

Introduction to ethics of mHealth

mHealth is a **disruptive** phenomenon. This sounds threatening, violent even, but mHealth may disrupt for the good, as well as as present a danger or risk. It all depends how these technologies change and shape our lives. Actually, one important thing to note when thinking about mHealth from an ethical perspective, is that a lot of what mHealth does on a societal and individual level is really very *good*. mHealth has the potential to change many people's lives for the better, for example by expanding on the possibilities for chronically ill patients to engage in self-care, by helping people to fight addiction or by providing valuable tools in controlling epidemics. That being said, there appears a broad consensus that mHealth will change the way things are - it is disruptive in the sense that old structures and categories are remodeled, borders and distinctions are redrawn or dissolved and powers relations are redefined.

META examines the legal, social and ethical implications of these changes. This part of About mHealth focuses mainly on the ethical implications of these changes, although the legal and social aspects are relevant here too.

Not everyone means the same thing when they talk about 'ethics'. When we talk about ethics, we mean the systematic study of questions on what is right or good to do as an individual, as groups or as a (global) society. As such, ethics is not primarily about finding out what people *believe* is right or good to do, although this is relevant to the study of questions on what is right or good to do. Also, ethics is not primarily or necessarily about telling people what is good or right to do. Rather, ethicists try to understand what these questions entail and what is at stake when we talk about the right and the good.

The ethics of mHealth involves the study of the norms and values involved in the introduction and use of mHealth. Discussion of these norms and values often arises in response to cases that trigger our moral intuitions, for example when the provider of a health app accidentally discloses private information to a social media provider or an insurance agency, with potentially harmful consequences to the user. Or when the distribution of benefits from technological developments is perceived to be unfair or harmful to particular individuals or social groups. This introduction outlines some of the major themes in the ethics of mobile health. More detailed discussions can be found in Stories and our blog. Note that although our aim is to eventually cover all topics mentioned here in the stories, we currently offer only a handful of these, which necessarily presents a somewhat narrow view of the relevant topics. In particular, we currently have no stories yet that cover the global dimensions of the ethics of mHealth. Also, although we have some stories lined up about positive aspects, most of our stories are about more mixed examples, where it is not always obvious that changes in the use of technologies amount to changes for the good. We are continuing to develop stories and welcome ideas and inspiration.

Innovations aim to make things better. If new technologies didn't improve one way or another upon the way things are, we might as well not innovate. But the question is, better for *whom*? And: better *how*? If an app that purports to discover skin cancer in an early stage turns out to be unreliable, people may end up thinking they have cancer when they do not (false positives), or the other way around: put at ease when in fact they have a carcinoma and should consult a doctor (false negatives). Both false positives and false negatives are obvious instances of (potential) **harm** by mHealth.

If health technology harms people, that seems to be in conflict with the basic principle of non-maleficence. *Primum non nocere*, is how the hippocratic oath commences: first, do no harm. But the fact

that some mHealth has the potential to harm people, does not mean that they should therefore not be introduced. All medical procedures, applications and drugs have side-effects that may harm. The question is whether, on the whole, the harms outweigh the benefits. And the answer is, unfortunately, that for many applications we don't know yet. What further complicates things is that many mHealth applications are not considered medical devices, but rather aim for 'leisure' or 'wellness'. This distinction between medical and non-medical mHealth raises questions on the aims of these technologies and on what we may expect from them.

So, what is the aim of introducing mHealth - is it to improve health care, to save money, or to be able to do research? The promises of 'personalized medicine' often invoke a mixture of these goals, but they do not obviously align in all cases. More importantly, what is a benefit to some, may actually involve costs, burdens or even harms to others. Some of these practices could even be **exploitative**, when the burdens for the user are not proportional to the services offered. For example, insurance companies may save money by using data derived from mHealth applications, which does not necessarily benefit the users when this is used to charge some of them a higher premium. Or mHealth providers may do research which exposes vulnerabilities of users. This utilisation of data by mHealth providers raises questions on the **data economy**, most notably: who 'owns' the data, and what does ownership mean in this context?

This question brings us to perhaps the most famous of ethical worries in the context of mHealth, and a lot of other digital technologies: concerns on how data may be used in ways that are in tension with **privacy** rights. mHealth collects troves of data, some of which is quite sensitive. For example, mHealth may gather information on what conditions one is afflicted by, on one's sleeping patterns, or menstrual periods, or one's sex life. An important problem is that currently there is very little transparency on what happens to all this data. It is not always clear who has access to it, what they do with it, or what is being done to prevent third parties from stealing it. These are issues on the data ecosystem, the infrastructure of data, analytics and applications. The ubiquity of mobile health technologies shape this ecosystem in ways that challenge existing ideas on **confidentiality** and the distinction between what is public and what is private. Do mobile technologies put us in a situation of constant surveillance? How autonomous is one if body processes are constantly tracked, and if others have power over your data? Can **consent** counteract the emerging power asymmetries?

mHealth technologies may be discriminatory or display or worsen **epistemic injustices**. Algorithm-generated knowledge may for example be based on biased data sets or use biased definitions of success, leading to faulty predictions that turn out specifically bad for particular sub-groups. This is especially problematic if these sub-groups belong to already marginalised or discriminated demographics.

There are also ethical questions on autonomy in mHealth that move the scope beyond issues of consent. What do these technologies do with how 'we' view ourselves? This question raises issues on how self-tracking and datafication affect discourses about what is 'healthy' or 'normal', who should be held **responsible** for managing health, and on whether promoting efficiency comes at a cost. Are technologies informed by the user's own experiences and knowledge about their body or is it deemed superior and users' knowledge disregarded? How should physicians deal with patients who acquire a new level of self-knowledge and thereby **expertise** by means of tracking technologies? Perhaps an ethos of self-optimisation, as sometimes promoted by proponents of the ideal of personalized medicine, takes away attention from what really a **determining factors in health and disease**: poverty, inequality, addiction and malnutrition.

As we zoom out from the individual perspective to a public, and even global, health perspective, new ethical questions arise on access to technology, the digital divide, the effect that mHealth technologies have in areas where there is no fully functioning health care system and so on. Addressing these questions means confronting issues of **global justice** and coming to terms with the way in which the history of **colonialism** has partly shaped the perspectives and the categories that we use to describe the implications of mHealth technologies.