

# Data Design Futures: Who is Responsible?

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## ABSTRACT

With the imminent ubiquity of data, the healthcare domain is turning to data to increase efficiency and effectiveness. Health data tracking in everyday life introduces challenges around user protection, data quality, and transparency about data goals. While adhering to GDPR legislation, data design practice has done little to protect users of health tracking tools from their data and associated mental health problems. Additionally, the quantification that many data trackers facilitate can lead to comparison, competition, and addiction. Finally, it can be difficult for users to oversee the consequences of sharing their data in consumer and research contexts.

We argue that designers should take responsibility for data curation and protection when designing with data, especially in healthcare. We introduce a new breed of designer: the data futures designer, who actively seeks out the edges of data tracking and discusses these with future users to inform them, probe their responses and consequently define the future of data design, together.

## KEYWORDS

internet of health, responsible IoT, health tracking, quantified self, ethical design, design reflection

## 1 INTRODUCTION

In modern society, there is very little you can do without it being documented somewhere, from all our behaviour online to movement through the city [24]. Data has become so embedded in our lives that the extent of data collection is no longer visible and comprehensible for the majority of society. With data legislation such as GDPR [5] and its world-wide counterparts, governments are increasingly moving to better protect the privacy of citizens. Nevertheless, the way in which this or similar legislation is implemented in user data collection processes is often sneaky and obscure.

With recent advancements in health tracking technology and countless healthcare apps being released every week, the trend of data collection has also expanded itself into the medical domain, coined as the Internet of Health Things [3, 19]. Users are rewarded for sharing personal data such as their mood and consumed meals by lifestyle apps or are pressured to consent to data sharing to receive access to specific content and functions such as activity reports from their fitness tracker. Not only do users skip reading the policies that they consent to, but if they would read them they

would most likely not comprehend the potential consequences of sharing their data.

In order to unwrap the issue of (over)extensive data tracking, we look specifically at health tracking in the medical domain. Especially in the healthcare domain, the promise of data-driven healthcare has led to an enormous data surge over the last decade. We see two major movements: user-generated health metrics (bottom-up) and medical-industrial “data-fication” of healthcare (top-down). With the onset of the Quantified Self movement and the introduction of consumer health trackers such as Fitbit, Jawbone and the Apple Watch, an era of consumer health tracking has begun. Simultaneously, visions are being published on the healthcare of the future, promising P4 healthcare focused on medicine that is predictive, preventative, personalised and participatory [6]. To achieve these visions, many stakeholders turn to AI and big data as the technical means. Inevitably, health data will become more ubiquitous, detailed, personalised and quantified [1]. However, research has also shown that self-tracking can lead to an unhealthy self-image and mental health problems for some users, not all users have sufficient understanding of the technology to make sense of the data they collect, and use of data trackers also influences relationships between patients and their doctors. These arising issues indicate that user protection requires more than legal and ethical procedures, and that some of the problems that arise due to data collection and processing cannot be solved by laws alone. If we do not somehow acknowledge that data design practice has to play its part in user protection, consequences could be severe, not only for these users themselves, but also for society at a larger scale as it normalizes exploitative behavior with little oversight and regulation.

We argue for active data curation on the design and development side and for human-centred designers to think about which data tracking is actually necessary, and which data tracking is desirable for users. We lay out some of the main issues that exist in data collection processes today and in the recent past. In order to address these issues in the design process, we propose a new breed of designer: the data futures designer, who considers the use of data beyond the initial interaction between users and their data. We posit that this specific role should be laid out in order to protect consumers of health data tracking tools from themselves, the data-driven world around them and from unconscious harm to others.

## 2 ISSUES WITH DATA CURATION FOR DESIGN

While the recent developments in the field of health data tracking sound positive and promising, a societal counter-movement investigates the downsides of continuous tracking for one’s well-being. At present, design is often too comfortably associated with the former, not embracing the risk perspective enough. In this section, we approach the core issues of data curation for design from a societal

perspective, then focus on healthcare and data-enabled design as a form of a design research that targets data literacy and agency for design. Data-enabled design is an ideal setting to showcase how conventional design values and attitudes can lead to problematic data use, unintentionally harming end-users in the long run.

## 2.1 Self-tracking your freedom away

There are numerous studies that have indicated issues with data logging and extensive tracking of habits and bodily measures. These studies have shown that aiming at an always better, fitter, slimmer and healthier body can have severe consequences for the mental health of excessive users of health tracking technology [16, 23].

*2.1.1 Upward or downward spiral.* As there are always aspects of health, vitality and well-being that can be improved, your fitness tracker will never tell you that you are ‘done’, or that you have reached your ultimate healthy body and living pattern—conceptually an unbounded positive feedback loop. For some, constant competition can be motivating and lead to behaviour change, but these are also likely to already be interested in exercising and performing healthy behaviour. For many others, competitive motivation is not effective and quantification of exercise does not work as motivation for everyone [13]. Fitness tracking has led to addiction in the past, in extreme cases even resulting in death, e.g., when a cyclist went downhill so fast to beat a record in a cycling app that he propelled himself to his own death [16]. These obsessive behaviours are not strange when we look at the way in which health tracking apps and devices have been designed. They offer extrinsic rewards for healthy behaviours and push you to push yourself constantly and to always be self-critical.

*2.1.2 Competition and comparison.* Furthermore, health tracking apps often have elements of gamification, competition and performance sharing to keep users and their network engaged [28]. The constant quantification and comparison of one’s life to that of others can have detrimental effect on mental health and lead to compulsive or even addictive behaviours on the one hand, and lack of self-worth and depression on the other hand. Though users do quit these applications for the sake of their mental health through what is often referred to as a ‘detox’, feelings of guilt over not sharing progress or not “being their best self”, i.e., integrating and leveraging metrics in their everyday life successfully, remain [10]. This makes the health tracking addiction extremely complex as the habit of health tracking is still perceived as something that will improve one’s health, while it simultaneously causes aversive side effects to users’ mental health. To add onto that, the negative side-effects of self-quantification are not something that users are generally warned about, as the overall, net-positive effects of the habit are still seen as something positive. This form of utilitarian ethics [15] can fail for the individual: while it is by now generally accepted that packets of cigarettes state that smoking is addictive and deadly, that bottles of alcohol indicate a recommended daily maximum, and that borrowing money costs money, there is no warning or indication of the possible side effects that health tracking might have when you install an app or buy a tracking device. An app store is not a pharmacy, nor should it be.

## 2.2 Self-tracked data in a clinical context

In medical and even clinical settings, there is an increasing interest in collecting contextual and self-tracked data from patients [2, 9, 27]. The contextual and real-time information about patient well-being can for example be used to prevent chronic and complex diseases such as diabetes [6], predict and prevent hospital re-admissions, and reduce costs [1]. Self-monitoring is also being used to keep an eye out during rehabilitation processes, which has allowed patients to take more responsibility over their own health, even increasing medication adherence [8]. Furthermore, contextual data has made it possible to include the partners of patients in lifestyle change programs [9], as well as foster active collaboration between parents and care providers while diagnosing conditions in newborns [27].

*2.2.1 Care relationships.* However, when patients are asked to keep track of their health by either their doctor or through an application, this can change the relationship between patient and care provider. It can put a larger responsibility on the patient and the care provider needs to be more reactive when responding to versatile data that patients bring into the doctor’s office. When patients collect data, it is likely that they will assume that the data they track is also being looked at, which can put extra pressure on their doctors as they feel an obligation to use the data in their treatment [29]. At the same time, patients might feel less worried about potentially alarming health data when they are not getting any return on their data under the assumption that ‘the doctor has looked at it, so it should be fine’.

*2.2.2 Quantity over quality.* Additionally, the quantified data that is easiest to measure might move more to the foreground, and the qualitative data that is harder to capture at a larger scale might be neglected. Similarly, quantitative data is much easier to interpret and agree upon, as we generally can agree that a 10 is better than a 9, while it is much harder to decide whether it is better to be sad or to be angry. The former is generally accepted, while the latter might be different from person to person and from case to case. In many cases, however, the qualitative data such as how the patient experiences symptoms or how they are feeling at specific moments during a day might give much more information on how the patient would be best helped. As people use trackers more and more often to understand their own bodies and behaviours, they might also start relying on the numbers more. When your phone knows exactly what you need to do to be healthy, why would you still listen to your body? The same could count for healthcare providers: imagine that you are on the list for a stomach reduction surgery but your data indicates that you lack motivation to work on improving your lifestyle, which renders the surgery useless from your doctor’s point of view. While the numbers might not be in your favour, the surgery might still give you confidence, or the feeling that you are seen. Although these factors are not as measurable as a reduction in BMI, they could have an equal or even bigger impact on a patient’s quality of life—and set them on a different path in life. It is essential that these emotions and qualitative arguments are not lost when striving for optimisation and quantification.

*2.2.3 Health literacy.* Furthermore, few users of healthcare tracking devices actually have sufficient health literacy to know exactly how to interpret and use their own health data [25]. Health literacy

in self-tracking can be compromised in many different ways, from understanding which tools are appropriate for achieving certain health goals, to knowing how to interpret the collected data, to knowing how to change behaviour to achieve better results [25]. The same counts for the side of the health providers. While they may have an extensive understanding of the condition of their patients, they might not know how to interpret contextual data, or they might not even trust data that has not been gathered with clinically approved tools [29]. Currently, interpreting the data still requires collaboration between care providers and their patients [14]. Furthermore, it could be hard for users of smart products to understand underlying technical aspects of their devices [21], and thus to understand whether the device and the advice it gives are trustworthy.

Overall, these arguments show that merely sharing quantitative data is often not enough and requires some additional explanation in the shape of qualitative data. This explanation is required on both sides: on the side of the user it is important that they are guided in interpreting and understanding their data, but also on the side of the care provider it is important that qualitative and quantitative data are balanced to give an accurate representation of the patient's condition, while keeping the amount of data manageable in its everyday use.

### 2.3 Consequences of self-tracking for others

The undesirable consequences of sharing one's own personal (health) data are relatively straightforward. What might be less straightforward are the secondary and tertiary consequences of sharing your own personal data.

**2.3.1 Unintentional exclusion.** The Dutch government recently announced that it will soon be possible to download a report indicating which vaccinations you have received, to be used as proof for receiving a COVID-19 vaccination. Three out of four Dutch citizens have already indicated to be in favour of showing proof of vaccination to enter a pub<sup>1</sup>. However, for someone who did not get the vaccination for whatever reason (e.g., religion, political standpoint, health risk or lack of access), this development can quickly become a source of discrimination and exclusion. Thankfully, Dutch government has since deemed rewarding people for vaccination undesirable<sup>2</sup>.

**2.3.2 Opting out.** As health tracker use is being promoted in the medical domain, and as more and more people start participating in the movement, it might become much harder for patients to opt-out of sharing this data in the future. Health insurers have already actively started promoting the use of health trackers [18, 23], and the implementation of trackers in regular care programs might make patients feel that medical care is only optimal with tracker use, much like websites are increasingly becoming unusable when you refuse cookies. Similarly, employers around the world have also started handing out activity trackers to employees [17]. As an employee, you are still free to wear the tracker or not, but not using it might be frowned upon, or rewards could be offered to those who do wear it. Without strict regulation, it is only a small step from this development to economic discrimination and marginalization

<sup>1</sup><https://nos.nl/nieuwsuur/artikel/2361109-met-vaccinatiebewijs-toegang-tot-de-kroeg-driekwart-nederlanders-is-voor.html>

<sup>2</sup><https://nos.nl/artikel/2361134-kabinet-ziet-weinig-in-voordelen-voor-gevaccineerden.html>

in the workplace and beyond. Furthermore, an ongoing critical movement in the IoT domain has investigated dark patterns in connected devices, drawing attention to the security of IoT devices, and highlighting the possibility for providers to manipulate IoT for their own benefit [4].

The above points indicate how acceptance of health tracking technology can have impact beyond the individual, through normalisation. Both through social pressure and through changing infrastructure, society changes along with new technology. This does not have to be a bad thing, but the problem is that if it turns out to be bad after all, it is incredibly hard to turn it back when it has been accepted and adopted by most. Everyone that shares their personal health care thus contributes to normalisation of health data tracking.

### 2.4 The designer is complicit

As HCI experts, designers and design researchers, we are increasingly dealing with data in our design processes through methodologies such as data-driven, data-informed, data-aware and data-enabled design [7, 11, 26]. Acknowledging data streams within our design work is important, but it has become clear that being aware of data within our design work alone is not enough and that a new perspective on data design practice is necessary [12].

**2.4.1 Different types of data.** Designers often end up in a conflicted position, trying to understand and satisfy user needs on the one hand, and trying to satisfy the needs and business goals of their employer on the other. Adding data into this mix makes it even more conflicting as data can be used in different ways. Building on data-enabled design, design research works with two types of data: research data and solution data. Research data is data that is collected to perform research through design: to monitor how a design is being used in practice in order to improve the design or to learn something new about user behaviour. Solution data is part of the design: it is required in order for the design to function, e.g., by training an algorithm such that it gives personalised recommendations [26]. As we design novel healthcare applications that work with data, we are complicit in the collection and curation of both types of data, and there might sometimes be overlap or confusion about the purpose of collecting specific data. We want to collect both types of data as we want to learn how to make our design better and understand our user, while at the same time we want to deliver a satisfying user experience. For a user, that confusion is bound to be even bigger, especially when we also start using the data to change the design that they are using along the way. When users are asked to provide a lot of research data at the beginning, they might expect to get a big return in the shape of solution data as well, or even analysis or interpretation of the data. These expectations create a continuous back-and-forth between user and designer which could almost be seen as a negotiation between both parties: who will get the most (data) out of it?

**2.4.2 Reward and risk.** The proposed benefits of using data in this real-time manner—that both sides can use the data—often blur the line between research and solution data: the user can potentially get feedback on the personal data that they share, while the design researchers learn about the context and motivations of the user. The

risk is that the boundary for users to share their data is explicitly lowered by the design researchers by offering the users something in return (i.e., insight into their data and themselves). As users are offered something in return, they might not realise that they are actually allowing the design researchers into some of the most intimate corners of their lives, and that they are thus giving the researchers the possibility to understand motives and behaviours at a far deeper level than they would be comfortable with. When data is collected and processed across individuals, inter-personal patterns might emerge that the individual would never want to share. At the same time, with highly automated data collection comes the risk of misinterpretation and problematic data analysis chains. This is compounded by sharing data beyond the design researcher, perhaps in anonymised form or as a trained model. For example, users might be more willing to share details about their exercise patterns with a designer who is committed to designing something to improve their personal lifestyle than they are willing to share the same information with their doctor to determine a treatment plan. However, what they might not realise is that this doctor will eventually use the data gathering tool that the designer developed. The designer is thus not a separate, neutral entity, but complicit in the data gathering goals of their employer or business client, which might not always be in the user's best interest. Far more than for traditional products and research objectives, we need to be clear and communicate truthfully to our users not only about the purpose of the research we conduct, but also where the results of this research could lead us in the future.

### 3 WHAT DESIGN CAN DO

Design and related disciplines such as data science, engineering, and politics play a key role in defining how data is being used in everyday life. The entanglement of many different disciplines in the design of data technology makes the situation inherently complex. Even more complex is to point out the discipline that is responsible for the consequences of data technology. As practices are intertwined, it is inherently important that these different disciplines each take on part of the responsibility for the well-being of society as well. For design, this includes not only the responsibility to do well by our users, but also to consider the bigger picture and the (peripheral) consequences of wide-spread data collection on different aspects of life and society.

In order to do well by our users and design with their interests and societal interests in mind, we should actively involve users not only in our design process but also in our thought process, considering them as individuals, as groups and families, and as a heterogeneous collective. This includes clear communication about our objectives to study participants but also actively seeking out opinions of potential users, in particular from those opposed to our ideas. Design education should thus address these processes in detail and make designers aware of their ethical responsibility, especially around data, privacy and ways in which data technology could inflict harm. But perhaps we should take it much further than that. Beyond only asking users for their opinion, we could provide them with scenarios to have an opinion about. Being open about data means proactive confrontation with what could be. After all, we are the designers and we have a vision for where we want

data and intelligence technology to go. If not, we should seriously question what we are trying to achieve. Instead of asking users for consent for cookies once our plan has been rolled out, we should ask them before whether our terms are something they would consent to or if they object to (parts of) it, and why.

Besides an ethical perspective, there are also political and economic perspectives to take into account. From a political standpoint, new technology asks for new legislation. Legal and regulatory processes that are already in place are important safeguards that need time to be implemented fully and sometimes need to be tested in courts. We also see that their focus might need to be adjusted. While current legal processes are aimed at risk assessment, research quality control and participant safety, their focus might shift more towards the 'why?' and the 'what for?' of design research—not so much in terms of assessing a data need for a study, but to assess the impact of collected data more broadly. A political question also arises about whether governments should impose restraints on health tracking technology that is being used in public health services.

From an economic perspective, collecting and selling data has slowly become one of the most effective business models in the tech industry. As a result, IoT researchers are increasingly looking into how to design for consumer privacy [20, 22]. The question here is how designers can increase consumer awareness about privacy, and whether consumers will care enough about their data and the consequences of sharing it to pay (more) for the products and services they use. This will be a complex endeavour as by now, so many free products and services have been made available on the consumer market.

In light of these different perspectives, perhaps it is time for a new profession, one which exists at the junction of ethics, design and formal data regulation. Such an expert could go by the name of 'data futures designer'. Their tasks would include informing the public about new innovations and presenting them with scenarios for future use of data and intelligence. Besides collecting public opinion, they would also be tasked with investigating and documenting possible consequences of data collection, data processing and intelligent technology. On top of consequences for users, these would also include the consequences for others who are indirectly affected and society from a broader, futures perspective. Data transparency is key for the data futures designer, covering both transparency about data being collected and the ultimate goal that it is being collected for.

We should think about which data best captures the situation and challenge ourselves to find richness in health data by collecting as little of it as possible. How do we decide which data really matters and reduce this to the bare minimum to decrease the impact on user privacy, security and potentially well-being? We should not shy away from the qualitative data simply because it is difficult to gather or difficult to process. We should, however, shy away from it once it becomes invasive or ethically questionable to collect it. "It's just for this one time," or "It's only for research" can no longer be arguments when we are collecting real-time data in real contexts with real people. When conducting data-enabled design, it is never just for research, and collecting the data will always have an impact on the research subjects.

Society is changing, we are finding new ways to interact with the world around us and navigating through a new data dimension which is often invisible, but always there. As the world around us changes, our task as designers changes too, and so do our responsibilities. We argue that we need to change and boost a new definition of user experience in design, qualities that transcend human-product interaction and redirect designers' attention to what really matters nowadays—with potentially reinforcing connections between traditional user experience design and new aspects that concern the integration of the human individual in the design and the design process (through their data) and their struggle for transparency of agency that is currently being lost.

## 4 CONCLUSION

Data is taking up a prominent position in design practice and designers are finding new ways to embed it into their design processes. Tracking technologies are becoming ubiquitous in everyday life. Future healthcare needs data and intelligence to evolve and to cater to the changing needs of our connected society. However, we see a struggle between sharing and protecting personal data that designers are complicit in and need to respond to. We characterise the problem by the case of data-enabled design and lay out the various issues that health data tracking can bring. We argue that these issues cannot be addressed by legal and ethical processes alone and suggest a new breed of designer: the data futures designer. The data futures designer creatively envisions the future and actively seeks out diverging opinions about it, to point to directions how to address emergent issues.

Future work to further this field includes a quest towards ways in which the data futures design perspective can be embedded in data-enabled design projects. This will be a continuing search for the best way to design with data while simultaneously addressing all the pressing issues around data design. In this light we seek to conduct interviews with experts in the field of medical data and self-tracking, as well as experts in the field of data design, data processing and AI in order to combine them into a data futures design process.

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