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Abstract

This article investigates the claims and complexities involved in the platform-based economics of health and fitness apps. We examine a double-edged logic inscribed in these platforms, promising to offer personal solutions to medical problems while also contributing to the public good. On the one hand, online platforms serve as personalized data-driven services to their customers. On the other hand, they allegedly serve public interests, such as medical research or health education. In doing so, many apps employ a diffuse discourse, hinging on terms like "sharing," "open," and "reuse" when they talk about data extraction and distribution. The analytical approach we adopt in this article is situated at the nexus of science and technology studies, political economy, and the sociology of health and illness. The analysis concentrates on two aspects: datafication (the use and reuse of data) and commodification (a platform's deployment of governance and business models). We apply these analytical categories to three specific platforms: 23andMe, PatientsLikeMe, and Parkinson mPower. The last section will connect these individual examples to the wider implications of health apps' data flows, governance policies, and business models. Regulatory bodies commonly focus on the (medical) safety and security of apps, but pay scarce attention to health apps' techno-economic governance. Who owns user-generated health data and who gets to benefit? We argue that it is important to reflect on the societal implications of health data markets. Governments have the duty to provide conceptual clarity in the grand narrative of transforming health care and health research.

Keywords

mHealth, health apps, social media, datafication, digital platforms, open data

Introduction

Over the past five years, a burgeoning field of online health platforms has emerged; in 2014, there were over 100,000 health apps listed in the Google Play Store and Apple's App Store, and the number of fitness apps has since been growing explosively (Burke, 2013; Lupton, 2014a). So-called mobile health (mHealth) apps have drawn much attention from researchers who are interested in their applicability in clinical or research practices; as such, they are understandably concerned about these apps' claims with regard to medical truthfulness, validity, or accuracy. Much less attention has been paid to mHealth platforms as techno-economic constructions in the context of a global online infrastructure. As media scholars, we are interested in establishing a framework for understanding the claims and complexities involved in the online dynamics in which health platforms are entangled. Such approach requires a constructivist view that examines online dynamics at the intersection of technology and society.

We will concentrate on a double-edged logic inscribed in these platforms, promising to offer *personal* solutions to medical problems while also contributing to the *public good*. On the one hand, online platforms serve as *personalized* data-driven services to their customers. On the other hand, they allegedly serve *public interests,* such as medical research or health education. In doing so, many apps employ a diffuse discourse,

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hinging on terms like "sharing," "open," and "reuse" when they talk about data extraction and distribution (Fiore-Gartland and Neff, 2015). Equally confusing is how platforms deploy terms like "communities" and "partners" when they refer to customers or (corporate) associates in data handling. So how do privatized prerogatives tally with claims that they serve the public good?

To set up an analytical framework, we will first define what we mean by "platforms" as a technical, economic, and sociocultural framework for managing online traffic. Second, we will argue how their dynamics are inscribed not just in individual platforms but also more generally in the ecosystem of connective media (Van Dijck, 2013). The analysis concentrates on two aspects: datafication (the use and reuse of data), and commodification (a platform's deployment of governance and business models). We apply these analytical categories to three specific platforms: 23andMe, PatientsLikeMe (PLM), and Parkinson mPower (PmP). Each of these platforms employs the logic of private gain versus public good, but their claims are different as they operate from different *organizational premises*.

The last section will connect these individual examples to the wider implications of health apps' data flows, governance policies, and business models. Regulatory bodies commonly focus on the (medical) safety and security of apps, but pay scarce attention to health apps' techno-economic governance. Who owns user-generated health data and who gets to benefit? We argue that it is important to reflect on the societal implications of health data markets. Governments have the duty to provide conceptual clarity instead of adding to confusing propositions in the grand narrative of transforming health care and health research.

The promises and premises of online health platforms

Over the past 10 years, researchers, patients, and doctors have discovered major social network sites (Twitter, Facebook, Google+) as platforms for health communication and research (Fox, 2011; King et al., 2013; Santillana et al., 2014). Recently, there has been a spectacular growth in the development of specific health and fitness apps: online services that promise to advance the health, fitness, and physical or mental well-being of users. mHealth platforms actively distribute apps and mobile devices that solicit all kinds of health data—clinical data, performance data, experiential data—that deliver personal information to patients, doctors, and researchers (Adibi, 2015). Data generated from individuals—the healthy and the sick, the fit and the frail—is automatically aggregated, analyzed, and processed in order to inform a variety of services.

We are using the term "platform" here to refer to online sites that facilitate and organize data streams, economic interactions, and social exchanges between users. Platforms, in this sense, are neither mere technical constructs, nor does the term refer to all things digital (Bogost and Montfort, 2009). Platforms are simultaneously technological, economic, *and* sociocultural configurations (Gillespie, 2010). Their owners and a wide variety of other societal actors assemble them; these actors include users, but also companies that rely on online infrastructures and data. Platforms are made available through websites and apps.[1]

All online platforms are mutually connected through a shared technological infrastructure, which is fueled by *data*, directed by *algorithms*, and structured by *governance protocols* and *business models*. This ecosystem of connective platforms, which is crucial for each app's widespread distribution and global reach, is not a level playing field: some major platform operators in this ecosystem (Google, Amazon, Facebook, Apple, and Microsoft) are more powerful than others. When we speak of a platform infrastructure for online services, we refer to the complex interaction between users, practices, technologies, and business models—a combination of human and nonhuman actors. Health platforms and the apps they produce form a rapidly growing field within this ecosystem; other sectors, for instance the transportation or hospitality sectors, are confronting a similar development, in which many platforms compete for users and attention, with Uber and Airbnb in the lead.

Online health platforms constitute a wide-ranging category (Coiera, 2013; Lupton and Jutel, 2015). On one end of the spectrum, there are *fitness* apps that are mostly used for tracking a person's physical performance and condition; examples include Fitbit, Strava, and Runkeeper. On the other end, we identify *medical* apps that are meant for (self-) diagnosis of symptoms or conditions (e.g., 23andMe, Doctor Diagnose, WebMD, Virtual Doctor). In between those two ends are various categories. *Patient experience exchange* platforms serve simultaneously as patients' social networks and data exchanges; examples include PLM, CureTogether, Health Unlocked, and Alliance Health (Lupton, 2014b). *Health monitoring* platforms help individuals monitor vital signs or symptoms of disease; examples include apps for weight loss (Lose It), sexual activity (SexPositive), sleep cycles (Sleep Diary), pregnancy (What to Expect), glucose levels for diabetics (Glucosio, Glucose Buddy), or symptoms of Parkinson disease (PmP). This typology is neither exclusive nor exhaustive, but it serves to illustrate the broad range of platforms that are currently being developed.

The growth of health apps is being driven by a powerful *set of arguments* that can be regarded as a "discursive

regime'' informing a commons sense logic (Kitchin,2014: 113). Health apps often promise to offer *personal* solutions to medical and lifestyle challenges—a healthier lifestyle, a quick diagnosis, a proper monitoring device, a speedy update, a form of peer support, etc.—while also contributing to the *public good*—for instance, improving public health, educating a general audience, or contributing to medical research. Articulating this double-edged logic, it often remains unclear *whom* gets served by data-based platforms: individuals, communities, private industries, researchers, or society as such. The dual claims are often articulated in a diffuse rhetoric, where terms such as "sharing," "open," "transparency," and "reuse" seem to be ambiguous, thus propelling different agendas. As Rob Kitchin (2014) argues, the discursive regime of Big Data is "to offer a radically new way of understanding and managing all aspects of human life" (p. 114). In this article, we will examine how the "big promise" of public good and private gain is taking shape as part of a wider struggle over how a data-driven platform society should be organized.

Digital platforms are also driven by a powerful *set of mechanisms*, two of which we would like to highlight here: datafication and commodification.[2] *Datafication* is the most fundamental underpinning principle of health platforms: it means that every aspect of one's physical or mental well-being is translated into data—vital signs, objective measurements, subjective experiences, medicine intake, personal information, test results, etc.—and subsequently can be transformed into new kinds of value (Mayer-Schoenberger and Cukier, 2013). Data can be private and personal (e.g., recorded symptoms, experiences) or they can be public and collective (e.g., clinical research data, health demographics, statistics); data can be user-generated and reported automatically through devices, such as electronic heartbeat apps, or users themselves can contribute data consciously, for instance through deploying pedometers. The question at stake here is what kinds of (user) data do platforms collect, how do they collect them, and how do they process and reuse those data?

Commodification refers to the way in which datafied information is transformed into (monetary) value. In most cases, this means we will look at business models of online platforms, which act as strategic mediators in the process of turning personal data into valuable goods. Some platforms sell health information products to customers sometimes in combination with advertisements; other apps are free to users in exchange for their personal data, which may be shared with paying industrial partners or copatients. Looking at the governance and ownership of health platforms, we have to conclude that mHealth platforms are overwhelmingly for profit. Virtually all platforms collaborate with partners, mostly high-tech firms and pharmaceutical or medical equipment companies; some also partner with universities, government services, or a combination thereof, mixing for profit and nonprofit. A minority of health platforms is operated via government or nonprofit organizations, intent on pursuing public values and yielding public goods. The question here is which business model is used for what purposes, who owns and operates the platform, and who gets to benefit from its products?

In the sections below, we will examine the ambiguous claims by analyzing three digital health platforms: 23andMe, PLM, and PmP. 23andMe was launched as a *medical app* that is marketed for profit. PLM is a *patient experience exchange* platform that is "not-just-for-profit." And PmP is a *health monitoring* app, which is nonprofit and intent on providing data to researchers. In the next three sections, we will analyze how the rationality of personal solutions and public good becomes manifest through the lens of its underpinning mechanisms—datafication and commodification. To what extent does it matter that the three online services operate on the basis of different economic and organizational premises? Is it possible, in this ecosystem of online platforms, to develop noncommercial platforms based on key public values? To address these questions and find information about each site's operation and intention, we have examined their explicit platform policies as well as interviews with owners or operators in general information sources and trade journals.

23andMe

The platform 23andMe started as a personal genome service in 2006, offering customers worldwide a record of their DNA profile. Data is collected both offline and online. The offline method is for customers to send in a bit of saliva through a special kit; after paying a fee, they receive a complete overview of their genetic makeup, including a risk report stating their personal chances for genetic disease and conditions. Besides the commercial offline transaction of genetic data, the company approaches customers online to submit phenotype data through "fun" questionnaires that pop up on your screen. The additional data allegedly help to compile an even more accurate profile of one's personal state of health. On the website we can read:

> Part of 23andMe's mission is to give people access to their DNA, and this is just another way to put that information at people's fingertips. Over time we hope to improve the app as we get more feedback from customers. Along with giving customers access to their DNA, 23andMe wants to educate people about the science around genetics. (23andMe, 2015)

Data is collected from customers on two different grounds: the promise of receiving a validated genetic profile as well as the promise of donating their genotype and phenotype data to help genetic research in general (Harris et al., 2013).

The first promise turned out to be a dubious proposition. In 2013, the American Food and Drugs Administration (FDA) banned the test kits because they were giving customers inaccurate information based on misleading predictive algorithms. As a result of this setback, the platform dropped the medical component and shifted its focus from diagnosis to ancestry identification. 23andMe currently features a "genome compass app" in the Google Play store and urges its customers to find out "what your DNA says about you and your family." However, the platform's website still hints at its underlying aim to deliver personalized predictive medicine. In 2014, after slightly changing its rhetoric, the company sought approval from the British Health Authority (MHRA) who then argued that the kit was no longer marketed as a diagnostic test but as an "information product." As a result, 23andMe can ship the test kit to customers residing in the UK and 50 other countries all over the world (23andMe Customer Care, 2015). Since there is no global guidance for standards reviewing a product's claims, each company can look for a regional or national market whose regulatory policies allow it to be marketed as a medical app (Yetisen et al., 2014: 838).

The second promise that users' genetic information will be used towards the public interest is part of the same claim. As Harris et al. (2013: 250) point out, 23andMe's rhetoric slips smoothly from notions of personalized health care to a celebration of "consumers" research participation as a form of "gift exchange." According to the website, the gift of saliva enables medical researchers to find genetic patterns and treatments for a number of diseases. 23andMe also appeals to users' need for solidarity in pursuing health-related goals. The site instills in its customers the noble goal of giving away their DNA—a sense of collectivity that emerges independent from the idea of forming a community. According to the site, donating personal health details allows researchers, in the long run, to detect patterns of genetic aberrations and develop algorithms to predict and prevent disease at the individual level. Even after the FDA's mandated discontinuation of 23andMe's medical diagnostic prerogatives, the grander research-oriented goal still echoes on the website now promoting its "health and ancestry" app:

> We are building a powerful, diverse, and ever-growing *resource for research* that combines advances in genetic analysis with the power of the Internet.... So when you send in that DNA sample, you're not only learning about yourself, you're *joining a community of motivated individuals* who can *collectively impact research* and basic human understanding. (23andMe Core Values, 2015, emphases added)

However, the altruistic motives for participating in genomic sequencing efforts, solicited by appealing to the customer's inclination to "collectively impact research" are misleading. "Collective community" implies there is a kind of active patient group involved in this effort, which sharply contrasts 23andMe's proprietary claims on these data. In May 2012, the company was granted a patent for "polymorphisms associated with Parkinson's disease," sparking a controversy among its clients who felt misled (Sterckx et al., 2013: 382). To what extent were patients "tricked" into donating their data to a company that subsequently monetized their data gifts? The same can be said of another acquisition. In 2012, 23andMe acquired CureTogether—a patient experience exchange site much like PLM—incorporating the data from communities reporting on some 600 medical conditions. While 23andMe appears to be part of a *gift* exchange where users participate in research, they are in fact part of a *data* exchange where individual data is turned into economic value: data is gathered not with the prime intention to make them public goods but to privatize their yields (Harris et al., 2013).

This brings us to 23andMe's business model, which clearly hinges on two principles. First, it sells "genetic profile service kits" to customers, whom are charged between $99 and $199. Second, by sending their saliva samples, customers sign away the right to sell their information to third parties; in other words, 23andMe has a right to sell and repurpose its users' data for financial gain (Sterckx et al., 2013). When the FDA's ban on the company's medical claims substantially hurt its revenue stream based on the first model, 23andMe shifted its marketing strategy to commoditize its lucrative by-product: raw genetic data which can be monetized by giving drug companies access to its resources. In January 2015, pharmaceutical company Genentech paid $60 million to 23andMe for accessing its 3000 DNA profiles of patients with Parkinson's disease (Regalado, 2015).

23andMe's multisided business model is fully attuned to the larger ecosystem of connective platforms, by distributing its apps through the Google Play Store. The strategy to find the most profitable revenue model for a single health app very much depends on its integration in the app ecosystem of platforms (Ragaglia and Roma, 2014). The choice for Google is not coincidental; Google was one of 23andMe's first financial investors. Moreover, the platform's owner, Anne Wojcicki, is also the (ex-)wife of

Sergey Brin, Google's cofounder and executive. Major pharmaceutical companies and medical product developers have since invested substantially in 23andMe. Investors envision a future where combinations of health databases are the prime resources for patentable drugs and treatments. In May 2015, 23andMe announced it would go into drug discovery and development. The business model thus evolved from consumer testing service to drug developer, based on the premise of turning user-generated individual data into corporately owned private goods. Hence, the appeal to users to donate their personal data to researchers for the benefit of the "public good" is a rather dubious claim, as the donation goes straight into a proprietary platform that monetizes its data resources for corporate (rather than public) gain.

PLM

The double ambition to serve personalized health schemes while enhancing the public good also surfaces in patient experience exchange site PLM (PatientsLikeMe.com, 2015). PLM encourages patients to keep track of their personal conditions by uploading facts about their symptoms, vital signs, and medicine intake, and also to report more subjective information, such as experienced pain levels, mood fluctuation, emotional impact, or side effects. Through the website, users can keep detailed reports, replete with graphs and charts, and take them to doctors' visits. PLM is not just used for compiling personalized health reports, but also for exchanging information and advice, and for soliciting support from fellow sufferers. The site primarily focuses on creating so-called communities of patients: individuals suffering from the same disease can make sense of their data by comparing symptoms, course of their condition, and effectiveness of treatment relative to other patients. They can call on each other for help and support in disease-centered patient assemblages. So besides taking the form of structured information, datafication of patients' personal illness also takes place through narrative accounts.

How does PLM gather their data from patients? Most data collected on this site are solicited from individual users through various interface prompts and incentives. Indeed, analyzing self-reported data may be useful for examining patients' perceived side effects; the online process of self-reporting data enables the accumulation of individual scores. The site deploys so-called patient-reported outcome measures (or PROMs) to quantify the patient experience. Such self-reported data on symptoms, vitals, treatment, and effects serve to find personalized remedies, for instance to systematically screen for signs of depression, to help patients "capture pain trends between doctor visits" or to help people "choose

between surgical options" (PatientsLikeMe, 2015). PLM rewards members who frequently update their information with "stars"; obtaining three stars means you receive a free t-shirt with the PLM logo.

PLM also collects data by invoking a sense of solidarity between patients to entice them into data sharing; the interface organizes its users around disease categories, ranging from diabetes to cancer and from ALS to depression. When PLM talks about "communities" it is referring to its patient-support function where patients can exchange information about their disease to get peer support in return. It is important to note that, while PLM may provide individual empowerment to patients suffering from the same disease, they do not in principle provide *collective* empowerment in the way that activist patient groups pursue (Wentzera and Bygholm, 2013). As Deborah Lupton (2014a) found in her research, many health platforms claim to serve communities:

> While some apps may feature the opportunity to people to engage with a community of like-minded individuals who are attempting to achieve the same ends, very few are directed at broader social change or activist politics in the spirit of the new public health. (p. 615)

It is important to distinguish the "community" appeal to "share" personal experiences and private data from the potential of pursuing collective aims or contributing to the public good.

The site's contribution to health as a *public good* comes in the form of the claim that PLM data inform a new research paradigm. All personal data generated through the platform, combined with known medical data on specific conditions, form the input for aggregate data sets that researchers may use to find cures and effective treatments for any ailment. According to its home page, "PatientsLikeMe aggregates patient-reported data from over 300,000 members on 2,300 diseases, analyzes them, and shares the results with health care and life science companies to accelerate research and develop more effective treatments" (PatientsLikeMe, 2015). PLM's philosophy of "openness" starts from the idea that sharing "patient-reported outcome measures" with companies and researchers leads to potential treatments and cures. Self-reported data constructs the foundation for "evidence-based medicine" resulting in personalized health care and treatment. Data is not just collected from labs, university halls, or doctors' offices, but from the everyday lives of patients who diligently report their scores and fill out the standardized forms provided by PLM.

PLM claims that the site helps patients select and report health data not just to seek personalized information and treatment, but also for the greater

good: to provide researchers with relevant testing material (PatientsLikeMe Data for Good, 2015). The idea of patient-driven health research, using patients' self-reported data for clinical testing, has gained traction over the years. In 2010, PLM used its patient networks to test a scientific hypothesis propelled by Italian researchers who suggested that lithium carbonate might slow down the symptoms of ALS. About 160 user patients obtained the drug and started to self-track their progress through PLM-validated rating scales. In less than nine months, this patient-led effort led to a refutation of the claim originally made by the Italian scientists—a refutation that was confirmed much later by three conventional clinical trials. The results were published in an open access academic paper, complete with data sets and statistical analysis (Wicks et al., 2011). Patient-led efforts to generate experiential data, according to PLM executive Paul Wicks, prove that this new type of "citizen science" can complement large-scale, longitudinal clinical research by conducting observational research "on the fly."

Not unexpectedly, medical researchers have responded critically to PLM's validity claim: how valid are the results put forward by this new scientific paradigm propelled by a health platform and by user data? Detractors argue that sites like PLM fundamentally breach the protocols of medical research by allowing a group of *self-selected* patients *self-administering* drugs or treatment to *self-report* results without proper protocols that guarantee double-blind testing or control groups (Gorski, 2012). Whereas proponents like Wicks laud the qualities of speed and direct involvement of patients, criticasters like Gorski warn that such patient-driven trials, relying on massive quantities of subjective data, are unscientific experimentations that benefit neither science nor patients. The belief in the objectification of self-reported data should not distract from solid scientific paradigms such as double-blind testing, he argues. A side effect of this paradigm shift towards user-generated, demand-driven data-based health research might be that it puts the onus of scientific evidence in the hands of patients, according to Gorski.

The discursive logic of PLM equates user-generated data with user engagement and parallels patient communities with "citizen scientists" for the benefit of medical research. How does this relate to PLM's commodification strategy, its business model, and governance? According to its homepage PLM is a "for-profit company (with a not-just-for-profit attitude)." The platform presents itself in its promo-video as a patient-centered site; obviously, it has no products to sell like 23andMe's personal genome service kit, so it positions itself as a patient experience site—patients helping each other and themselves with information and tracking. PLM

does not allow advertising on its site; however, it does sell "research services" which means they sell aggregated, anonymized data to third parties.

In contrast to 23andMe, PLM is very explicit about its intention to sell its users' health data to partners supporting the platform, which are all listed on their website (PatientsLikeMe Partners, 2015). These partners include the world's leading pharmaceutical companies, medical device makers, and research institutions. *How* PLM goes about selling data and contracting partners is not described in detail. In all fairness, the website explicitly warns their users about potential exploitation of submitted personal data, about example by "medical and life insurance companies who have clauses that exclude pre-existing conditions or employers may not want to employ someone with a high-cost or high-risk disease." Most PLM users will not read these details; but unlike many other sites, PLM does not hide this information in small print user-license agreements—agreements that no one ever reads and which can be changed without a user's consent.

In line with its "not-just-for-profit attitude," PLM has to walk a fine line between patient's trust and its monetizing intentions (Sillence et al., 2013). The site's invitation to "donate your data for good" and to "make healthcare better through sharing, support and research" reveals an ambiguous claim towards opening up private health data to benefit the public good. On the one hand, PLM presents itself as a proponent of open data; the platform developed an online tool called the Open Research Exchange—a tool that allows for the prototyping, testing, and validation of patient-reported outcome measures, questionnaires that measure symptoms and impact (PatientsLikeMe Open Research Exchange, 2015). However, "open data" in the context of PLM does not mean that anyone can use them; you have to become a "partner" in order to reprocess data donated by patients—to turn data into validated knowledge or as input for new drugs or devices.

Compared to 23andMe, the "not-just-for-profit" platform PLM explicates its commercial goal to turn data into economic value; the qualifier "not-just" before "for-profit" refers to its function as a patient experience forum and its support for health research. Unlike the genome service, PLM defines communities as patient groups exchanging information about diseases, even if they do not rally around collective interests. In terms of donating data to the public good, PLM promotes active participation of users in research. In other words, users are addressed as consumers, patients, citizen-scientists, and partners, all at the same time. The fusion of the platform as an *experience exchange*, a *data exchange*, and a *research exchange* is cemented in a dual nonprofit and for-profit business model. The term "research exchange" is equally

ambiguous, as it turns out to mean that only (listed) research partners who pay for the privilege can use the data. Before we turn to the implications of this ambiguity, let us first look at a site that makes similar promises from different organizational premises.

PmP

The third platform in our sample analysis solicits patient data through a health-monitoring app called PmP. Part of a broader research program, PmP is a "patient-centered iPhone app-based study of symptom variation in Parkinson's disease" that helps monitor actual patients' signs in real time (Parkinson mPower, 2015). Such signs include assessing or measuring tremor, balance, memory, and gait before and after taking medication. Using Apple's ResearchKit, researchers gather data from participants through easy-to-complete surveys via their iPhones. The study collects additional data reported by patients themselves, including automated physical measurements from wearable devices and assessments through online surveys or designated tasks. Unlike PLM, PmP uses no reward motivators for individual patients, such as gamification elements or t-shirts (Lister et al., 2014). PmP requests full names, e-mail addresses, and identity, to make sure they are dealing with real persons, and it uses the digital equivalent of a consent form. The site subsequently anonymizes a user's identity from its data; even though they warn for potential data breaches, they guarantee users' privacy.

Clearly, the app's prime focus is explicitly on gathering research data that will ultimately help all patients suffering from this disease. As the website claims:

> By participating in this study you will help us learn the range of PD [Parkinson's disease] symptoms and find out whether mobile devices can help measure PD progression and manage these symptoms better. In this unique study you will be a *partner in the research* process. (Parkinson mPower, 2015, emphasis added)

According to its principal investigator, the reason to run these studies is "to see whether we can turn anecdotes into signals, and by generating signals find windows for intervention" (Business Wire, 2015). Scientists are in great need of precise real-time information about the various Parkinson's signals to better their understanding of disease phenotypes. Research data in PmP is gathered in a structured fashion as part of a medical research framework, even if the researchers do not presume to know exactly beforehand what data to collect on the basis of a prespecified thesis, "but instead to work with patients to learn about the disease, with the app serving as an intermediary" (Business Wire, 2015). Patient users are primarily addressed as

"research partners" in this online clinical study. There is no explicit promise of helping individual patients or providing a platform for support and interaction; what is learned from user-generated data is later reported back in the form of a "dashboard" that allows patients to track their personal disease progress.

Data collection through mobile devices such as an iPhone will likely change the practice of clinical trials. It is becoming increasingly normal to automatically track one's vital signs, and PmP smoothly fits the larger trend to constantly wear monitoring apps to datafy every movement of an individual—as part of the emerging "sensor society" (Andrejevic and Burdon, 2015). As one of the leading researchers points out, having 20,000 participants in an app-based study can generate more specific information than most clinical trials that have at most 500 participants (Business Wire, 2015). And instead of collecting data from patients every couple of months, iPhones can collect data every few days or even hours. Data collection on PmP differs from PLM because its researchers predefine the parameters of standardized tests. Researchers would stand to benefit most from patients' massive "gift" of personal data; the only promise patients get in return is that eventually, in the long run, their data might contribute to (personalized) treatment or cure.

How does PmP's prime aim of contributing data to the public good of Parkinson's research tally with its business model and data governance? The platform is part of a consortium, including medical researchers from Rochester University, UC San Francisco and headed by Sage Bionetworks, which is a "nonprofit biomedical research organization, founded in 2009, with a vision to promote innovations in *personalized medicine* by enabling a *community-based* approach to scientific inquiries and discoveries" (Business Wire, 2015, emphases added). The organization is funded by foundational grants, and there is no identifiable business model, neither to monetize data nor to capitalize on research results—confirming its status as a nonprofit. Sage Bionetworks' grander claim is to "activate patients and to incentivize scientists, funders and researchers to work in fundamentally new ways in order to shape research, accelerate access to knowledge and *transform human health*" (Business Wire, 2015, emphasis added). In other words, the platform can be squarely positioned in the nonprofit health sector, which means that data will only be used for research purposes. This does not mean, however, that PmP subscribes to the "open data" philosophy, meaning that anyone (researchers and companies) can freely access and reuse. We will return to this point shortly.

An interesting additional aspect of its nonprofit governance and business model is the fact that PmP uses Apple ResearchKit for the distribution of its app.

Apple ResearchKit is a recently developed hub for researchers poised to function as data broker; introduced by Apple as an open source software framework, it allows researchers to create apps for medical research. ResearchKit works seamlessly with Apple's HealthKit—a service to store one's personal health data in a secure location where the user can decide which data can be shared. Through HealthKit, researchers can access more relevant physical data for their studies, such as calorie use, heart rates, step counts, etc. Integration in the Apple ecosystem of apps implies both an opportunity and a limitation. An opportunity because researchers can connect its research data to "vital signs" collected through HealthKit. A limitation because users of iPhones are by definition coming from restricted demographic, age, and gender backgrounds. Moreover, integrating PmP with the wider ecosystem of major private platforms means data principally become owned and repurposed by Apple. As gatekeepers of *all kinds* of data, not just health and fitness, these large data exchanges allow for endless opportunities to combine and reuse stored databases. Apple's HealthKit, like Google Fit, automatically collects all types of health data from sensors built into their respective smartphones and other devices. In the future, it is not unthinkable that tech companies may operate central storing and processing locations for health data in the cloud.[3] It is thus impossible for individual platforms such as PmP to operate independent from the general ecosystem's mechanisms of datafication and commodification; they are "entangled" in this larger apparatus, an "assemblage of technological innovations, and the social uptakes of new media technologies" (Banning, 2016: 497).

Both PmP and ResearchKit are nonprofit organizations that allegedly serve the public good, but what exactly do they mean by using the "partner" in relation to their patient contributors, and the term "open" with regards to their data? Of course, the very word "partner" is misleading in this context: patients donating their data are not participating on equal terms with researchers. They are data subjects and research subjects at the same time. Moreover, the word "partnership" is confusing because often times it refers to companies or research organizations that are indeed collaborators in a trial. The same ambiguity applies to "open." Neither Sage Bionetworks nor Apple ResearchKit (despite its use of open source software) subscribes to the open data principle, which is a principle and standard that is increasingly promoted by governments and institutions in the public sector. Open data means that data is not proprietary, but can be reused by any (app) developer or researcher. In the larger ecosystem of connective platform, it is very difficult to define who "owns" data or even who

gets access to them and in what form. How data are used and which analytics are applied remains opaque to consumers and citizens. According to Nosowitz (2015), most apps claim to contribute to the world of open data and to serve the greater good, but they cannot or do not want to explain to users what happens with their data in the Big Data universe.

Health platforms as a field of contestation

The double-edged logic inscribed in mHealth platforms—to offer personal solutions to medical problems while also contributing to the public good—is part of a wider struggle over how a data-driven platform-based society *is* and *should be* organized (Rich and Miah, 2014). As we have argued in the previous sections, the rhetorical strategies deployed by health platforms are strikingly similar, in spite of their different aims or missions. All platforms use terms like "open," "sharing," "communities," and "partners" to convince patients to volunteer their precious personal data. They are seduced by promises of personalized health advice, lured by communal forms of information and experience exchange, and simultaneously called upon to perform their civic duty to donate their data. Evidently, 23andMe, PLM, and PmP operate from distinctly different organizational *premises* (for profit, not-just-for-profit, and nonprofit), but their *promises* are conspicuously similar: they want to transform medicine into personalized health care with the intention to serve the public good. When looking at mHealth platforms, what are the wider socioeconomic implications involved in this grand narrative?

For one thing, the notion of health care as a public good for private gain is nothing new: US hospitals and the health care industry have profited from the appropriation and reuse of patients' data for decades. What is new in this era is the *automated collection of large data flows* and the potential to *combine* health information with many other *data types*. Individual platforms have mounting power to collect and trade voluminous data sets, and the emergence of dominant data brokers makes all individual platforms prisoners of the larger connective ecosystem. A score of online broker platforms such as Validic, Fitabase, Open mHealth—besides Google's Fit and Apple's HealthKit—serve as connectors between databases and algorithms. Each of these brokers aims to make data streams interoperable, and while some are depending on open source software, very few of them, including the ones that operate on a nonprofit basis, aim at sharing all data with all individual users. There is a growing divide between those who have access to, and control of, data flows and those who have not. The "big data divide" as Andrejevic

(2014) argues, aggravates "the asymmetric relationship between those who collect, store, and mine large quantities of data, and those whom data collection targets" (p. 1673).

The power of corporate data brokers is growing at the expense of collectives and publics, despite the rhetoric of individuals as "partners" in research. Governments and public institutions are running behind in defining what counts as public good in a databased and algorithmically driven ecosystem.[4] Local and national legislators are currently sorting out important issues involved in the proliferation of mHealth platforms. Understandably, regulatory bodies primarily focus on the medical safety and security of health apps (Hamel et al., 2014; Treacy et al., 2015; Yetisen et al., 2014). Privacy is also one of the important concerns tackled by regulators on both sides of the Atlantic. Some critics argue that regulatory agencies focusing on safety, security, and privacy are missing out on the larger implications of the proliferating mHealth sector as they are ill equipped to address fundamental issues such as open versus proprietary data or collective resources vis-à-vis privatized benefits (Seife, 2013; Lupton, 2012; Karanasiou and Kang, 2016).

Indeed, it takes a broader socioeconomic and ethical–legal approach to address such issues and anchor crucial definitions into society's governance. The question of who "owns" data, after all, is a complex and convoluted one because it pertains to a bundle of rights: the rights of individuals to control one's own data; the rights of companies to collect, aggregate, and mine them; the right to trace data back to the data subject, to name a few. Such profound reflections on the "ownership" of health data are important when weighing societal values against economic values in a quickly emerging global market of Big Data flows. In recent years, the "platformization" of the health sector propelled by mechanisms such as datafication and commodification has triggered responses from both civic groups and governments to regain control in a "big data knowledge economy" (Ruppert et al., 2015; Volkmer, 2014). Civic groups such as the Open Knowledge Foundation have called for "open data" defined as data that "can be freely used, modified, and shared by anyone for any purpose" (Open Knowledge International, 2015).

Governments have also called for "open data"; however, their use of the phrase "open" is again different from the meanings we have identified above. According to the US government, "open data" basically means the freedom to create economic value out of data collections; in the United Kingdom, open data is considered instrumental in procuring citizens' access to affordable services, such as health care or education. American and European governments have both started their own "open data" initiatives. The American government, through its Health Data Initiative, aims to make large numbers of *public* data sets available to scientific institutions and industry innovators.[5] They encourage private companies to monetize open health data, developing new patentable products. The British government started Genomics England in 2013, a company that is fully owned and operated by public institutions, hospitals, and researchers all coordinated by the NHS (Genomics England, 2015). Genomics England aims to compile 100,000 genomes in order to stimulate a UK genomics industry and start a personalized medical service. Both the American and British initiatives somehow confound "open" with "public" data, which is not the same: public is more restricted than "open."

Conceptual clarity is often the enemy of popular rhetorical persuasion. As we have noticed in all three sampled platforms, frequently used normative concepts are loaded with ambiguity: "communities," "partners," "public good," "open," "sharing," "exchange," etc. The paradox of private benefit and public good in relation to health care platforms thrives on the fuzziness of these terms. The problem is that most concepts are still cemented in a predigital system of institutional governance in which corporate, private, government, and nongovernmental sectors were clearly separated—an ideal that has never actually existed and which has further disintegrated over the past decades. The three mHealth platforms analyzed in this article are symptomatic of a discursive regime that seeks to persuade people into accepting not only the promise of transformative health care, but also the societal premises on which this logic is erected. It is important to expose such fuzziness in the promotional discourse of the mHealth sector. Many word pairs—*open data* and *public data, patient communities* and *research partners, personal gain* and *public good*—are used as interchangeable terms, but they do not pertain to the same set of normative values and ideals. Governments have the obligation to stipulate conceptual clarity instead of adding to confusing propositions in the grand narrative of transforming health care and health research. Citizens need alternative models of trust for app reviews that are sustainable and free of conflicts of interest (Powell et al., 2014).

If we regard the emerging sector of online health platforms as a field of contestation that is still under construction, it is important to look beyond the utilitarian regulatory scope that most governments are currently envisioning and understand the technical and social dynamics underpinning the ecosystem. We also need to develop a more comprehensive view of the political consequences of a global platform society that goes beyond deconstructing digital newspeak. The ontological distinction between open data and proprietary data, the normative division between public and

private, and the legal difference between nonprofit and for profit are the implicit premises on which the double logic is built. But these diffuse premises do not warrant the promises of a revolution in mHealth care. Whereas legislators are commonly called upon to redefine such ontological and normative standards, their power seems weakened in the face of an emerging global eco-system of online platforms whose techno-economic dynamics appear to operate autonomously. It takes the concerted efforts of citizens, governments, responsible scientists, and entrepreneurs to secure the checks and balances in the organization of health care in a future platform society.

Notes

1. The term "app" is used as shorthand for "application." An app is a more specific term than the term "platform." An application causes a computer to perform tasks for users in order to interact with a data system on a device (e.g., a mobile phone or a laptop). One platform can thus issue a number of apps, for different devices or for various types of users (e.g., data professionals, patients, health professionals, etc.). Please note: in this article, we sometimes use "health apps" as shorthand for their platforms.
2. These two mechanisms are extensively described as part of an analytical framework in Van Dijck and Poell (2013).
3. In that respect, Amazon also counts as an important central hub in the ecosystem. Amazon Cloud Service, like Google Genomics, offers to store and analyze large genomic data sets.
4. The European Commission is still working on the legislation of mHealth apps; the European Medicines Agency, and the Medicines and Healthcare Products Regulatory Agency are expected to introduce guidelines regulating mobile medical apps similar to the FDA (Green Paper on mobile Health, 2014).
5. The Health Data Initiative's goal is to make more and more data from HHS vaults (from CMS, CDC, FDA, and NIH, to name a few sources) easily available and accessible to the public and to innovators across the country. This information includes clinical care provider quality information, nationwide health service provider directories, databases of the latest medical and scientific knowledge, consumer product data, community health performance information, government spending data, and much more.

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