

When digital health meets digital capitalism, how many common goods are at stake?

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journals.sagepub.com/home/bds**Tamar Sharon**

Abstract

In recent years, all major consumer technology corporations have moved into the domain of health research. This ‘Googlization of health research’ (‘GHR’) begs the question of how the common good will be served in this research. As critical data scholars contend, such phenomena must be situated within the political economy of digital capitalism in order to foreground the question of public interest and the common good. Here, trends like GHR are framed within a double, incommensurable logic, where private gain and economic value are pitted against public good and societal value. While helpful for highlighting the exploitative potential of digital capitalism, this framing is limiting, insofar as it acknowledges only one conception of the common good. This article uses the analytical framework of modes of justification developed by Boltanski and Thévenot to identify a plurality of orders of worth and conceptualizations of the common good at work in GHR. Not just the ‘civic’ (doing good for society) and ‘market’ (enhancing wealth creation) orders, but also an ‘industrial’ (increasing efficiency), a ‘project’ (innovation and experimentation), and what I call a ‘vitalist’ (proliferating life) order. Using promotional material of GHR initiatives and preliminary interviews with participants in GHR projects, I ask what moral orientations guide different actors in GHR. Engaging seriously with these different conceptions of the common good is paramount. First, in order to critically evaluate them and explicate what is at stake in the move towards GHR, and ultimately, in order to develop viable governance solutions that ensure strong ‘civic’ components.

Keywords

Digital health, digital capitalism, Googlization of health research, moral repertoires, common good, public values

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‘It feels good to do good’
(Verily, 2018)

The ‘Googlization of health research’ and the common good

In the last few years, every major consumer technology corporation, from Google to Apple, to Facebook, Amazon, Microsoft and IBM, has moved decisively into the health and biomedical sector. 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 and the large amounts of data they already have

access to, are becoming important facilitators, if not initiators, of data-driven health research and healthcare.

This ‘Googlization of health research’ (GHR), as I have called this process elsewhere (Sharon, 2016), promises to advance health research by providing the technological means for collecting, managing and

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analysing the vast and heterogeneous types of data required for data-intensive personalized and precision medicine. Apple's ResearchKit software, for example, which turns the iPhone into a platform for conducting medical studies, allows researchers to access diverse types of data (sleeping patterns, food consumption, gait), to recruit larger numbers of participants than average in clinical trials, and to monitor participants in real time (Savage, 2015). Similarly, the new analytics techniques and data repositories offered by consumer technology companies seek to overcome limitations in traditional medical analytics methods and infrastructure. DeepMind, for example, Google's London-based artificial intelligence offshoot, is applying deep learning for the prediction of cardiovascular risk, eye disease, breast cancer and patient outcomes, in collaboration with several hospitals (Poplin et al., 2018; Ram, 2018). Verily, Alphabet's life science branch, is developing new tools to capture and organize unstructured health data, for example in its 'Project Baseline' in partnership with Stanford and Duke University. The study will collect and analyse a wide range of genetic, clinical and lifestyle data on 10,000 healthy volunteers, with the aim of comprehensively 'mapping human health' (Verily, 2018). Google, Microsoft, Amazon and IBM have also begun packaging their clouds as centralized genomic databases where researchers can store and run queries on genomic data.

Many of these techniques still have not delivered on their promises, all the while introducing a host of new challenges and limitations, such as new selection and other types of biases (Agniel et al., 2018; Hemkens et al., 2016; Jardine et al., 2015). Yet their potential, if not over-hyped, remains promising (Fogel et al., 2018), and places these corporations in a privileged position in the move towards personalized medicine and Big Data analytics – and broader healthcare vistas. Indeed, most recently a number of these companies have begun moving into the domains of electronic health record management, employee healthcare and health insurance (Farr, 2017; Farr, 2018; Wingfield et al., 2018).

Beyond these promises, GHR also raises a number of challenges and risks. First amongst these are concerns of privacy and informed consent. GHR is an instance of data-intensive research characterized by the use of large digital datasets and Big Data analytics, where traditional mechanisms put in place to protect research participants are increasingly under strain. These issues may be exacerbated in situations where consumer technology companies, whose data-sharing practices often are not subject to the same privacy-protecting regulations and codes of conduct as those of medical researchers, are involved (Zang et al., 2015). The potential for 'context transgressions' (Nissenbaum, 2010), whereby data may flow between medical, social and commercial contexts

governed by different privacy norms, is greater here. Furthermore, broader questions about the value of personal health data and publicly generated datasets, and what market advantage is conferred to commercial entities who can access them and develop treatments and services based on this access, will emerge. In other words, in GHR initiatives, concerns that are common in the practices of digital capitalism are imported into the health realm (Sharon, 2016).

A recent controversy surrounding a data sharing partnership between Google DeepMind and the NHS illustrates how some of these issues are already playing out. Announced in 2016, the collaboration between DeepMind and the Royal Free London, a NHS Foundation Trust, granted DeepMind access to identifiable information on 1.6 million of its patients in order to develop an app to help medical professionals identify patients at risk of acute kidney injury (AKI). The terms of this agreement have been analysed in depth by Powles and Hodson (2017, 2018), who argue that it lacked transparency and suffered from an inadequate legal and ethical basis. Indeed, following an investigation, the Information Commissioner's Office (ICO, 2017) ruled that this transfer of data and its use for testing the app breached data protection law. Namely, patients were not at all aware that their data was being used. Under UK common law, patient data can be used without consent if it is for the treatment of the patient, a principle known as 'direct care', which the Trust invoked in its defence. But as critics argue, insofar as only a small minority of the patients whose data was transferred to DeepMind had ever been tested or treated for AKI, appealing to direct care could not justify the breadth of the data transfer.¹

Of course, GHR collaborations taking place in different jurisdictions will be provided with different opportunities and face different legal challenges. And despite the global profile of the corporations in question, national and regional guidelines for the management of AI and Big Data in health will impact what GHR collaborations can and cannot do. But the DeepMind case also raises questions beyond data protection, privacy and informed consent, which have to do with the newfound role that tech corporations will play in health research and healthcare, and new power asymmetries between corporations, public health institutions and citizens that may ensue. For example, will these corporations become the gatekeepers of valuable health datasets? What new biases may be introduced into research using technologies, such as iPhones, that only certain socio-economic segments of the population use? What role will these companies, already dominant in other important domains of our lives, begin to play in setting healthcare agendas? These are questions that concern collective and societal benefit – broadly

speaking, the common good. They point to the need to situate the analysis of GHR in the wider context of the political economy of data sharing and use, and they foreground a number of concerns that move beyond (just) privacy and informed consent, including social justice, accountability, democratic control and the public interest.

These values are the focus of the growing body of literature in critical data studies that draws on a political economy critique to address the development of new power asymmetries and discriminations emerging in Big Data infrastructures (Taylor, 2017; van Dijk, 2014; Zuboff, 2015). In this context, new Big Data divides can be expected based on access to and ownership of data, technological infrastructures and technical expertise, with important repercussions for who shapes the future of (health) research (boyd and Crawford, 2012). However, by focusing on the new power asymmetries emerging between data subjects and corporations, critical data studies tend to frame data sharing in terms of two incommensurable logics: public benefit and private, corporate gain. In this article, I argue that this dichotomy is limiting, insofar as it only allows for one vision of the common good, while a plurality of conceptualizations of the common good are at work in GHR. In the following, I use the interpretive framework of economies of worth developed by the sociologists Luc Boltanski and Laurent Thévenot (2006 [1991]) to identify a number of moral repertoires that each draw upon different conceptualizations of the common good and that are mobilized by actors in GHR-type initiatives. Doing so depicts a much richer ethical terrain of GHR than is accounted for in most critical analyses of digital capitalism.

This is valuable for several reasons. First, it is paramount that the moral orientations of actors in GHR be taken seriously, insofar as they influence and guide decision-making processes that are currently taking place. Here I draw on the constructivist tradition that views the discourses, repertoires and logics that convey moral orientations as performative; as contributing to the enactment of technological futures (Foucault, 1965; Latour and Woolgar, 1979). Critical research on GHR must engage with these competing moral orientations and conceptualizations of the common good. Second, this type of mapping is a necessary first step towards critically evaluating different moral repertoires, insofar as it contributes to rendering explicit the trade-offs that will be involved in the enactment of different repertoires. In the current situation, where no comprehensive ethical and policy guidance for GHR exists, this is required if we are to have serious public deliberation about what is at stake in the move towards GHR. Finally, while Boltanski and Thévenot's framework

was developed as a descriptive project, I argue that it can be used to help develop normative guidelines for governance of GHR-type projects, and that this should be further developed into a research programme. Here, solutions can be thought of as combinations of repertoires, where different repertoires can check and balance each other. Such solutions will have a good chance of adoption insofar as they will appeal to a wide range of actors. Further, if what Boltanski and Thévenot call the 'civic' order of worth embodies the most publicly legitimate conception of the common good, we can design solutions that ensure the presence of strong civic components. For this, however, the civic repertoire must be 'updated', so to speak: it must first engage seriously with competing conceptions of the common good that are mobilized in the empirical reality of GHR. The article thus seeks to map and analyse the different orders of worth invoked by actors involved in GHR as a first step towards this endeavour.

A plurality of common goods

Digital clinical labour

In recent years, critical studies of digital capitalism have been very useful for analysing who stands to benefit and how from data flows; for articulating the question of the common good. Here, a dichotomy of public benefit vs. private gain provides a framework for understanding data generation and data sharing practices in numerous domains across our increasingly datafied and digital society. The notion of 'digital labour' (Fuchs, 2013; Terranova, 2000) has been paramount in this approach.

A number of scholars have adopted this framing in the health context, highlighting a profoundly problematic merging of digital labour with 'clinical labour' (Cooper and Waldbay, 2014) – more problematic than mere digital labour insofar as participation in health-related research is associated with a sense of public good in ways that participation in other online activities are not. Here, the mobilization of the language of the public good, altruism and solidarity by corporations is seen as a particularly pernicious and effective rhetorical strategy for exploitation and value extraction. Thus, for example, Deborah Lupton (2014) contends that the sharing of patient experiences online, motivated by personal and altruistic reasons, has been commodified and exploited for financial profit. Similarly, in their illuminating analysis of the intermingling logics of gift and commercial exchange underpinning participatory practices in 23andMe research, Harris et al. argue that,

altruistic notions of participation and gift exchange are used by the company to draw attention away from

what we have suggested is a form of free labour – contributing information on the internet through completing surveys – and clinical labour – submitting the saliva sample for analysis. (2013: 250)

And in their study on user reactions to 23andMe's first patent obtained using its customers' data, Sterckx et al. (2013) also highlight the uncomfortable dissonance between users' altruistic motivations for donating their data for research and the company's commercial motivations as indicated by patent-seeking.

These studies help cultivate an acute critical sensitivity to the risks raised by the presence of powerful consumer technology actors in health research. They help situate a phenomenon like GHR in the broader political economy of digital capitalism, where public values including accessibility and openness, transparency, democratic control and fairness take centre stage. This is necessary if we are to move beyond the current focus on individual privacy to broader questions about social value and the common good. Yet, while the pitting of public benefit vs. private and financial gain may go some way in distinguishing genuine from strategic and rhetorical uses of notions like solidarity, altruism and public good, this framework is limiting.

First, because digital health and the digital economy more generally are increasingly characterized by new relationships between public and private, for and not-for-profit, and financial and social value. While many social scientists, including those discussed above, have acknowledged this entanglement, for and not-for-profit practices still tend to be identified as distinct archetypes in their orientation towards the common good, as indicated above. Yet, increasingly, these orientations are converging, and 'doing good' is becoming an inalienable – not an additional – dimension of corporate activity (McGoey, 2015; Prainsack, 2017a). Rather than interpret this as a simple co-optation of the rhetoric of the common good by the corporate world, it may be more fruitful to understand this convergence as an expression of the incorporation of multiple conceptualizations of the common good.

Second, and in light of this, the dichotomy of public good vs. private, financial gain fails to account for the presence of other evaluative regimes – in addition to altruistic and market logics – that may be at work in GHR. Doing so risks both misunderstanding motives for participation in this type of research, and overlooking new forms of ethical innovation that may be introduced, including by corporate actors. In other words, if what we seek to secure is public benefit, social value and the common good, broadly construed, then we need to first acknowledge that there may be more than one conception of the common good present in GHR.

A framework for mapping the moral landscape of GHR

In their seminal work *On Justification* (2006 [1991]), the economic sociologists Boltanski and Thévenot argue that an important yet neglected dimension of social interaction is the way people justify what they do. People typically do not invent false pretexts to explain their actions, they argue, but rather try to act in ways that can withstand the test of justification. The justifications that people use to explain the worth of their own acts or to criticize those of others, furthermore, are not purely subjective, but are based on higher common principles that are generalizable and can be recognized by others. The authors refer to these as *moral repertoires* or *orders of worth*: coherent vocabularies of argumentation and justification that are each organized around one vision of the common good. They suggest that six such repertoires, each based on different philosophical foundations concerning moral worth, are commonly appealed to in Western liberal societies: what they call the 'market', 'civic', 'domestic', 'fame', 'inspired' and 'industrial' repertoires. They later expanded this typology to include two more repertoires, the 'project' and the 'ecological' (Boltanski and Chiapello, 2005 [1999]; Lafaye and Thévenot, 1993). Each repertoire acts as a logical, harmonious order of statements, objects and people, that provides a general sense of justice.

Boltanski and Thévenot's typology offers a useful framework for identifying the moral orientations of different actors in GHR.² Importantly, it assumes a richer ethical pluralism than is allowed for in the dichotomous framing of data sharing in terms of public or private benefit. It presumes that there are a number of visions of the common good that typically compete, clash and might be reconciled in practice. This entails taking actors' own justifications and moral vocabularies seriously. Indeed, Boltanski developed his 'sociology of critique' in response to Bourdieusian 'critical sociology', which he saw as being based on trying to unveil the 'real' motivations and desires of people and explaining them in terms of habitus and structure. Instead, Boltanski's sociology of critique requires engaging seriously with the different conceptions of the common good that are being put forward in GHR – including those of corporate actors – rather than assuming that certain groups of actors are motivated by benevolent or malevolent intentions, or authentic or rhetorical appeals to the common good.

In the following, I use the framework of justification to identify a number of different repertoires and visions of the common good mobilized in GHR. Not just the *civic* (doing good for society) and *market* (enhancing wealth creation) repertoires, which make up the

Table 1. Moral repertoires present in GHR.

Repertoire	Common good	Values	Example	Health(care) as
Civic	Collective well-being	Inclusivity, solidarity, equality	'Becoming part of something bigger' (tech firm)	A human right
Market	Economic growth	Competition, consumer choice, profit	'Competition is awesome; it forces people to up their game' (director, health coalition)	A market good
Industrial	Increased efficiency	Functionality, expertise, optimization	'Transforming health and care through technology' (public health provider)	A (data) system to streamline
Project	Innovation and the network	Activity, experimentation, connection	'Healthcare is ripe for disruption' (practitioner)	A project requiring innovation
Vitality	Greater health	Good health, life, vitality	'Help them lead healthier lives' (executive, tech firm)	Intrinsically worthy

GHR: Googlization of health research.

dichotomous framing provided by critical data studies described above. But also the *industrial* (increased efficiency) and the *project* (innovation and experimentation) repertoires, and what I identify as a repertoire of *vitality* (proliferating life). The data used for the analysis is taken from promotional material of GHR-type initiatives by companies and research institutes, policy documents and articles on digital health and the digital economy, and preliminary interviews with participants in GHR-type collaborations. Table 1 offers an overview of the identified repertoires. My main question in undertaking the analysis is, which orders of worth are appealed to by different actors, including academics, corporate actors, patients and governmental and public health officials, in order to justify or encourage collaboration in GHR-type initiatives?

The civic repertoire

The antagonistic evaluative regimes of public good and private gain identified by critical approaches to digital capitalism and digital health correspond to what Boltanski and Thévenot call the *civic* and the *market* orders of worth. The civic repertoire emphasizes the collective or general will over and above that of the individual. Here the common good is conceptualized as collective well-being. Civic justifications will foreground values such as equality, participation, solidarity and inclusivity, expressed in things like rights, laws and procedures, and include subjects configured as citizens, partners and collectives. The civic repertoire is perhaps most commonly associated with general appeals to the 'common good' and 'public good', as that which benefits society as a whole.

In the health context, medical professionals and public representatives will typically appeal to this

repertoire to justify the efforts and sacrifices demanded of *all* citizens in the aim of advancing scientific research and improving healthcare. Thus, the NIH's Precision Medicine Initiative is aptly called 'All of Us', and is depicted as an 'active partnering', with universities, patient organizations and private companies – including Google Verily³ – to 'accelerate health research and medical breakthroughs... for all of us' (NIH, n.d.). In civic justifications, patients will typically be framed as 'partners in research', as is the case for example in both the 'All of Us' programme and commonly in Apple ResearchKit studies. Civic justifications will find their way into technology design as well. Discussing some design features of ResearchKit apps, John Wilbanks of Sage Bionetworks, the organization that helped develop some of the first ResearchKit studies, has identified altruism as an important motivator for participation (Comstock, 2016). The apps, he explains, are designed in such a way that clarifications about how participation helps others is made explicit at each step of the process. Similarly, new attempts to create citizen-run health data commons, in the form of self-governing communities and cooperatives, draw predominantly on the civic order of worth, whereby collective decision-making, reciprocity and shared benefit are foregrounded, and the social value of health data is prioritized over its economic value (see for example <https://www.personalgenomes.org/#>; <https://www.openhumans.org>).

Civic justifications are, as critical theorists rightly point out, commonly appealed to by corporate actors as well. On its website, 23andMe frames participation in their research as 'becoming part of something bigger' (23andMe, n.d.), and Facebook's collaboration with the University of Michigan is called 'Genes for Good' (University of Michigan, 2018). Such examples abound,

and are reiterated and refined in statements made by these companies' leading executives. Mustafa Suleyman, one of the co-founders of Google DeepMind, has said about starting the company that it 'was our best shot at having a transformative, large scale impact on society's most pressing challenges' (Shead, 2018). Similarly, Apple CEO Tim Cook has explained that the motivation behind creating Apple was to be 'a force of good' (2017). When discussing the ResearchKit software, he explains that there is 'no business model there. Honestly, we don't make any money on that. But it was something that we thought would be good for society and so we did it'.

The market repertoire

The market order conceptualizes the common good as economic growth that eventually benefits everyone, as a by-product of wealth generation. Here the values of competition and consumer choice are foregrounded. As indicated above, when executives at tech firms justify their entrance into the health domain, the civic repertoire is typically mobilized. But the market repertoire will never be far off. Indeed, while Cook claims that Apple is not making any financial profit on the ResearchKit, he explicitly speaks of Apple's interest in health in general in terms of a 'business opportunity', where 'medical health activity is the largest... component of the economy'. He adds, '[t]here's a lot of stuff that I can't tell you about that we're working on, some of which it's clear there's a commercial business there. And some of it it's clear there's not. And some of it it's not clear' (Cook, 2017). Suleyman has similarly explained that, while the business model for DeepMind's involvement in health may not yet be explicit, it will be in the near future: 'Right now it is about building the tools and systems that are useful and once users are engaged with them we can figure out how to monetize them' (in Wakefield, 2016). These statements indicate that civic and market justifications do not clash for these actors, but can be juxtaposed in ways that are 'not clear', because, ultimately, they both seek to maximize the common good.

In the health sector, market justifications that frame commercial digital innovation as a means of both driving economic growth and of reducing health care costs are common. As the director of a coalition of patient groups and provider organizations has said about Amazon, Alphabet and Apple's push into the health sector, 'Competition is awesome; it forces people to up their game' (Pratt, 2018). Governments make similar appeals to the market order of worth to justify digitalization of health that is mediated through private entrepreneurship or public-private partnerships. This is one of the basic ideas, for example, behind Europe's Digital

Agenda, which envisions 'quadruple helix' collaborations that bring together academia, industry, government and civil society in new ways as the basis for the future knowledge economy (European Commission, 2016). Importantly, then, endeavours to unmask the market logic, which ultimately position it as diametrically opposed to the public or the common good, fail to comprehend it as an additional moral orientation to the world (Lehtonen and Liukko, 2010), one that also seeks to justify actions in terms of the common good, of which notions like profit and competition, and actors like entrepreneurs and consumers are part and parcel.

The industrial repertoire

In the industrial order of worth, the common good is conceptualized as increased efficiency. In this order, typical worthy persons are engineers and experts, and typical objects will include graphs and charts, tools and methods. The industrial repertoire is a dominant one in the context of healthcare today, where digital technologies promise to propel medicine forward through early diagnosis, the development of precision treatments and the rendering efficient of inefficient healthcare systems (see e.g. Department for Business, Energy & Industrial Strategy, 2017). The prevalence of the industrial repertoire also has to do with a general discourse that associates the public sector with lethargy, bureaucracy and inefficiency, and the private sector with waste elimination and productivity (Mazzucato, 2015). While this repertoire often draws on elements of the market repertoire in this sense, it is the skilful engineer, rather than market forces, that is prominent in this order, and who can bring 'solutions' to 'broken' systems.

In this repertoire, healthcare and health science are often reduced to a logistics process of data flows between scientists, practitioners and patients. For example, the director of a Dutch research centre that is partnering with Verily says he expects technology companies to 'resolve friction' between practitioners and patients, just as they have done between end users and providers in other sectors, such as tourism and travel (Wouters and Kraniotis, 2018). Similarly, Jessica Mega, Verily's Chief Medical Officer, has said that medical scientists 'have been using new technologies for centuries (...) But where we are today is about thinking about new ways to exchange information' (2018). When health and science are framed as problems of the effective management of complex data, experts in data management inevitably become experts in health.

Scientists collaborating in GHR projects also often draw on the industrial repertoire. Here too, justifications are predicated on the belief that these companies have the technological expertise required to achieve

scientific breakthroughs in an age of large datasets and personalization. On the website for Apple's ResearchKit, one scientist declares, '[w]e've gone as far as we can with traditional research. Now we have technology in our pockets that lets us go further' (Apple, n.d.). Speaking about the Verily Baseline Project, one of the involved Stanford researchers has explained that the study is one of the most extensive longitudinal cohort studies ever attempted in terms of the amounts and types of data being collected (Rogers, 2017).⁴ The financial capacities of a company like Verily play a determining role here, to be sure. But it is their *technical* abilities which are winning over the hearts of some members of the scientific community. As Robert Califf, one of the Duke cardiologists working on the study has claimed, Verily has 'obviously got the computing power to do things on a bigger scale than other people' (Kaiser, 2014).

The project repertoire

Boltanski and Thévenot did not intend their original typology to be exhaustive. Some years after publishing *On Justification*, Boltanski and Chiapello (2005) identified an emerging order of worth in what they call the network or *project* order. In the project order, the common good is conceptualized as innovation, specifically innovation that expands networks. Values that are foregrounded here include activity, experimentation, flexibility, change and connection, and persons of worth are 'network makers' who initiate new projects and whose talent is the capacity to forge new connections between ideas and people. The discourse of 'disruptive innovation' is typically an appeal to the project order, and one that is very common in the framework of GHR. Here, this repertoire is mobilized to justify collaboration not with just any industry partner, but specifically companies like Google, Apple and Amazon, as newcomers who breathe creativity and novelty into old, hierarchical and monolithic healthcare structures. Explaining her enthusiasm for Amazon's recent interest in geriatric health, for example, one physician claims, 'Health care – especially for seniors – is at its breaking point and is ripe for disruption (...) what Amazon has figured out is that to provide high-quality health care for seniors, physicians must be innovative – and disruptive (...) we look forward to seeing what comes next from Amazon' (Schayes, 2018).

Mobilizations of the project repertoire will be at work wherever notions like experimentation, innovation, 'thinking out of the box' and 'shaking things up' are promoted as valuable. Thus, the idea of working together on an exciting new future by approaching the research and healthcare system in an entirely innovative way runs through many statements on

digital health and collaborating with tech giants. Here, governmental and academic partners often deploy a deterministic discourse that portrays network projects as imminent and inevitable, a future that will either be shaped with or without them. In these instances, a sense of urgency and opportunity are inherent justifications for partnering with tech companies. For example, the director of one research centre has described collaborating with technology firms as 'driving a bus', which you can help drive yourself, or for which you can wait at the bus stop and purchase a ticket to get on (personal conversation). Similarly, in a recent interview for *Wired* detailing France's 'AI strategy' and its importance in sectors like healthcare, PM Emmanuel Macron explains, AI is 'the next disruption to come. So I want to be part of it. Otherwise I will just be subjected to this disruption' (Thompson, 2018).

In some cases, project justifications can be mobilized to legitimize a violation of rules and norms, involving a clash between the project and the civic order. For example, when the recent ICO ruling concerning the DeepMind / NHS agreements discussed above declared that more should have been done to ensure informed consent and privacy (ICO, 2017), DeepMind appealed to project justifications, writing apologetically in a blog that, in the 'initial rush to collaborate', they were too focused on 'finding exciting new ways to improve care' (Suleyman and King, 2017). In other cases, the project repertoire can be mobilized against the market order: 'Health care delivery is a big, ugly problem', a business professor explains, 'it might take companies that are better at innovation and less committed to protecting existing market shares and profit structures' (Finley, 2018). Thus, the project repertoire will emphasize innovation, sometimes at the cost of civic rules and market growth, as the best way to achieve the common good.

The repertoire of vitality: A new order of worth

In the justification analysis I conducted, a recurrent repertoire that was not identified in Boltanski and Thévenot's works emerged in the form of what I call a healthist or *vitalist* order of worth. The repertoire of vitality conceptualizes the common good as greater health; of individuals, of the social body and of humanity. Here, good health, life and vitality are upheld as the highest values, (human) life and its proliferation is understood as having intrinsic value, the pursuit of the good life is framed in terms of the quest for health, and society is organized around the management of its biological life (Foucault, 1990). Each of Boltanski and Thévenot's orders of worth are rooted in specific politico-philosophical canons of the society where they are available. In the same way, the

repertoire of vitality can be linked to a long tradition linking health and vitality to virtue (e.g. Hippocratics), to an ethics beyond morality (e.g. Nietzsche), and, more recently, to individual worth (Crawford, 1980).⁵

The vitalist repertoire is mobilized by all actors involved in GHR-type initiatives: patients, medical professionals, industry and government officials. For example, it is the repertoire of vitality that the director of research at Moorfields, a hospital partnering with DeepMind on a glaucoma detection project, appeals to when he claims, ‘what we learn from this research will benefit people around the world’ (Ram, 2018). And Apple COO Jeff Williams, while drawing on elements of the market repertoire by addressing ‘customers’ and ‘consumers’, mobilizes the vitality repertoire as Apple’s ultimate justification for launching its personal health records feature: ‘Our goal is to help consumers live a better day... we hope to help consumers better understand their health and help them lead healthier lives’ (Comstock, 2018). Similarly, Verily and DeepMind at various times mobilize the industrial repertoire in the name of a vitalist order of worth. On Verily’s website, one can read that the company’s mission is to ‘make the world’s health data useful’ (*industry*), ‘so that people enjoy healthier lives’ (*vitality*). The vitalist repertoire will foreground health and vitality as values in and of themselves. That is, not in terms of a human right, that all individuals should have access to (*civic* repertoire), nor in economic terms as a good that can reduce the burden of public expenditure (*market*), nor in terms of efficiency and expertise, as a system that should be streamlined (*industry*), but as values that are intrinsically worthy.

Towards a research programme on GHR and the common good

The presence of vitalist justifications may be unsurprising in the context of a health-related phenomenon like GHR, but it illustrates that different evaluative regimes are at work in GHR, and the analytical clarity that applying Boltanski and Thévenot’s interpretive framework provides. The added value of this analytical clarity is three-fold.

A richer ethical terrain

First, it depicts a much richer ethical terrain than is accounted for in most critical analyses of digital capitalism, where (moral) civic justifications tend to be pitted against (a-moral) market motivations. Instead, it foregrounds a panoply of moral orientations of actors involved in GHR. It is paramount that these moral orientations be taken seriously, insofar as they influence the decision-making, actions, and technology

development undertaken by these actors. Indeed, in the current situation, where no comprehensive ethical and policy guidance for GHR exists, these orientations may be the main driver of practical solutions that are taking place on the work floor.

The framework of justification was developed as a research tool to make a pragmatic study of empirical conflicts possible, such as when a conception of the common good based on one principle of justification is criticized according to criteria based on another. This is useful for gaining more insight into what is at stake in conflicts that are and will emerge in the context of GHR. Justification analysis can thus help unpack conflicts by identifying the multiple values that are at stake in them that cannot always be reduced to solely civic vs. market orders of worth. For example, when 23andMe announced in 2012 that it filed a number of patent applications, it came under harsh criticism on the part of customers and academics. The situation seemed to present a clear clash between the company’s civic rhetoric and its profit-oriented practice. Yet, as some commentators have argued, user comments posted to the company’s blog at the time indicate that it was less the profit-seeking motives of 23andMe and more the lack of transparency surrounding these intentions that was the source of outrage of users (Sterckx et al., 2013). In other words, what Boltanski and Thévenot call the *domestic* order (not analyzed in this article), which mobilize the registers of loyalty, family and trust, seems to have been just as significant in this conflict as the civic order. The typology offered by Boltanski and Thévenot can thus help understand and analyse experiences of research participation in more nuance and more granularity. This is necessary in order to adequately address what, exactly, is problematic in such cases, for example the need for more transparency and honesty or the need for more legal specifications in user Terms of Service.

Critical evaluation of repertoires

In a second instance, providing a richer description of the ethical pluralism at work in GHR is important because from here we can begin to critically evaluate the use of different orders and appeals to the common good. Boltanski and Thévenot’s project in *On Justification* is a descriptive, not a prescriptive one. They do not provide one overarching norm by which to adjudicate between repertoires. However, several steps can be taken to critically assess the use of repertoires without effacing their heterogeneity.

First, orders of worth are coherent, harmonious wholes, that come with their own internal criteria of worthiness. In this sense, justifications can be subjected to their own criteria: one can ask if appeals to

repertoires live up to their promises of achieving the common good, or if there are inconsistencies between rhetoric and practice within the use of specific repertoires. For example, if the market repertoire promises to achieve the common good by enhancing market competition and consumer choice, we can ask how this sits with increased monopolization of the internet economy by consumer tech corporations, and with increased market share gained by network effects rather than competition. Conversely, if the civic repertoire is being mobilized to justify the use of the Apple ResearchKit, insofar as it promises to increase inclusivity in research by reaching out to millions of iPhone users, we can ask how this sits with the fact that only a specific socio-economic demographic – owners of iPhones – can participate in ResearchKit studies. This raises not only issues of population bias, but also undermines diversity and inclusion. Subjecting the use of repertoires to their own internal criteria can thus contribute to ‘debunking’ practices and policies that are justified as promoting the common good *on their own terms*, rather than attempting to unmask these as profit-driven practices that are not aimed at promoting the common good.

This is not to say that stakeholders are accountable to their appeals to repertoires in the same way that they are accountable to, for example, a policy manifesto.⁶ But the assumption in the justification framework is that people find it important to justify what they do and that they will continually seek to justify their actions when confronted with criticism. This is a potent but still mostly untapped force in discussions on how to regulate the digital economy. Furthermore, Boltanski and Thévenot’s plea to take actors’ justifications seriously is also a means of entering into dialogue with stakeholders in which there can be agreement about a set of moral principles; an agreement which we can expect stakeholders to feel some responsibility towards.

Second, beyond achieving this internalist critique, such a critical assessment can help render the trade-offs involved in the enactment of different repertoires more explicit. For example, perhaps Alphabet is indeed the only actor with the data expertise and financial resources necessary to realize the promise of data-driven health research today. But the price of upholding efficiency and expertise as a higher good (*industrial* repertoire) must be made explicit: that technology companies may decide who gets access to valuable datasets⁷ – here open science is at stake – and that healthcare services developed on the basis of these may become more expensive – here social justice is at stake. This analysis needs to be undertaken for all repertoires, not just the market or the industrial, insofar as all repertoires can be expected to have drawbacks. Thus, a dominant *vitalist* repertoire can also have significant

adverse effects, beginning with ubiquitous medical and lifestyle surveillance as the price to pay for better health outcomes. Moreover, this type of evaluation needs to be extended to situations where *civic* justifications made by civic actors are prominent as well. For example, participation in citizen-run health data collectives and cooperatives, proposed as a solution to what is perceived as a new ‘enclosure’ of the health data commons (see e.g. Symons and Bass, 2017), require a high level of citizen involvement. But is it fair to expect this level of engagement on the part of all citizens? Might it lead to ‘participation fatigue’, and eventually to a situation where inclusivity becomes a luxury of the well-informed and well-to-do? And we can question if this is the best way of ensuring democratic control and enhanced collective agency in the context of digital health and capitalism?

Development of normative solutions

The critical evaluation of repertoires and the explication of the trade-offs that their enactment may entail is a crucial exercise, that opens up the space to reflect and deliberate about what is at stake in the move towards GHR, where repertoires could, so to speak, compromise, balance and check one another. This can lay the groundwork needed to develop normative guidelines for governance of GHR, in the form of combinations of repertoires that will invoke justifications that appeal to a wide range of actors.

One important criterion here should be that such combinations always involve an important civic component, insofar as the most salient challenges concerning GHR are, as discussed, societal value and collective benefit, rather than just privacy. We might imagine, for example, a guideline based on the idea that the technological expertise of a consumer technology company is needed to advance research (*industry*), but that GHR-type collaborations require a separation of roles (*civic*), whereby corporate actors cannot both provide the technical infrastructure used in the research project (i.e. collect and store data) *and* be in charge of data analysis. Another combinatory solution could entail that corporate actors are entitled to a return on investment (*market*), but that a tax on data use generated in the public domain (*industry*) redistributes wealth for public needs in the health sector (*civic*).⁸ Or, following the 23andMe patent and the DeepMind/NHS controversies, that trust (*domestic*) is enhanced not solely by increasing the specificity of informed consent (*civic-procedural*), but by increasing transparency concerning the potential commercial gains, even if these are not yet known (*civic-reciprocity* / *domestic-respect*). Good combinations will thus have strong civic components, as safeguards for the perversions of other orders of

worth, but these will be the result of civic justifications having engaged with other industrial, market, project and vitalist justifications, and *their* visions of the common good.

Conclusion

In this article, I argued that GHR is a new model of multi-stakeholder, data-driven health research that is emerging at the intersection of digital health and digital capitalism, and which must be situated in the broader context of the political economy of data sharing if we are to grasp the full spectrum of challenges it raises beyond privacy harms – namely the more politically salient question of collective benefit and societal welfare. While critical studies of data sharing practices are helpful in foregrounding this, they tend to frame these practices in terms of public benefit vs. private, financial gain, a framing that allows for only one conception of the common good – a *civic* one. Using the framework of justification analysis, I showed that beyond this dichotomy, multiple conceptions of the common good, in the form of competing moral repertoires, are present in GHR.

This analysis was carried out on a relatively limited set of data. Subsequent interviews with more actors involved in ongoing GHR-type initiatives will likely reveal additional recurrent justifications and visions of the common good. Furthermore, a closer look at how repertoires and combinatory solutions are limited and enhanced by and embedded in national, regional and international legislation and policy-making on AI and Big Data in health needs to be carried out. The current descriptive work provides a better understanding of the complexity of the moral landscape of GHR and digital capitalism broadly speaking, which is necessary if we are to develop new governance models for the digital era. Namely, if the civic order of worth, which emphasizes collective welfare, solidarity and social value, is jointly upheld as the most publicly legitimate conception of the common good, it needs to be strengthened and rendered ‘present-proof’ in light of the empirical reality of GHR. To do this it needs to engage seriously with competing conceptions of the common good, so that it can position itself as a safeguard against the perversions and drawbacks of other conceptions (and be aware of its own), and work to incorporate components from other conceptions where valuable.

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Notes

1. In addition to the ‘direct care’ loophole, Powles and Hodson also argue that DeepMind, though branding itself a simple ‘data processor’, in practice took on the more prominent role of joint ‘data controller’ in the partnership. DeepMind has disputed the findings of this study in a letter (King et al., 2018), to which Powles and Hudson (2018) have also responded.
2. This framework has been successfully used to analyse phenomena as varied as the promotion of private health insurance (Lehtonen and Liukko, 2010), to the globalization debate and local political disputes (Ylä-Anttila and Luhtakallio, 2016).
3. Verily, formerly ‘Google Life Sciences’, is Alphabet’s research organization devoted to the study of life sciences.
4. In addition to ‘traditional’ clinical, molecular and genomic data, the study will also collect data on stool, saliva, tears, sleep patterns, physical activity, social media activity and psychological variables.
5. The philosophical grounding for this emergent order of worth calls for a much broader discussion than is possible in the scope of this article.
6. I thank a reviewer for bringing my attention to this very important point.
7. According to one researcher working on Verily’s Baseline Project, Verily plans a ‘lockout period’ when only paying customers and Verily’s academic partners will be able to access the collected data (Piller, 2016).
8. Prainsack (2017b) is developing precisely this type of solution, involving a tax on data use that would not be ‘in the public interest’. Similarly, Parry and Greenhough (2018) discuss the value of developing a new system of ‘bioinformation taxation’ based on their earlier work on compensation mechanisms for the use of resources like animal and microbial bioinformation.

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