potentially even individual apps or sensors, might carry specific concerns, calling for a case-by-case analysis.

A digital health ethics that has a global scope but is yet informed by the socio-political specifics and needs of particular local contexts might be necessary. The ethics ought to understand, incorporate and address the above-mentioned shifts and transformations.

The overall aim of this piece, and ultimately of our larger research project “META”, is to support responsible, socially and globally sustainable and user-centric innovation in mHealth. With this brief discussion of the complex ethical, legal and social dimensions of mHealth on individual, population and global levels and their implications, we hope to have contributed towards achieving this aim.

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