

## **DIGITAL TWINS IN HEALTHCARE FOR CITIZENS**

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## **ABSTRACT**

Digital twins are gaining attention in healthcare, especially in fields like hospital management, simulating surgeries, or providing personalized health. As digital replicas based on users' data, digital twins can inform citizens in-depth about their lifestyle, medical data, and biomedical data. Hence, there is the assumption that digital twins could facilitate preventative healthcare at home, bringing healthcare closer to citizens, yet there are underexamined ethical concerns. In this paper, we explore the ethics of digital twins based on citizens' perspectives on digital twins in healthcare via recent literature and research. Although digital twins have great potential, citizens have concerns about surveillance, data ownership, data accuracy, and personal and collective agency.

# 1 INTRODUCTION

We generate health data via a variety of applications—either through mobile applications or internet of things (IoT) devices. On top of this, biomedical data are increasingly digitized in hospitals and the practice of medicine in general is transitioning to the digital world. Against this backdrop, the notion of the digital twin in healthcare is emerging. A digital twin (DT) refers to a digital replica or a virtual presentation of a physical asset that serves as a digital counterpart (Grieves, 2014). This definition was formulated by Grieves in 2002, with the idea that a “digital information construct” connected to a physical object or asset, could be an entity on its own, becoming a “twin” of a person, object, or process by holding information about the original entity. Huang, (2022) refined the definition as it pertains to healthcare: “a digital twin for personalized health care service is a data-driven, interactive computerized model that aims to offer health-related information that properly simulates or predicts the health conditions of a particular person” (Huang, 2022, p. 12). This definition might not yet be complete and may be open for debate.

We see a digital twin as a layered technology that holds different data layers of a person, such as their environment, lifestyle, biomedical data, and other facets. A person’s digital twin (DT) could also hold social health determinants<sup>28</sup>—that is, information on where citizens are born, live, and age, which are nonmedical factors that influence health. As a digital twin can predict, describe, and prescribe, the fact that a DT takes social health determinants into consideration for personalized medicine and treatments might give different insights into the backgrounds and needs of citizens in personalized healthcare. The notion that a DT could be available at home for citizens to manage, simulate, or predict their health has not been researched “in the field” thus far. Thus, a recent study (De Maeyer, 2022) that we conducted on DTs in healthcare at home offered insights on how citizens view and may use a DT. We found out that people would prefer DTs as qualitative representations rather than quantitative representations and wanted to be able to use both options in case of emergencies. Notably, the predictive features of DTs were not favored by citizens, mostly because they did not want to know what the future holds and wanted to live in the present. So, contrary to extant research (e.g., Huang, 2022) we may have to rethink definitions of DTs in light of what citizens want from the future of digital health. In this paper we propose a critical look at the ethics of DTs, such as how surveillance could lead towards new business models and policies in healthcare. We emphasize that how DTs are now conceptualized by professionals does not match citizens’ expectations or needs, particularly since citizens we interviewed largely do not want their health states to be predictively portrayed by DTs.

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<sup>28</sup> [https://www.who.int/health-topics/social-determinants-of-health#tab=tab\\_1](https://www.who.int/health-topics/social-determinants-of-health#tab=tab_1)

## **2 ETHICAL CHALLENGES**

### **2.1 THE PUBLIC GOOD**

We start with the presumed public good of DTs before diving into critiques. As DTs generate summative and predictive data on populations, they offer an opportunity to evaluate and create new insights that are broader than those offered interventionist healthcare. DT could be made available for academic research in different fields related to healthcare and well-being in general for preventative healthcare at home (Rasheed, 2020; De Maeyer, 2021). Citizens could give consent that their DT could be used for the greater good of a population. However, broad access is needed to get data sets that represent different layers of society and avoid discriminatory biases. Experts see a role for the government in overseeing the regulation of DTs, together with an expert board of different stakeholders, medical professionals, lawyers, ethicists, etc. Such an expert board could establish guidelines around this new technology. (De Maeyer, 2021; Boulos, 2021; Rasheed, 2020). In addition, an educational framework for educating professionals and citizens is an important aspect of embracing this emergent technology, starting with teaching children early on together with parents to create awareness on preventive healthcare (Barricelli, 2019; Rasheed, 2020). Yet the utopian vision of how healthcare DTs can serve the public good in a preventative manner is contentious, as we addressed below.

### **2.2 SELF-SURVEILLANCE**

Simply put, self-surveillance means paying attention to one's own behavior. In 2007, Kevin Kelly and Gary Wolf popularized the quantified-self movement. Early self-tracking devices and mobile apps became available on the market and could be used to track different bodily aspects, such as physical activity, mood, calories, sleep and so forth. This is one of the drivers of the idea of DT, together with other digitized health data that are available in hospitals and with medical professionals. From a sociological perspective, critics have expressed the notion that the quantified self could empower individuals to manage their own health, going from “‘health is the responsibility of my medical professionals surrounding me’ to ‘I’m responsible for my health’” (Swan, 2012, p. 108). Much of this discourse still holds for a DT concept, especially if it were be available in a home environment. These self-tracking apps or devices could be imposed or pushed on citizens by different stakeholders for different purposes—for instance, to get personal information for a given person, which we widely saw with COVID-19 tracking applications. It can help when an individual consents to tracking their heartrate or blood pressure, as well as their use of medication—this may offer insights that are useful before and after a surgery. This is regularly done when agreed between patient and

GP, for instance. Yet, the thinking is that such personal information would then be available in the DT of that specific citizen, allowing near real-time monitoring.

As health applications are easily available today, they become part of our daily lives, and self-surveillance has almost become a norm in our society—it is now nearly an obligation to actively observe oneself (Han, 2017). Doctors are quoted as saying “within 10 years I want to be able to open my laptop during consultations to view the stress data of the patient sitting in front of me”<sup>29</sup>. This illustrates what self-tracking modes may entail in the upcoming years for healthcare in general. Lupton (2014) defines five modes of self-tracking. There is private self-tracking, referring to voluntary self-tracking activities, and pushed self-tracking, referring to self-tracking coming from another agent or actor, and usually encouraged externally by a general practitioner, for example. Communal self-tracking involves voluntary sharing of personal data in communities, e.g. sharing physical activity data in Strava.<sup>30</sup> Hence, imposed self-tracking, usually by other parties, can be expected in health care environments, but also in work environment to optimize citizens’ labor in general; this may easily become exploitative self-tracking, where self-tracked personal data are repurposed for other means, usually commercially, such as for reward systems as customer’ loyalty programs (Lupton, 2014). These modes also could apply to a DT as it can push, impose, or exploit citizens. What is different about DTs is that their status as *replicas* of citizens while taking a *predictive* stance; by predicting people’s futures as replicas, DTs can push, impose, or exploit citizens to change their behavior via *predicted future states*. Rather than intervening on current health states or ailments, citizens are exposed to and can be expected to act based on data-driven future versions of themselves. Hence, self-surveillance in the present paves the way for forecasted future surveillance of citizens, further endangering our agency and privacy.

### 2.3 AGENCY

Agency is discussed in two ways. One is the loss of collective agency, and the other is personal agency, and the two of these are related. Collective agency, in the context of this paper, refers to the democratization of healthcare in which, as per above (the public good), we can exercise preventative healthcare through DTs, in which society at large benefits through data-sharing and preventative health management. Researchers have stated that DTs could be social equalizers but they could also broaden the digital divide gap; DTs could lead to social sorting, social segmentation, and increasing discrimination (Bruynseels, 2018; Boulos, 2021). The idea that DTs would enhance humans could also lead towards a new class of people, disrupting democratic processes when citizens are treated

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<sup>29</sup> <https://www.tijd.be/dossiers/de-meetbare-mens/burn-outs-voorkomen-met-data/10351299.html>

<sup>30</sup> <https://www.strava.com/>

differently and unfairly through DTs (Fukuyama, 2002). With broad access to DTs for citizens, social sorting or specific segmentation is a worry.

In relation to collective agency, we discussed the loss of personal agency perceived by the participants we interviewed (De Maeyer, 2022). As several participants noted, a DT could be connected to health insurance providers, which could then see how a citizen performs and adjust insurance pricing accordingly. Furthermore, insurance providers could create reward systems, according to an expert: *“incentives for sharing data could be rewarded through vouchers or loyalty cards”* (De Maeyer, 2021). Looking at business models in this perspective, one of the experts also mentioned, *“the danger of connecting financial information to a digital twin might evolve towards more of an economic exchange system than a healthcare system”* (De Maeyer, 2021). There is a clear divide between what experts think and citizens think. Citizens argue that they do not want their DTs to be connected to insurance providers or financial information. One citizen stated: *“I think it should be protected, if my hospitalization insurance is giving up on me, because according to them I don’t fall within the standards, I don’t want that, so I don’t want them to know, actually”* (De Maeyer, 2022).

Other participants commented further that they would prefer an offline system in which they could control and synchronize their data when they saw fit. In other words, people want to have control of the DT and its data. Due to the close link between the digital replica and the citizen, the question arises of whether people will be able to make the right decisions autonomously and whether they are able to interpretate the data correctly. Furthermore, the proposed decisions DTs make are likely to be algorithmic. This may be a new form of “dataism,” in which a DT becomes a “medical patronizing system” (Bruynseels, 2018). A human should be in the loop, not only to support decision making but also to check the results presented by a DT (Rasheed, 2020). Yet this may not be enough considering privacy issues.

## **2.4 PRIVACY IN AND OF DIGITAL TWINS**

Barricelli (2019) explains that deploying DTs would demand seamless connections, sensors, and know-how to foster interest in DTs for researchers and doctors but also for the citizens. As a DT makes use of cloud-based services to collect health data, the privacy and robustness of this technology is of major importance, especially due to the medical and lifestyle information that a DT holds. The EU’s General Data Protection Regulation (GDPR), which has been in force since April 25, 2018,<sup>31</sup> is a step forward towards protecting individuals’ privacy (Rasheed, 2020). A problem is that the GDPR

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<sup>31</sup> <https://gdpr-info.eu/>

is broad and not adequate for use with DTs. Another issue is how DTs designed and developed outside the EU may or may not be compliant with GDPR. As with other digital applications, it is unclear how citizens become aware of the aggregation of DT data from within Europe with non-EU compliant data and where the data handling responsibility resides. What makes DTs different from other digital applications is that they are taken to be the “replica” of citizens; if surgery simulations are undertaken or health predictions made with DTs, there are additional privacy concerns. For instance, a DT could be hacked or be infected with viruses, meaning that people are greatly vulnerable due to the sensitive health data and predictions in their DTs. If a citizen’s DT is hacked, then inaccurate health forecasting could be implanted in the DT, which could impact high-stake situations like surgeries that depend on data held in the DT. Beyond concerns about healthcare insurance premiums, real-time life or death decisions—e.g., through wrongly simulated operations—become a major concern when privacy cannot be guaranteed.

## **2.5 HEALTH FORECASTING AND SIMULATIONS**

A strong reason not to predict people’s health through DTs is that citizens may not want this. While forecasting and simulations are one of the features of a DT, we noticed that citizens, with the exception of one outlier, were not keen on using that feature. The notion of forecasting health felt too confrontational, together with the excessive number of uncertainties and variables that influence our wellbeing, like a user argued: *“for me, personally that is scary, I feel more vulnerable than before, friends that are dying, it all becomes so visible”* (De Maeyer, 2022).

As Braun (2021) puts it, if a health prediction points to a severe illness, it will change the life of the citizen or patient; the DT will influence thinking and might have power over the person, limiting their freedom. This relates to earlier discussions on surveillance: Influencing people’s presents and futures via simulated future health states can severely limit their collective and personal agency. Yet, interviewees welcomed the prospective use of DTs as reflective tools rather than predictive replicas. Citizens can take a reflective stance on what being healthy may individually mean, according to our study. Thus, participants preferred a qualitative representation rather than a quantitative representation. For one, the interpretation of quantitative data would be hard for some to understand and to cope with. A qualitative representation, like a digital painting as a landscape of one’s moods, could represent their well-being while leaving room for personal interpretation. But, quantitative representations—e.g., calories consumed as graphs—could create and enhance feelings of vulnerability. In sum, citizens and experts may have differing opinions on how they expect DTs to develop.

### **3 CONCLUSION**

In this paper, we explored citizens' perspectives from a previous study (De Maeyer, 2022) and interwove these explorations with background research on digital twins in healthcare. We covered the surveillance aspects of a DT in healthcare from the citizens' perspective, building on the modes of self-tracking practices. DTs are said to offer public good in evaluating and analyzing the mass of data that will become available on a population, if citizens consent, thus democratizing healthcare. But we see a divide in the views of experts and citizens, mainly in the need for DTs to have forecasting abilities. People would prefer a DT that served more as a tool for reflection than forecasting. Data protection, privacy, and the robustness of the technology should be ensured, but such practices still leave out deeper ethical concerns, such as the surveillance of currently healthy "sick people of the future," thus endangering our collective and personal agency.



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