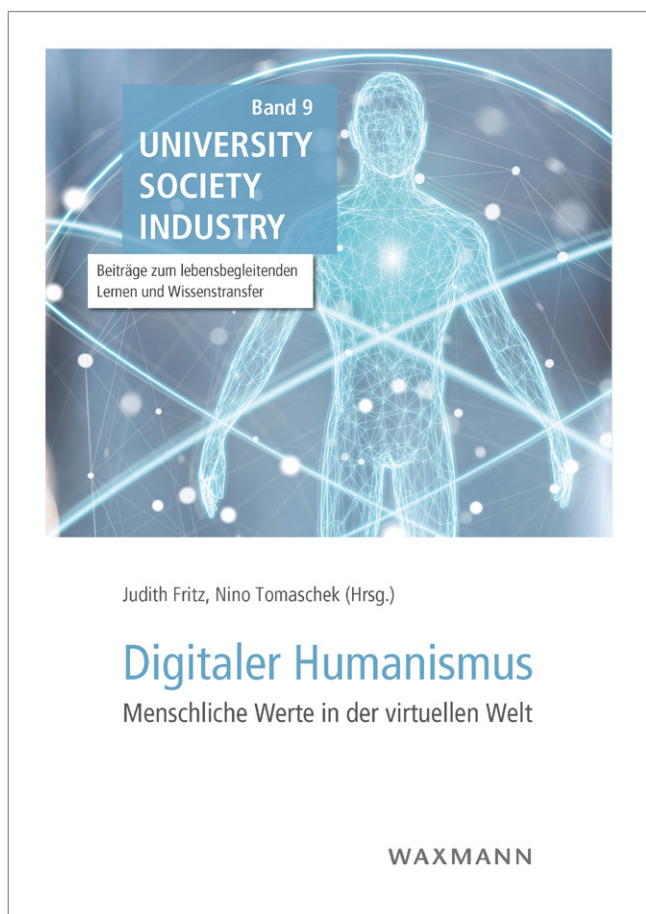Ulrike Felt, Susanne Öchsner & Robin Rae

The Making of Digital Health:
Between Visions and Realizations

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Digitaler Humanismus
Menschliche Werte
in der virtuellen Welt

The Making of Digital Health: Between Visions and Realizations

Ulrike Felt, Susanne Öchsner & Robin Rae

1.   Introduction

On 11 April 2020, the German magazine *der Spiegel* published an article under the headline "The new digital elite". It underlines that the 'corona crisis' is accelerating the digitization of important areas of society, specifically work, education, economy and social life. All this happens, the author stresses, without carefully considering the questions of justice and inequality that might emerge as a spill-over effect of these processes (Schultz, 2020). Health-related digital practices were not addressed, even though we encounter rising debates in the public arena. This attention to digital health during the pandemic was reflected in discussions on using apps (e.g. the so-called Red Cross App in Austria) to trace potential encounters with infected people, or in the fact that de-identified mobile phone data were used by the Robert Koch Institute in Germany to observe the flow of people in relation to pandemic hotspots. Both are examples of data which suddenly become health-relevant, even though most of us would not have conceptualized them as belonging to the realm of digital health. In the Austrian context, the corona crisis also led the chairman for the conference of Austrian social insurance institutions to underline that 'data can save lives', using this as an argument for passing on relevant pseudonymised health data of citizens stored in the electronic health record (EHR) to the Ministry of Health for research purposes. This happened without any broader public debate, and despite the fact that access to EHR data was seen quite negatively in the Austrian context up until the outbreak of the pandemic – 'the fight against Covid-19' would make this move seem obvious.

This short introduction is not meant to question that health-related data are essential for advancing medical research, treatment, and care, or to say that EHRs should not potentially be made available for research purposes. Rather it should draw our attention to two things. First, it makes visible how the coexistence of available digital data, the capacity for easily handling ever bigger amounts of data, and the dominant framing of the situation as 'us against the pandemic' have changed our perception of the legitimate use of data. Second, it opens up the question of what health-related data are in the first place, turning our mobile phones into powerful resources for informing about potential threats to our health. While these aspects became highly visible and relevant during the corona crisis, the observations are valid well beyond, and should lead to reflection on how the future of digital health (infrastructures) is envisioned.

Indeed, well before the corona crisis, the digitization of health has been high on policy agendas, promising to become the solution for many of the challenges that Europe's health care systems were facing. These challenges were described, for example at EU-level, as

ageing, multi-morbidity, health workforce shortages, and the rising bur-
den of preventable non-communicable diseases [… as well as] a gro-
wing threat from infectious diseases due to increased resistance to an-
tibiotics and new or re-emerging pathogens. Public spending on health
and long-term care is steadily rising in EU Member States and is ex-
pected to continue to do so (European Commission, 2018).

Digital solutions for health and care are then thought to "increase the well-being of
millions of citizens and radically change the way health and care services are deliv-
ered to patients, if designed purposefully and implemented in a cost-effective way".
And they can support

the continuity of care across borders […], can also help to promote
health and prevent disease, […] can support the reform of health sys-
tems and their transition to new care models, centred on people's needs
and enable a shift from hospital-centred systems to more community-
based and integrated care structures.

The creation and implementation of digital tools are expected to support "citizens
[to] remain in good health, thus helping to ensure that they do not turn into pa-
tients". And finally, the health data generated become a valuable resource, potential-
ly "enable[ing] a better use of [them] in research and innovation to support personal-
ised healthcare, better health interventions and more effective health and social care
systems". In short "data is a key enabler for digital transformation" also in the do-
main of health (European Commission, 2018).

While these visions of future digital health solutions are rather promising, we
should not overlook the potential challenges encountered in their realization. In this
paper we want to explore some of the challenges related to building the technologi-
cal infrastructures, i.e., a health data platform, that are required for the realisation of
such a digital health vision. Concretely, we will use our experience in the large-scale
Horizon 2020 project *Smart4Health*[1] to reflect on the potential tensions between
promise and realisation. The project aims to develop a prototype of an interoperable
health data platform which will allow European citizens to collect, store, access, and
share diverse sets of health-related and health care data, and to also contribute these
data, if wanted, to research. The project is much in line with the general vision just
described, operating with the assumption that such a data infrastructure would em-
power citizens to become agents and managers of their own health and thus support
a health care system under pressure. It thus contributes to realising a data-driven un-
derstanding of health-related research and care.

In what follows we will trace some of the emerging tensions between visions
of digital health for individual and collective benefits and the realization of these
through the development of a specific sociotechnical infrastructure – a health data
platform. After explaining the framework and aspirations of the project, we will in-
vite readers to reflect on both the potential and the limitations of this transformation
process – i.e., of the making of one version of digital health. This is done in three

steps. First, we will explore what the creation of this digital health infrastructure entails, and what demands closer consideration. Second, we will discuss the ways in which users are imagined and inscribed into this health data infrastructure, and how design choices might bring about specific kinds of in- or exclusions. We thus invite the reader to consider questions of justice and inequality. Finally, we will engage with the potential implications of a data-driven platform vision for our understanding of health and our bodies. The conclusions will reflect on how processes of envisioning digital health are connected to questions of responsibility, how we have to understand digital health as a socio-technical transformation process which in turn redefines what health and illness mean, and what the very notion of empowering the citizen means for different members of society in practice.

2.   Smart4Health – Building a Prototype for a Citizen-Centred European Health Data Platform

Smart4Health is a large-scale Horizon2020 research project that aims to develop, test, and validate a data platform prototype for the European Electronic Health Record exchange. The aim is to build a prototype of a data platform where citizens can on the one hand collect health-related data from EHRs and data provided by traditional health care actors (e.g., diagnostic test results, medical images or medication lists). On the other hand, citizen-generated health-related data from wearables and other sensors can be added, which broadens the scope of what data may be relevant for the provision of health care. The development of platform prototype includes a data infrastructure through which citizens can provide their health data for medical research purposes.

The project comes with a vision that in part builds on the implementation logic of the European General Data Protection Regulation (GDPR) of May 2018, transferring agency from the collective to the individual level when it comes to decisions about the use of personal health data. The figure of the citizen, empowered through the availability and use of the health data platform, is a central element of the *Smart4Health* vision. Methodologically, citizens are expected to be involved throughout the project in processes of co-creation that allow them to articulate needs, values, and concerns, and to test and validate the platform and its functions in a number of everyday life settings. This approach aims at ensuring that the platform is aligned with citizen articulations of problems and solutions and thus that it will be appropriate and useful to them. Conceptually, the project is guided by the idea of giving more agency to citizens with regard to their health data, and of turning them into central actors in the health care system. If citizens can in this way be transformed into responsible and responsive contributors to the infrastructure, various benefits are envisioned.

One immediate anticipated benefit to citizens is that they would have an up-to-date, structured and digitally accessible repository of their health records at their disposal, at all times and from wherever they are. This is expected to facilitate data-based communication with health care professionals at a national and international level. If doctors and other health care professionals can access the entirety of health and health-related data and, thus, look at longitudinal digital representations of

health, the decision-making of health care professionals and the health care that they provide can be improved. Also, if in an emergency situation a citizen cannot speak, an emergency dataset can speak for them. Furthermore, if citizens allow their data to be used in research, they contribute to large-scale data collection that – so the vision goes – allows for the development of personalized health services and individual therapies based on big data analyses and therefore brings both collective and individual benefits. The realization of these envisioned benefits does not come without a number of challenges, some of which we will explore in the forthcoming sections.

3.   Co-Creating a Digital Health Infrastructure: Potential Challenges

How to construct a health data platform in a way that addresses future users' expectations, values, needs, and concerns? We approach this core concern in two steps. First, we reflect on the health data platform as a new infrastructure providing the undergirding of digital health and mediating new forms of exchange. This will allow us to focus on the technopolitics that are embedded in such an infrastructure, which seeks to organize the health domain through a technological (digital) intervention "that seem[s] far removed from formal political institutions" (Larkin, 2013, p. 328). Second, analysts investigating the (non-)use of personal EHRs stress the importance of "align[ing such a new health infrastructure] closely with people's attitudes, self-management practices, identified information needs, and the wider care package (including organisational routines and incentive structures for clinicians)" (Greenhalgh, Hinder, Stramer, Bratan & Russell, 2010, p. 11) and thus engaging in user-centred methods of co-creation. Not doing so might increase the risk either of abandonment (even after initially inscribing) or of the non-adoption by users, both of which would severely hamper the sustainability of such a digital health approach.

What needs to be considered when building a digital health infrastructure? An infrastructure is never a straightforward single technological realization, but should rather be understood "as a bundle of heterogeneous things (standards, technological objects, administrative procedures) [...] which involves both organizational work as well as technology" (Slota & Bowker, 2017, p. 531). This means focusing on the socio-technical arrangements in which „technical, political, legal, and/or social innovations link previously separate, heterogeneous systems to form [a] more powerful and far reaching network" (Edwards, Bowker, Jackson & Williams, 2009, p. 369). In the case of Smart4Health, all of these different dimensions are in the making. While the innovative capacity of such digital health infrastructures is constantly emphasized, we have to consider that infrastructures never "grow de novo" and therefore always have to "wrestle with the 'inertia of the installed base' and inherit strengths and limitations from that base" (Star & Ruhleder, 1996, p. 113). In the case of Smart4Health, infrastructure is built on pre-existing information infrastructures and relations in the context of health care, both on their strengths and vulnerabilities (e.g., how information was collected and stored before and how good and standardized this information is).

While it is helpful to understand infrastructures as socio-technical arrangements, we suggest not only focusing on the product that is being developed – i.e., the health data platform – but rather understanding the building of a health data platform pro-

totype as a large-scale endeavour in infrastructuring health through digitization. By using the notion of infrastructuring (Grisot & Vassilakopoulou, 2017) we draw attention to practices of imagining, researching, designing, making, and adapting, as well as testing, using and appropriating, a health data infrastructure. Engaging in infrastructuring digital health entails bringing the health and information practices of a broad set of actors (from patients to different health care professionals) and from different use contexts (in personal environments, in a hospital, at the doctor's, in research) into one socio-technical network. At the same time, it opens up new channels through which otherwise distant actors can connect and thus coordinate themselves. Being attentive to infrastructuring therefore shifts our analytic gaze to go beyond the interconnections of a number of nationally or locally organized health infrastructures, to the tensions as well as new opportunities that can occur through this process.

The new digital health data platform has to be somewhat compatible with the pre-existing systems that are located in different national contexts, health care segments, and insurance systems. This cross-national integration of health-related data will be challenging on at least two levels: the *technical interoperability* of systems required to exchange data and the *socio-cultural interoperability* (Felt, Öchsner & Rae, 2019) needed to make a data platform fit the quite diverse European sociocultural and technopolitical environments of future citizen users.

Therefore, it is crucial to engage potential users in the process of creating the platform: in short, to use a co-creation approach. Concretely, this means enabling citizen as well as professional users to make creative contributions in the formulation of future needs and to be engaged in development choices, drawing from their expectations, knowledge, and experiences. Co-creation thus aims to bring different parties together in order to jointly produce a mutually valued outcome. This is much in line with the principles of the Responsible Research and Innovation (RRI) approach embedded in the European framework program Horizon 2020. RRI can be seen as an attempt to ensure that both the process and outcomes of research and innovation are acceptable and socially desirable, based on interactive processes through which societal actors and innovators can become mutually responsive to another. This means that market mechanisms should not be the sole or leading force in deciding "the normative dimension of what counts as an 'improvement'" (von Schomberg, 2013, p. 54). Instead, processes of engagement and deliberation which integrate citizens and civil society actors should allow for a more inclusive assessment of the value of particular innovations (Felt, 2018).

4.   Inscribing Users and Non-Users

Who are these future users that should get a voice in the process of developing this digital health data platform?

While the project's "citizen-centeredness" hints at the role that should be attributed to individual users, it is imperative to more deeply question who "the user" is, or is imagined to be. Indeed, when speaking about 'citizens' in more general terms, insufficient attention is often paid to the diversity of individuals, groups, and communities that are addressed through these generic terms. As infrastructures are often

taken for granted and become unquestioned and unquestionable once they are successfully introduced, we need to address how specific values are realized through infrastructures and what in- or exclusions they might bring. Here the value of diversity is fundamental, a value that has more recently become a central notion in contemporary health care provision and points to the growing attention given to addressing human differences in contemporary societies (Vertovec, 2012; Penkler, Felder & Felt, 2020).

Similarly, what about non-users, who might be 'created' through the conceptualization and design of the health data platform developed? Health care professionals (such as doctors or nurses) and the contexts of use in which data sharing could become essential must also be considered throughout the process. These groups are at the other end of the data interface, and it is important to understand what kind of data is paramount for them when performing their professional tasks with and for citizens. "Who is the user?" then becomes a highly non-trivial question, in particular when this means prioritizing one user's needs over another, or when balancing privacy issues with big questions of health care (Oudshoorn & Pinch, 2003).

In general, in Smart4Health the user is imagined as 'the' EU citizen. Considering the dynamics of "configuring the user as everybody" (Oudshoorn, Rommes & Stienstra, 2004) throughout the design process means being attentive to the relation of the technology being designed and to the identities of users imagined. For example, studies have frequently shown that age and gender are often insufficiently considered in the design of information and communication technologies, even though both are relevant for the large majority of users (Oudshoorn, Neven & Stienstra, 2016). This also entails being aware of where designers situate their own experiences and identities, to avoid the persuasive use of what Akrich (1995) calls 'I-methodology'. Designers' experiences, attitudes and expectations tacitly flow into the design, making pre-selections that can hardly ever be compensated for, even through processes of adaptation and participation.

It is helpful here to think the research, development and design process using Akrich's concept of a 'script' as being part of any technological innovation. Akrich (1992, p. 208) suggests: "like a film script, technical objects define a framework of action together with the actors and the space in which they are supposed to act." Accordingly, design processes can be understood as key moments where scripts are brought into being, as well as where responsibilities are distributed in specific ways. Thus, building a health data platform will create new "geographies of responsibility", i.e., create a new distribution of responsibilities or transform or reinforce existing ones (Akrich, 1992, p. 207–208). As Petersen, Tanner & Munsie (2019, p. 4) highlight, technologies supporting the digitalization of health are "arguably integral to 'responsibilising' citizens, making them accountable (and potentially blameworthy) for health decisions, in line with a broad shift in the politics of citizenship under neoliberalism".

A specific point of consideration in this regard is the degree of data literacy that is expected of future users, how technologically literate they have to be, and what understandings of health and related individual responsibility they are ready to subscribe to. A recent study argues for expanding the concept of data literacy to "data infrastructure literacy" (Gray, Gerlitz & Bounegru, 2018, p. 1) so as "to include not just competencies in reading and working with datasets but also the ability to ac-

count for, intervene around and participate in the wider socio-technical infrastructures through which data is created, stored and analysed". Inclusiveness during the development and design of a platform, and close reflection of potential consequences of design choices are thus key. This, however, is by no means an easy or straightforward task. Different groups of actors might favour different scripts and even in groups that seem homogeneous contradictions might arise. Users might, in the end, reject a chosen design, create their own understandings and forms of use of the technology, or, even after initial acceptance, stop using it. For the health data platform developed in the framework of Smart4Health, it is essential to carefully consider the different user categories that potentially might be excluded, and also on what role these absences (can) play with regard to shaping the prototype. While, for example, minors are deliberately excluded during the course of the project, the presumed basic familiarity of using a digital platform can certainly impact the engagement with users at the upper end of the age spectrum. Similarly, even though 'the' EU citizen is centred in Smart4Health, the platform prototype only has a limited number of languages available, which will also favour specific users in shaping the design (languages available will be expanded slowly over the course of the project but will ultimately not be comprehensive).

The strength of the Smart4Health co-creation approach is, however, its duration over several years, which allows different user groups in different contexts and at different development stages of the infrastructure to voice their visions and concerns. This allows for a consideration of the different affordances that diverse use contexts help to articulate, as well as engagement with new and existing users who can follow the process together. Thus, not only design and development processes matter, but also contexts of use – where, when, and how users interpret and appropriate a technology. This explains the importance of taking co-creation seriously; i.e., of giving voice to diverse sets of users with their visions, concerns, and preferences for certain "problem-solution packages" (Fujimura, 1987) over others.

5.   Contributing to and Engaging with Mediated Visions of Health

Having discussed what the creation of such a digital health infrastructure entails, and how visions of future users, their roles, and their capabilities are all inscribed into a health data platform, we will now look more closely into the effects of a digital approach to health on our visions and interpretation of our health and bodies. We will in particular look at the potential effects of a mediated vision of health that emerges as citizens add their data and have to engage with them. And we will have to scrutinize the imaginations of a new distribution of responsibility when it comes to caring for one's health (data).

The platform developed in Smart4Health will do more than simply collecting, describing, and (re)presenting citizens' health and health-related data. Through the data platform, human health and bodies become visible in new ways, which enables and invites specific forms of action. Citizens will be able to contribute to and engage with their health data, continuously building up and caring for a body of data that is always ready to be accessed when needed and shared if desired. We know that technologies always mediate relations between humans and the world, between peo-

ple and the social and material environments they live in. Since the 1980s, analysts such as Langdon Winner (1986) have pointed to the fact that technological innovations are shaped by values and, in turn, impact upon the ways in which we can live in the world, often in invisible ways. Technologies can, as Latour put it, "authorize, allow, afford, encourage, permit, suggest, influence, block, render possible, [or] forbid" human action (Latour, 2005, p. 72). Thus, when building technologies in specific ways and not others, designers and developers are doing "ethics by other means" (Verbeek, 2006). As technologies mediate between humans and the world, they shape our perceptions and expectations, as well as our actions and practices: what we can and what we should do. They mediate morality (Swierstra, 2015). We therefore need to attend to the value orders which get built into our technological infrastructures, the potential actions they allow for, and the patterns of exclusion and injustice that they may create – the latter of which is particularly important when it comes to questions of human health and illness, prevention, and treatment.

The platform envisioned in Smart4Health goes beyond collecting 'classical' health data, which has traditionally been stored in institutional data infrastructures. Citizens will be able to assemble data that has been produced and collected both by health care professionals and by themselves, including health data from EHRs and health-related data collected via wearables (e.g., concerning one's posture during the workday) or via smartwatches (e.g., heart rate). While this means that new types of data move into the realm of health data, these data are not just there, but have a history to be taken into account. Take, for instance, the first type of data that can be collected on the platform: health data from EHRs. It would be a fallacy to take data from EHRs as a direct representation of citizens' health or of the progression of an illness that someone has. Instead, the data in an EHR offers a glimpse into someone's interactions with the health care system. The medical history of a person is expressed via their interactional data with institutions and health care professionals and the – often national – specificities of these (Agniel, Kohane & Weber, 2018). What health data infrastructures enable is therefore the objectification and representation of interactions between citizen and health state.

While this issue is crucial for those who draw on data made available for research to reflect upon, it also means that citizens/patients need to learn how to read available data, understand its limitations, and refrain from drawing hasty conclusions from such data about their health status. When building such a platform, we therefore have to continuously and carefully reflect on and test how citizen users create a relation between the available data and their health status, in particular since we are witnessing a shift in which responsibility for one's health data collection is being outsourced to the individual. The mediated version of health that comes into being is based on the health data platform involving citizens in the assembling of their own potential patienthood; citizens, thus, are simultaneously contributors and beneficiaries.

From the outset, the development of the health data platform has inscribed a vision of citizens and their desires, whose platform contribution and engagement enables individual and collective benefits. This has been done already in the project proposal by employing two fictitious quotes that were assigned to future health data citizens, who – in the here and now – already serve as testimonials for what is yet to be developed in the course of the project:

– I am supported in managing my own health.
– I can help others by donating data.

The 'I', here, refers to the figure of 'the citizen' who has fully subscribed to the log-ic of the health data infrastructure and its associated practices. The new data citi-zen is expected to care for their individual health in new ways – by managing it and by collecting, handling and sharing a variety of health and health-related data, with health care professionals, trusted people such as family members or friends, and re-searchers. Providing data to research is staged as an act of solidarity with others in need of help, thereby also contributing to collective benefits.

This requires data citizens who can act as health data managers. They are as-sumed to be willing and capable of monitoring, self-managing, and interacting with their personal health data, of taking individual control over their data (and of being in the position to do so, e.g., in relation to their health care professional), as well as of taking responsibility for their health records (e.g., by deciding to collect a specif-ic dataset but not another, by keeping it complete or not). And they are expected to have the capacity to exercise the right to 'their data', to be knowledgeable and data-literate – as well as data-infrastructure literate.

As of now it is unclear how these visions will unfold, what exactly they will mean for the everyday practices of health data citizens, and how the platform will redefine the relations between bodies, selves and health. Still, we want to outline a number of areas of concern. The data-mediated vision of health and the body will certainly bring along new kinds of practices of engaging with one's body and health. It will also bring new roles and responsibilities, as well as different kinds of ac-tions that are perceived as being necessary, if one wants to be a responsible data cit-izen. In order to collectively realize the promises associated with the health data in-frastructure, individual data citizens may have to perform a lot of work. Citizens are expected to manage their data, to determine with whom they want to share their data and with whom they do not, and to take decisions regarding the provision of some or all of their data to research. They will need to collaborate with the platform and to attend to the completeness of their personal data collection, all of which will require continuous engagement and care – care for the completion of the collection, care for the data body (Mager & Mayer, 2019) that comes into being, and care for where it may or may not travel. Furthermore, the combined collection of health and health-related data and, thus, citizens having a very specific representation of their health (data) at their disposal at all times, will certainly have effects: on the relationship with health care professionals, on how people experience themselves, on how they see their bodies, on practices of how health and illness will be expressed and ana-lysed and, thus, on what it means to be healthy and to be ill.

6.   Conclusion

What can we take from these reflections – always keeping in mind that we are only at the beginning of this co-creation process? How can we ensure that we build a dig-ital health system in a way that ensures that these technological opportunities are taking shape in accordance with human values and needs?

From our experiences so far, four points seem particularly key.

First, we want to point out that projects like Smart4Health should be understood not only as development projects but as a "visioneering effort" (Sand, 2018, p. 42); i.e., as "a technoscientific practice that enmeshes utopian narratives to propagate visionary technological pathways in public and business contexts with the practical managing, designing, researching, and making of novel technologies." This new infrastructure does not only create the prototype of a digital space where citizen patients, caregivers, and researchers can meet and engage around collected data and issues of health care, it also contributes to changing understandings of care. And it creates new kinds of responsibilities, both for the visioneers – as their visions have tangible impacts on how potential futures might look – and for the citizens who are expected to care for keeping their data bodies in shape. From a design perspective, it subscribes to a vision of health care that is made up of intertwined systems resulting from the combination of human-centered values and practices, health (care) related needs, knowledge, and information technology. While this is a clear vision, promising improvement and empowerment for all, we have also pointed to the fact that design processes – even if they build on a co-creation approach – could potentially also produce "collateral futures" (Felt, 2013), i.e., unintended futures which might create a heavy burden for citizens to document their health status digitally, or the exclusion of some citizens due to a lack of literacy with regard to data and their digital handling, which is not in line with the project's digital imaginary.

Therefore, secondly, when carrying out and analysing this and similar digital health development projects it is essential to keep in mind that there is never a clearcut, straightforward problem at the outset, and a corresponding technological solution at the end of the innovation process. In the area of building digital health we witness how both problems and solutions evolve in the course of a digitization of health. They shape each other, forming specific "problem-solution packages". Just think of the quote from the European Union communication which stressed the problem of an ageing population, spoke of financial stress, and called for raising efficiency, while also underlining the importance of offering better care for Europe's citizens. What remains to be seen is what happens when certain sets of values come in conflict with others – when, for instance, cost efficiency and quality of care do not go hand in hand as smoothly as envisioned. It is therefore crucial to understand digital transformation of health care as a socio-technical process. This has the consequence that any successful health data infrastructure – or more widely speaking any digital health innovation – needs to be closely aligned with users' attitudes, values, norms and concerns – be they citizens, patients or professional users. It also needs to consider practices of personal and systemic health care, as well as carefully assess the work that needs to be invested in sustaining the data infrastructure. If these aspects are not considered, digital health infrastructures run the risk of not being adopted or of not becoming a sustainable part of the wider health care system. Digital health solutions have to be conceptualized as a socio-technical system in the making, ready to continuously adapt and engage with its users.

Third, we have to acknowledge the transformative power of data-driven health systems for defining what it means to be healthy or ill. Collecting data and investing work into upholding a health data infrastructure also changes the perception of one's body and its health status. We thus have to open a debate and to closely fol-

low how, in practice, both doctors and patients connect the data collected through different measures to the human bodies producing these data. Developing a health data platform such as the one described above will not only be a space for managing health-related data, it will also enable a newly mediated vision of citizen users' bodies and health. This, in turn, has the capacity to change their perceptions and experiences, as well as the relationship between citizens and health care professionals. We have learned from studies of quantified-self communities (e.g., Lupton, 2018), that the focus on data as a mode of self-observation closely ties into imaginations of self-optimization, potentially becoming the source of new concerns. Thus, not only empowerment emerges out of the digitization of health, but also new forms of (self-) surveillance and control. This calls for a careful monitoring of the transformative processes and the related infrastructures while they are being developed.

Finally, we want to close this analysis by returning to the beginning of this article, specifically by asking questions of justice and equality. While the buzzword of 'empowerment' through access to health data is omnipresent in policy discourse, we need to carefully observe what this means for different segments of society in their respective everyday health-related environments. Building a health data platform, we have underlined, is a socio-technical endeavour. Visions of 'the user' get scripted into such an infrastructure, imagining specific situations of use and demanding work from citizens to keep this platform alive through feeding it with data on a regular basis. However, we also know that both digital literacy and the affordances of people in terms of time and skills are unequally distributed. Therefore, the digital divides that we can already observe in contemporary societies – for instance in the corona crisis we have seen a lack of access to computers and internet for many of the children placed under home-schooling regimes – might be reinforced by their connection with already existing health disparities. Indeed, digital visioneering of health care needs to carefully reflect upon pre-existing power relations and inequalities, which will not disappear through the introduction of digital health, as is often hoped, but may be reinforced, or new inequalities emerge.

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