

**8th Els Borst  
Lecture**



Centrum voor  
**Ethiek** en  
Gezondheid

**Tamar Sharon**

# **Health disrupted**

On the loss of public  
values in the stride  
towards better  
(digital) health

Centrum voor  
**Ethiek en**  
Gezondheid

**Colophon**

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### About the Els Borst Lecture

The first Els Borst Lecture took place in 2013 on the occasion of the tenth anniversary of the Center for Ethics and Health (*Centrum voor Ethiek en Gezondheid*, CEG). The CEG identifies and informs the Dutch government and general public about new developments at the intersection of ethics, health and policy. The lecture is named after Els Borst, who as a former minister of Health, Welfare and Sport was one of the leading figures behind the foundation of the CEG. During her career, Els Borst-Eilers (1932-2014) has directed extensive attention to various medical ethical topics. She will be remembered for her significant contribution to ethics and healthcare.

Ladies and gentlemen, it is an immense honor and a great challenge for me to give the Els Borst lecture this year. An honor because I feel privileged to join and complement the work that Els Borst and the Centrum voor Ethiek en Gezondheid (CEG) set out to do. A challenge, because, as you may have already noticed, lecturing in Dutch is a skill I still need to master. I will try to do both to my best.



Health today is super-value. Numbers tell this story very clearly. Public expenditure on health, research budgets dedicated to health and medicine, individual spending – on health insurance, fitness, healthy food: these make up large parts of public, scientific and domestic budgets. Of course, the amount of money a society spends on a good is only one means by which a society expresses the worth of that good. Another means is to be found in the performative language of public morality. There is almost no moral polemics of health in Western liberal societies: one does not argue “against” health.<sup>1</sup> Health has been, through a convoluted history of secularization and scientization, almost indistinguishably linked with virtue; and the good life today is a prolonged life lived healthily. Digitalization, with its new affordances for widening the range of health interventions and its greater penetration into the personal life of the individual, is now playing a part in this history as well.

## Health today is 'super-value'.

I do not want to argue against health either. But I do want to problematize health as a super-value within our current moment of digitalization. Not in terms of the substantial financial costs of digital innovation in health and medicine, nor in terms of the unhealthy effects our preoccupation with our health may have, nor in terms of the moral judgment that accompanies unhealthy lifestyles. The recent reports of the CEG on e-health have successfully foregrounded these and other issues. Rather, I would like to ask which other values are at risk of being traded off against health in the context of digitalization. That is, what might we lose when we gain better health facilitated by novel digital technologies? I would like to argue that some values and goods in particular require vigilance and safeguarding in the ongoing digitalization of health. And that in order to do this it is essential that we take a broader, societal perspective to the effects of digitalization in health. I will focus on the values of autonomy, fairness and the common good.

<sup>1</sup> Of course, arguments “against” life do have a place in this public morality today, most strongly in the euthanasia debate. But rather than exceptions to a pro-health morality, these are better understood as reinforcing it; as maintaining that a life not lived healthily is not worth living.

## I. The digital disruption of health: a physical and conceptual geography

But first, let me suggest an overview of how digitalization has transformed, or “disrupted”, the spatial and conceptual landscape of health and medicine in three trends, before zooming in on each of these values.

### 1) The introduction of new types of data

Digital innovation has enabled a significant expansion of the domain of health and medicine; it has extended its traditional physical and conceptual limits. First of all, to include areas and activities that have not traditionally been related to health or that have not traditionally been seen as markers of health and disease. Things like a person’s consumption patterns, their social media activity, their dietary habits, how they sleep, where they live. All of these activities, which have not traditionally been thought of as medical or health-related activities, have become increasingly important for understanding human health and disease today (ESF 2013).

One could see this as new forms of medicalization, of ever more activities and areas of social life receiving medical labels, but I think this is a somewhat different phenomenon. It is not that these activities become pathologized and the subject of treatment, as the medicalization critique upholds, but that they have become relevant to health and medicine in novel ways. And this, because with the possibilities offered by big data today, almost any type of personal data can be used to infer information about an individual’s health when cross-linked with other data (Aicardi et al. 2016) – if these are data generated by wearables and apps, or data from loyalty cards, or data about one’s social media use. I will say more about this later. But this links to the second trend in this expansion.

### 2) New technologies, techniques and expertise

It is only because these activities and areas of social life can be quantified and translated into data, allowing them to be counted, measured and compared, that they become meaningful in the biomedical context. And for this we have all kinds of new digital technologies to thank: smart sensors, monitors, wearables and apps. All of these little gadgets that can capture and quantify information about people’s everyday lives.

Not only new means of capturing and quantifying data are important here. The explosion of data that these means have given rise to has also led to the need for new technologies that can store and manage all these data – such as clouds – and technologies that can make sense of them – like artificial intelligence.

And so, the second trend in this expansion is the inclusion of new kinds of techniques and skills, that lie beyond the expertise of traditional clinicians and researchers.

### 3) New stakeholders

Lastly, digitalization has also enabled the entrance of various new actors into the arena of health and medicine.

On the one hand patients and even healthy citizens are increasingly configured as active participants in both research and care. Some scholars speak of a “participatory turn” (Hood and Auffray 2013), which has been facilitated by new digital technologies. Eric Topol (2015), for example, a cardiologist and leading proponent of digital health, has likened digital health to medicine’s “Gutenberg moment”: much as the printing press took learning out of the hands of a priestly class, he maintains, digital technology gives patients more control over their healthcare and is democratizing medicine.

On the one hand, we have this much more active, involved patient, who, empowered by digital technology, has become an important actor in health and research (I am leaving aside the discussion if this participatory turn has been realized in practice or remains an ideal to strive for). On the other hand, data have become so important in the medical context that experts in data – be this data collection, data management or data analysis – are increasingly becoming important actors in healthcare and biomedical research. And by this, I mean also large tech corporations such as Google, Apple, Microsoft, and Facebook. These are actors who have little expertise in health and medicine, and who have had little interest in health and medicine in the past, but who by virtue of their data expertise are becoming increasingly present in health and medicine.

So, you can see, something quite radical is happening here. Digitalization has facilitated, if not driven, important shifts in *where*

health and medicine is being done – increasingly outside of the clinic; *how* we understand health – increasingly as something that involves all areas of our lives and as something that can be constantly worked on; and *who* has a say in how health and medicine is practiced and researched – increasingly, non-medical experts. This is how I understand the meaning of that term we hear so often these days, “the digital disruption of health”.

What I would like to do now is look at how each of these three trends that I have described (new types of data, new techniques and expertise, new stakeholders), is also putting strain on some core moral values and goods. For each trend I will focus on a different value: new types of data and the value of autonomy; new techniques and expertise and the value of fairness; and new stakeholders and the common good. Each of these values, of course, deserves at least an entire Els Borst lecture on its own. So I will discuss only certain aspects of these values with some paradigmatic examples. My aim is not to be exhaustive in how I address these values, but to show how some of our most fundamental values and goods are at risk of getting traded off in the rush towards better (digital) health.

## II. Autonomy

There are many definitions of autonomy. Here I refer to autonomy in a broad sense, as the capacity for individuals to determine for themselves, within reasonable constraints, the course of their lives. In health and medicine, respect for autonomy is a paramount principle, arguably the most important of bioethical principles (Knoppers and Chadwick 2005), and it has been translated in practice or operationalized through procedures of informed consent and, more recently, privacy. But what happens to informed consent and privacy in the digital disruption of health, specifically in relation to our first trend, the inclusion of ever more aspects of human activity, and ever more types of data, into the realm of health?

### Data-driven personalized medicine

To understand this, let us take a closer look at how this trend took shape. How did medicine and health become so data-driven? One way of understanding this is in terms of the shift toward what some have called “post-genomic” medicine (Richardson and Stevens 2011). In the early days following the sequencing of the human genome, there were

high expectations that knowledge of the human genome would provide deep insights into human health and disease. In this context, personalized or precision medicine largely meant the attempt to tailor drug treatments to the genetic characteristics of individuals. But it soon became clear that most health disorders are the result of a complex interaction of genetic and environmental factors, including a person's upbringing, her lifestyle, her social and natural environment. This led to a broadening out of which factors, activities, and predispositions were to be considered in order to obtain a full picture of an individual's health (Prainsack 2017).

And so, scientists began to incorporate a much wider range of data into their understandings of health and disease, from many different data sources. These began to include not just molecular and clinical data, but also user-generated data drawn from wearables, apps and smartphones on things like people's dietary habits, their sleeping patterns, their exercise routines, as well as data drawn from public archives, from loyalty cards, from credit card purchases and from social media platforms.<sup>2</sup> With new techniques for linking heterogeneous datasets, it started to become possible to infer health-related information from almost any data (Shen, 2015; Weber et al. 2014).

Increased precision, deduced from vast and ever-growing amounts of heterogeneous types of data, is only one dimension of the promises that are tied to personalized medicine. It also aims to be predictive and preventive. And here too, data play a crucial role. Proponents of this type of medicine, for example, envision the creation of personal health maps. Deviations from what an individual's data look like in good health could indicate that there is a health problem on its way, so that an intervention can be made before any symptoms emerge, or before a propensity turns into a reality.

### **The benefits of data-rich, continuous digital health**

The benefits of this data-rich, continuous digital health and care are quite clear. On the one hand, we may expect the proliferation of "virtual medical assistants" or "health coaches", that will help individuals stay

<sup>2</sup> Researchers have shown, for example, that the activity of young users on Facebook can be an indication of the onset of psychosis or other mental health issues (Birnbaum et al., 2019).

healthy by feeding them with personalized advice based on their data. On the other hand, this possibility to collect ever-more health-related data can be a significant boost to medical research. The "Project Baseline", for example, is a large-scale study conducted by Verily, the life sciences branch of Alphabet, and Stanford and Duke University, that aims to draw up a comprehensive baseline dataset of human health, by collecting a wide range of data on some 10,000 healthy volunteers. This includes some conventional types of medical data, like blood samples, genetic data, images from X-rays and heart rate, and data drawn from electronic health records. But it also includes a wide range of non-conventional data, such as samples of tears, saliva, stool and sweat, steps (collected by a watch that participants wear), data from insurance claims, phone calls, tweets, social media activity, and psychological assessments. Launched in 2014, the original idea behind the project was to "map human health", very much the way Google did for urban space.

Proponents of this data-driven, digital health and research see this as an important step in the shift away from reactive medicine to a new era of pro-active, preventive medicine that monitors people continuously and unobtrusively – including in times of good health. But this can come at a cost: the loss of a sense of autonomy and self-determination on the part of patients and citizens, which can be eroded when values and principles like privacy and informed consent are undermined.

### **Contextual privacy and meaningful consent**

Indeed, health-related data that are shared with a consumer app can be sold and shared. Some studies have shown that this is the case with health and fitness apps, that share data with third parties (Zang et al. 2015, Grundy et al. 2019). If users consent to this data sharing, it is not illegal. But the fact that it is not illegal does not mean it is ethical: studies show that 1) users spend little time reading terms of services before agreeing to them, 2) that if they do read them they are often not well understood, and 3) that users often feel resigned to agree to them, even when they are read and properly understood (Turow et al. 2015). Thus, while such data sharing may be legal, it is difficult to speak of meaningful consent here.

Contextual approaches to privacy, like the one developed by the legal philosopher Helen Nissenbaum (2010), are helpful for understanding

what is at stake in this moral ambiguity. Nissenbaum argues that privacy expectations differ depending on the different contexts in which information is being shared. Different contexts, that is, are governed by different norms of privacy: when we share information in a social context, or a medical context, or a work context, we have different expectations of what can and will be done with the information that we share. But digital data, Nissenbaum explains, can easily flow *between* contexts in ways that they did not in the paper age, thus transgressing context-specific norms of privacy.

The shortcomings of consent frameworks and breaches of privacy that characterize a digital economy driven by newfound values for personal data are something scholars and legislators are continuously grappling with. But as data that are generated outside of the traditional spaces of health and medicine become increasingly relevant for medical care and research, these questions should become central for scholars and practitioners of health and medicine as well.

Let us take the case of social media data for health research: In the past few years, Twitter has become a popular source for mining big data. There have been studies using Twitter data for tracking flu outbreaks, tracking cholera, physical activity levels, and mental health (Reece et al. 2017, Sinnenberg et al. 2017). Researchers are excited about using Twitter because it provides a unique big data source which has real-time content and is easily available. Indeed, Twitter data are publicly available. It is not illegal to scrape them and use them for purposes like research. But can we really speak of meaningful consent when these data are used for medical research? Would Twitter users tweeting about their struggles with depression and attention deficit disorder really be OK with this data being used in research without their knowledge? Is this not a transgression of privacy norms?

Certainly, it would not be unreasonable to argue that these data are being repurposed for the public good – for medical research that these individual tweeters will benefit from in the future. And indeed, the GDPR has provisions in place precisely for this type of data repurposing. But is it not this type of non-consensual participation in research that the development of bioethical principles originally sought to address? It is interesting, I think, that since the Snowden revelations, we have, as a society, become very wary of governments

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collecting our personal data in the name of national security, but much less so about the scientific community collecting personal data for health.<sup>3</sup> Health is a super-value – even more so than security. But we must ask how people’s sense of autonomy and self-determination may be undermined when privacy and informed consent are sacrificed for health in this way. To do this, I think scholars in the health and medical domain can learn from philosophers and social theorists who have been working on the effects of digital technologies on privacy, autonomy and self-determination in recent decades.

### Privacy and freedom from surveillance as necessary for autonomy

For these theorists, privacy is not only valuable because personal data in the wrong hands can be used in ways that negatively impact a person’s life chances, for example a health insurer who raises your premium when they find out how much of your weekly supermarket budget is spent on potato chips, or a future employer who decides against hiring you in light of your tweets about what how you cope with your ADD – though these are of course serious risks. Privacy is also, as Julie Cohen (2013) writes, the “breathing room we need to engage in the process of self-development”. It is an integral component of our sense of autonomy; a buffer, that gives us the space to develop an identity that is somewhat separate from the judgment of others and from the values of our society and culture. It is crucial for us to manage these pressures, and to form an identity that is not dictated solely by social conditions – to become autonomous agents of our lives.

Social and political theorists have been studying the disciplining and chilling effects of surveillance technologies for decades. The awareness that one is being watched they argue, changes one’s behavior. This gaze is internalized and comes to shape what we do, how we think and ultimately who we are. Surveillance curtails our autonomy. Most notably, Michel Foucault (1977), drawing on Jeremy Bentham’s architecture of the Panopticon, explored how surveillance in prisons, hospitals, schools and other institutions constitutes docile subjects, conform to the needs and norms of modern society. Little did Foucault

know how antiquated his image of a centralized prison panopticon would become within a few decades. Today, general surveillance and health surveillance in particular, enabled by self-tracking devices, the internet of things and social media, is *decentralized*: it is not just happening “from above”, but also laterally – by our peers, as we share information with them, and from within – as we monitor ourselves, in accordance with internalized norms of idealized health. It is also *ubiquitous*: it is not confined to the walls of the prison or the school or the hospital, but happens across spheres of social life and all of the time, as we have seen with the ongoing inclusion of what were previously considered non-health related activities and data into the domain of health. The breathing room that privacy or freedom from surveillance constitutes is essential for becoming a complete, self-governing and autonomous person. But it is currently under threat by the constant data collection, profiling, nudging and coaching that we are undergoing – and this is a high price to pay, even if this results in greater health, more personalized healthcare and better medical research.

### III. Fairness

If we return to my illustration, the second trend in the digital disruption of health concerns the new techniques and expertise that have become necessary not just for generating the vast amounts of data that are deemed essential for health and medicine today, but also for organizing, managing and making sense of them. This is not something that humans are very skilled at, but that artificial intelligence (AI), is proving to be very useful for.

**"The breathing room that privacy or freedom from surveillance constitutes is essential for becoming a complete, self-governing and autonomous person."**

AI is particularly good at recognizing patterns in large datasets; at sifting through large quantities of data and identifying recurrent patterns. Algorithms can then be

developed that, based on these patterns, can predict the probability or risk that something will happen – a crime, a climate event, a disease, the success of a medical treatment. In the past few years, we have seen more and more successful uses of AI in the medical field: for detecting the risk of eye-disease, the risk of breast cancer, cardiovascular disease, melanoma, even mental health conditions – for example using speech recognition to predict psychotic episodes or depression (Jiang et al. 2017, Wise 2018, Esteva et al. 2019).

<sup>3</sup> Though, this has recently been challenged in the debates around the development of contact-tracing apps in the COVID-19 pandemic, where privacy and civil liberties have typically been promoted as fundamental values that should not be easily traded off for better public health.

But AI systems, while very good at detecting patterns, are also vulnerable to bias. And these biases can lead to differentiating between groups and individuals in ways that are unfair and discriminatory. This is something we have begun to witness in a number of areas where algorithmic decision-making is being deployed, from recidivism prediction, to welfare fraud detection, to hiring decisions. But more recently also in health and medicine.

### Biased AI

Bias creeps into AI in a number of ways, one of the most common being that AI needs lots of data to be trained to identify patterns. But the datasets that are used to train AI may be skewed.

First of all, these datasets may be unrepresentative of reality. For example, if an algorithm is fed more photos of light-skinned faces than dark-skinned faces, the resulting face recognition system would inevitably be worse at recognizing darker-skinned faces. This is what happened when Google Photos recently mistakenly tagged black people as gorillas. But this also has important consequences for the development of medical apps. AI is currently being used to help predict skin diseases like melanoma. Apps are being developed that would allow people to take photos of skin lesions and determine a risk of melanoma. But the largest, public-access archives of pigmented lesions which are often used for training such algorithms include a majority of images of lesions from light-skinned populations (Adamson and Smith 2018). In practice, this means that such apps will be much better at identifying melanoma for light-skinned people, which, if these apps become widespread, may lead to dark-skinned people going undiagnosed or to delays in diagnosis.

Another way that datasets used for training AI may be skewed is that they are actually very representative – so representative that they include prejudices that exist in reality. This is what happened when Amazon discovered that its internal recruiting tool was dismissing female candidates because it was trained on historical hiring decisions that favored men over women, and so it learned to do the same. In the past year, we've begun seeing examples of these kinds of biases in healthcare as well.

A striking example made headlines last year, when it was revealed

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that an algorithm used in hospitals across the US for identifying which patients should get additional attention for complex health needs, such as home visits, had been systematically discriminating against black patients, by giving black patients who were just as sick as white patients a lower risk score (Obermeyer et al. 2019). This was a result of how the algorithm had been developed. It assessed risk using the predicted cost of care; it equated higher healthcare spending with worse health. This certainly seems like a reasonable assumption: the sicker you are the more you cost the system. But it turns out that historically, as a result of systemic racism in the American healthcare system, less has been commonly spent on black patients than white patients.<sup>4</sup> Health costs may seem like a benign label, which has nothing to do with racism, but here we see that it is an inaccurate and racially biased proxy for healthcare needs, which, when used in practice to identify risk, can increase existing social inequalities and have life-threatening results. A growing number of such stories are being revealed. Just recently, a new study has found that algorithms used for medical decisions from cardiology to obstetrics, and who gets sent for a C-section, are similarly tainted by implicit racial bias (Begley 2020).

### The opacity of predictive analytics

Population bias is a well-known problem in medicine – white adult men have been strongly over-represented in medical datasets well before the advent of AI in healthcare, just as racism and other forms of prejudice pre-date the use of predictive analytics in society. But algorithms, because the data they use are comprised of past human decisions, and because humans shape their design, can reproduce discrimination and unfair differentiation without us being aware of this; without there being any explicit racist or other discriminatory intentions in place (Benjamin 2019). This problem is exacerbated by the notorious opacity of algorithms. On the one hand, we may be less sensitive to the presence of biases because they hide behind a veneer of technical neutrality. Indeed, one of the promises of algorithms is that they will overcome human bias: as technologies they are not vulnerable to

<sup>4</sup> For various reasons, including the fact that, compared to white populations, black populations tend to get fewer check-ups and tests, have less access to care, have less insurance coverage and have previous experiences of racism within the healthcare system that prevent from seeking out care.

the prejudices, impartialities and fickle decision-making processes of individual humans, be these judges, mortgage providers or doctors. On the other hand, these biases are also very difficult to discover. With the amount of new categories of data that are being taken into account for making health-related predictions, as discussed earlier, it is becoming very difficult for both clinicians and patients to understand what considerations go into a decision.

In the US, again, there is a booming market for companies that offer fine-grained risk analyses to hospitals on patients and their likelihood of benefiting from specific interventions. “Jvion” is a company that uses 4,000 person-specific data points, including an individual’s car ownership, public transportation use, purchasing habits, ability to pay back loans, and lifestyle data (like alcohol consumption and exercise), in order to predict things like hospital readmissions, post-operative complications and for whom an intervention is likely to lead to improved outcome. Other companies use such data analytics to categorize patients as “highly stressed”, “motivated”, “diabetes-aware” or “non-compliant”. As the medical sociologist Linda Hogle (2019), from whom I borrow these examples, has shown in some frightening research, these classifications could then be used against patients in ways they are unaware of. For example, a patient who is stratified as “high risk” or “non-compliant” may have that label inscribed in her medical record, and this may influence if or which medical intervention she is provided.

The use of these technologies will have different effects in different healthcare systems, like the American one or ours, where access to healthcare is guaranteed by law. In this sense, it is not a coincidence that these examples are coming to us from the US. We can only stand in horror at the idea of a hospital denying a patient care because a predictive algorithm calculated that she will likely not benefit from an intervention because she has a history of non-compliance with taking medication, failing to pay back bank loans or rarely going to the gym. But we must remain very vigilant. In most of these examples, these predictive algorithms have been optimized to lower healthcare costs – rather than to increase access to care. To some extent, this is the result of the move towards “value-based care” in the US, in which hospitals are reimbursed by insurers based on patient outcomes, and in that sense, it is not surprising these examples come from America. But the

attempt to know which patients are likely to benefit from a treatment – for which these predictive analytics are used – is a cornerstone of personalized medicine, which Europe and the Netherlands have *also* embraced as the future of medicine and health. And here too, pressure to reduce healthcare costs is constant. If access based on need, rather than race, income, lifestyle and even likelihood to benefit, is to remain the underlying principle for fair healthcare systems in our societies, we will also need to make sure the algorithmic tools we implement in these systems are built to serve this principle.

#### IV. The common good

Now I would like to turn to the last trend in my mapping of the digital disruption of health and medicine: the entrance of new actors and stakeholders, and how this may affect the common good. I focus on one group of actors, tech corporations.

#### The Googlization of health

Digitalization and datafication are contributing to a reframing of health and medicine. These are increasingly being thought of as problems of data flows and data management. And when this happens, experts in data management inevitably also become experts in medical research. And so, in the past few years, every major data corporation, from Alphabet, to Apple, to Amazon, IBM, Microsoft, even Facebook, has moved decisively into health and medicine. These are companies that for the most part have had little interest in health in the past, but that by virtue of their data expertise are becoming important facilitators of digital health and research, either by collaborating with public health and research institutions, or by carrying out research and providing health services themselves. I call this the “Googlization of health” (Sharon 2016, 2018).

I’ve already indicated a few examples of this type of research, for instance Alphabet Verily’s “Project Baseline” in collaboration with Duke and Stanford University. A similar collaboration with Verily is also taking place here in the Netherlands, at Radboud University Medical Center. The “Personalized Parkinson Project” is collecting a vast array of multidimensional data on early onset Parkinson patients in order to gain insights into the disease. Verily has developed a wearable that collects data on patients throughout the day.

A few years ago, Apple launched the “ResearchKit” software, which allows medical researchers to carry out medical studies using the iPhone as a device for collecting personal health data. There are more than 20 of these “ResearchKit” studies currently running, with more than 100,000 participants.

23andMe is a direct-to-consumer genetic testing company backed by Google, that started out selling individual genetic profiling tests in 2007, but very quickly began doing research with the genomic and phenotypic data that customers would agree to give back to the company. They’ve published over 40 scientific studies using this database.

And this is all happening very quickly. I’ve been studying these companies’ inroads into health for the past six years or so, and it is difficult to keep up. This past year Verily has made a clear move from research to healthcare, with a new opioid addiction clinic in Ohio. Amazon has entered into a partnership with the National Health Service (NHS) in the UK to make its Alexa voice assistant a first point of contact for getting NHS advice. Most recently, with the outbreak of the COVID-19 pandemic, these companies were quick to contribute to pandemic response measures by developing COVID specific data collection tools for pandemic surveillance, developing screening and testing facilities, and dedicating significant funds for COVID related research. Most notably, Apple and Google developed the API on which virtually all digital contact tracing apps currently run – including the Dutch Corona Melder – effectively determining which apps can exist and how governments can use them (Sharon 2020).

This Googlization of health, like the other digital health developments I have discussed, may significantly advance research and care, and improve the health of individuals and populations. Take the Apple ResearchKit. This allows researchers to go beyond some of the limitations of traditional studies:

- by recruiting very large numbers of participants (basically anyone who has an iPhone can participate in a study, though these are currently limited mostly to the US)
- by allowing them to monitor patients in real time (our phones are virtually always on us)
- and by allowing them to capture many different types of data that iPhones can collect.

But the Googlization of health also raises new challenges. Privacy is the one that immediately comes to mind. And we've already had a taste of this. Three years ago, a partnership between DeepMind, an AI company owned by Google, and three NHS hospitals in the UK allowed DeepMind to access personal medical data on some 1.6 million patients without their explicit consent. This past year it was revealed that Google, in line with a partnership with Ascension, a company that runs hundreds of hospitals in the US, had access to medical data on 50 million individuals – also without any explicit consent.

### Beyond privacy: the common good

But privacy is far from being the only issue at stake in this phenomenon. It is really only the tip of the iceberg. We need to take a broader view, and examine the societal impacts of the shifts in power in the relationships between corporations, public health institutions and patients and citizens that are taking place here. We need to examine the effects of the Googlization of health on the common good – not just on health and research.

**"We need to examine the effects of the Googlization of health on the common good – not just on health and research."**

*We should be asking questions such as:*

- Will these companies become the new gatekeepers of valuable health datasets – datasets that will become indispensable for health research in the future? The database that 23andMe has amassed in the past decade is currently one of the largest databases of human DNA in the world. It is proprietary, and 23andMe can and does charge researchers to access to it.
- We need to ask who will be running the show in these collaborations, when these companies bring with them a novel and essential type of expertise – expertise in data management and infrastructure development. Will this crowd out traditional forms of expertise, as well as norms and values that have been essential to the health and medical sector?
- We need to ask what role these companies will begin to play in asking research questions and in setting research and healthcare agendas. Philosophers and sociologists of science know very well that *who*

asks questions in science determines *which* questions get asked. A case in point: Sergey Brin, previously the president of Google, has openly spoken about the hereditary form of Parkinson's disease that runs in his family as a driver for Google's investment in Parkinson's research.

### Digitalization as sphere transgression

Moreover, the Googlization of health is only one dimension of a larger "Googlization" of society (Vaidhyanathan 2011, van Dijck et al. 2019). Indeed, in every sector that becomes digitalized, we are witnessing a growing involvement of these companies – beginning with communication and moving to transportation, health, education, urban planning, even space exploration. One of the most important questions we need to address, then, is the impact of the amassment and concentration of power by these companies *across* these sectors.

In his seminal book, *Spheres of Justice* (1983), the political philosopher Michael Walzer elaborates a theory of justice based on the autonomy of spheres of social life. A just society, Walzer maintains, is one where advantage in one sphere – be this education, the market, politics, friendship or welfare – cannot be converted into advantage in another. Wealth, for example, an advantage procured in the market sphere, should not translate into better education, better medical care or political influence (even though it often does). Such illegitimate conversions, or transgressions between spheres, can lead to both a loss of meaning of those goods which succumb to the distributive logic of the wrong sphere, as well as to the dominance of some members of society by others. Walzer did not identify a sphere of digital goods in his sphere architecture. But I believe it makes sense to understand the Googlization of health in terms of a sphere transgression. From this perspective, the technical expertise developed by these companies has conferred them a legitimate advantage in the sphere of digital goods, which is currently being converted into an illegitimate advantage in the sphere of health and medicine, and other spheres of social life. The risks this poses range from new dependencies on corporate actors for the delivery of essential, public goods, like health and medicine, to the reshaping of sectors to align with the values and interests of non-specialist, private stakeholders. Across spheres, this could amount to what Walzer calls "tyranny". The fact that people may be healthier in such a tyranny makes it no less tyrannical.

## Conclusion

Is it fair to expect medical researchers and healthcare providers collaborating with these corporations to worry about the sphere transgressions at stake in the digitalization of health? Or about what happens to people's sense of autonomy and self-determination under self-monitoring and surveillance? Or the racist and other biases that creep into algorithms? Addressing these concerns is not what medical researchers and healthcare providers have been trained to do. Nor have these questions been the classic focus of bioethical inquiry, which has directed its attention to bedside issues, at the expense of more fundamental issues such as power, justice and equality (Churchill et al. 2020, Reardon 2020). But as health and medicine are disrupted and broadened out by digitalization, so must the critical awareness of medical practitioners and researchers and bioethicists.

At the same time, this is not their responsibility solely, but one that should be cared for in a concerted, societal effort. An awareness that health technologies, like all technologies, can have effects that go beyond individual harms, must be cultivated. Like cars that have effects also on people who do not drive – by polluting the air we all breathe, by reshaping our countryside and cities into a web of roads – health and medical technologies should not be assessed only in terms of their benefits to individual or even population health. We must also be wary of how they affect people's sense of autonomy and self-determination, how they may undermine fairness and exacerbate existing social inequalities, and how they can erode democratic control over a common good – our health data.

For this, more significant and extensive collaboration across the many disciplines which are today concerned with the societal effects of digitalization is necessary – including medicine and bioethics, political and social philosophy, computer and social sciences, critical data studies and law. And their insights must be translated into policy. New frameworks, for clinical practice, for technology design, for regulation and governance of digital health are needed. For example, as health surveillance becomes increasingly ubiquitous, we may need to establish a right to be free from surveillance, and the right not to be profiled, coached or nudged. The Rathenau Institute is doing some work in this direction, and we can think of adopting this to the health and medical domain (van Est en Gerritsen 2017). Medical researchers will

need to learn that just because data are available does not mean it is ethical to make use of them for research. Further, as we begin to better understand how AI can incorporate existing biases and undermine fairness, computer scientists developing these technologies need to work together with medical professionals and ethicists to understand which conceptions of fairness are meaningful in the health sector, and with social scientists, to better understand the real-life impacts of these systems once they are set free in society. Finally, as tech firms begin collaborating with public research institutions, we need new governance frameworks that can establish checks and balances with regard to responsibilities and control, and that can lay down the conditions by which we – as *citizens*, not just as patients – can reap the benefits from these collaborations without sleep walking into a tyranny in which every sphere of social life is shaped and governed by big tech. These frameworks, this awareness, these novel coalitions and collaborations will be needed, lest we trade off core moral values and goods for better (digital) health.

**"An awareness that health technologies, like all technologies, can have effects that go beyond individual harms, must be cultivated."**

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