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## **Chapter 1: Healthcare Activism, Marketization, and the Collective Good**

**Susi Geiger**

### Abstract

This introductory chapter charts the book's trajectory by engaging with three interlinked key dynamics of contemporary healthcare—marketization, digitalization, and individualization. It draws on several theoretical frameworks to conceptualize notions of the common, collective, or public good and to consider how healthcare activism may play into defining and defending the collective good when faced with the outlined societal, economic, and scientific dynamics. Presenting contemporary examples from the Covid-19 pandemic, the chapter argues that the way activists define and defend the collective good can only fully be understood by grasping how this good is shaped by other, often more dominant, stakeholders in healthcare: governmental institutions, professional experts, scientists, and private industry—the latter being a focal point of concern for this current volume.

### Keywords

collective good, public good, healthcare, healthcare activism, Covid-19, markets, marketization, activism, civil society

In this introductory chapter I aim to define and connect the different component parts of this book's title: healthcare activism, markets, and the collective good. I will argue that the way activists define and defend what they perceive as the collective good can only fully be understood by grasping how this good is shaped by other, often more dominant, stakeholders in healthcare: governmental institutions, professional experts, scientists, and private industry—the latter being a focal point of concern for this current volume. The central question that this book, across its individual chapters, asks is as follows: What is the role of civil society and activists in defining and defending the collective good in healthcare, especially in cases where that good is heavily shaped by market dynamics? It is a question that may never be answerable in full—as we will see in this chapter, even trying to define the public, common, or collective good is a slippery undertaking, and the answer to this question will always depend on the specific perspectives of those who embark on this definitional work. Likewise, tracing the activities of those who set out to advocate for it is likely to lead researchers into very diverse places that are often difficult to compare. Yet, this question has rarely been more pressing to pose than after a year where the world as most of us knew it was stopped in its tracks by a single, highly contagious, and often lethal virus. This virus has forced each country on the planet to reconsider the distribution of rights and responsibilities of their governments, companies, and citizens in relation to public and individual health. It has also reopened societal debates around what is “moral” or “right” for individual groups and society at large. The pandemic has in many places triggered calls for solidarity, a focus on community, and individual sacrifices for the good of society. At the same time, it has also highlighted the extent to which we have entrusted our collective welfare into the hands of a small number of often profit-driven firms.

## 1. Healthcare and Its Markets

One of the core propositions of this volume is that how healthcare activists define and defend the collective good is often in response to the role that the market as an institution and as an overarching logic (or way of thinking) has come to play in contemporary healthcare. This focus on the market may require some explanation, as for many, especially those of us living in countries with a universal healthcare system, the notion of the market does not sit naturally with healthcare. It may sit even less comfortably with healthcare activism, which tends to be directed at governments rather than private industry. For the purpose of this book I define

healthcare activism as political and pragmatic action aimed at criticizing and/or achieving change in the status quo of research, practice, and market structures in the healthcare domain.

Of course, most of us are aware that behind any medical product or service, even if delivered and paid for through public bodies, there is “a market”—there’s buying and selling; price-setting; negotiations and procurement; supply chains, research and development (R&D); and manufacturing. The market behind healthcare becomes apparent particularly in moments of breakdown, as for instance when manufacturers were unable to respond to the dramatically increased demand for personal and protective equipment for healthcare workers in the early stages of the Covid-19 pandemic. It became visible when certain medical supply chains were disrupted and patients left without vital medication; and it became a focal point of concern during the long wait for a Covid-19 vaccination, when certain nations negotiated advance purchase agreements of promising medications with pharmaceutical firms, threatening shortages in other regions (Matthews 2020). Yet, despite these apparent market breakdowns, the pharmaceutical industry was often portrayed as the only potential savior that could lead humanity out of the pandemic through its R&D prowess. Critical questions and concerns around who may gain financially from vaccine development, whether these gains would be justified, and what ‘good’ exactly the public would get in return for the subsidies governments had channeled into the pharma industry’s R&D laboratories, were often rebuffed by pointing to the public’s dependence on the pharmaceutical industry for the provision and manufacture of a safe Covid-19 vaccine.

To understand how we got to a point where the market seems to be the chief creator and curator of the public good in healthcare, let’s take a step back. The Covid-19 pandemic has hit humankind at a point in time where many healthcare systems have been increasingly “marketized”, as part of a broader historical move toward neoliberal governance regimes across public life (Amable 2010). Differing in degrees to which it was embraced in different countries and taking place over decades, marketization happened through three interrelated dynamics: the gradual defunding of public services, which left healthcare systems with little spare capacity, the increasing privatization of broad elements of the healthcare system, and the adoption of market tools, measures, and logics in those domains that remained under public management (e.g. Zuiderent-Jerak 2009; Caduff 2020; Mason and Araujo 2020—see also Prainsack and Wagenaar in this volume, Chapter 9). In neoclassical economic thinking, markets allocate resources and property rights, balance out supply and demand, and establish a price where value for both parties is maximized. Such markets are said to be efficient and

effective. In these markets, all the effects or “externalities” that the market creates are absorbed by its own pricing mechanisms, and a market’s boundaries draw a relatively clear line between what is “inside” and what is “outside” (Mountford and Geiger Forthcoming)—and by extension what is a private or a public good.<sup>1</sup> However, as Arrow (1963) so poignantly noted over a half-century ago, like many other markets, healthcare markets are often far removed from this neoclassical ideal. As amply demonstrated through the Covid-19 pandemic, demand for vaccinations, medicines, or hospital beds is rarely predictable; essential need leads to little or no price elasticity; know-how is unevenly distributed; and the patenting regime further distorts the market and often prevents market access for the most vulnerable in society (Geiger and Gross 2018). Market failure in healthcare, then, is not an aberration but an everyday reality. Some of these market failures may be worked out within the market itself. In spring 2020, manufacturers in the market for personal and protective equipment, for instance, quickly responded to shortages caused by the pandemic’s global onset by increasing production, and new entrants repurposed manufacturing equipment for clothing or sports gear lying idle. In other areas, regulation and public governance may be able to alleviate the most obvious failures, safeguarding central aspects of the public good or at least preventing the worst “bads” (or negative externalities, in economists’ speak). The European Union’s (EU) pledge, in early summer 2020, to ensure “universal access to tests, treatments and vaccines against coronavirus and for the global recovery,” represents one example of a “private” good being overlaid with (global) collective concerns.<sup>2</sup>

These few examples abundantly highlight that the healthcare market is never “just” a market but that its economy will always and forever be a moral and political economy. Thus, when personal and protective equipment started to be in short supply in March and April 2020, responding to these shortages became not just a logistical and manufacturing issue. It became a political target and show of national strength; it also became a social allocation conundrum, for instance in discussions around whether private nursing homes would be provided with personal and protective equipment by the state. And while negotiating with the major pharma manufacturers for advance purchase agreements of promising Covid-19 vaccines in confidential market arrangements, the EU and other world leaders also knew that shutting out the rest of the world from procuring these vaccines would ultimately be counter-productive (though this did not stop them from doing so). It is in the encounter and clashes between these different facets of healthcare—as a political entity, as a market object, and as a societal concern—that morality is being negotiated, struggles for the collective good take place, and

civil society voices can be heard or suppressed. Thus, where Brown and Zavestoski (2004) locate an important motor for healthcare social movements in countering the “scientization” of medical decision making, this volume focally considers the market and its governance in fueling public discourses and in triggering certain types of healthcare activism (though, as I will explain below, scientific and economic dynamics are inseparable—a certain kind of science always presupposes a certain kind of economic governance).

## 2. Activists and Their Struggles for the Collective Good

The World Health Organization states that “the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being” ([www.who.int](http://www.who.int)). Yet, the attainment of this human right has been and still is an elusive goal for many. Activism typically arises from this rights-based conception of healthcare in those places where individuals or communities find this right violated, for instance where medicines or healthcare services are prohibitively expensive or not available at all. In many cases, activists emerge among those individuals or communities who are most directly impacted by having their rights to healthcare access inhibited—people with illnesses and their families (see Rabeharisoa and Doganova’s Chapter 3 for a brief historical overview of patient activism). While patient advocacy in all its facets is a central aspect of healthcare activism, a broader take, adopted in this book, includes individuals or collectives concerned with healthcare issues even if not personally affected, as for instance parts of the Access to Medicines movement. Brown and Zavestoski (2004, 679) utilize the term “health social movements” in their classic paper on the topic, which they define as “collective challenges to medical policy, public health policy and politics, belief systems, research and practice which include an array of formal and informal organizations, supporters, networks of cooperation and media.” They categorize these health social movements into “embodied” movements (focused on the personal experience of illness), “access” movements (seeking equitable access to healthcare), and “constituency-based” movements (for instance women’s health or environmental justice movements). While broadly concurring with their definition, my preference for the word “activism” rather than “social movement” aims to signal the sometimes precarious state of the collectives that carry out the “activist” activities. Where “social movement” conjures up images of large and relatively well-organized networks potentially spread over many different organizations, the term activism fully acknowledges the political dimension of such

collective action yet also acknowledges that this action may not always be carried out by a highly organized or indeed internally cohesive grouping. The term “activism” also implies that change and contest can emanate from so-called “challenger” positions outside the market as well as from institutional insiders (Woodhouse et al. 2002; Martin 2007) – Geiger’s (2017) example of ‘physician activists’ would be a case in point. These actions may remain local and fleeting, as for instance when citizens protest against the closure of a local hospital, but they always include what Martin (2007) calls “direct action”: a clear critique and contestation of the institutional status quo.

We should note two points raised by Martin (2007, 24): first, not all those who engage in activism would use or even appreciate the label, with some considering their actions as “simply doing what is necessary to address a pressing problem.” In fact, in the empirical research done as part of our ERC MISFIRES project (grant agreement no. 771217), the label “activist” is one that is often critically debated by our diverse research participants. And second, activism is always embedded in specific and situated “ecologies of activism,” only able to blossom if a supporting, interested, or open context can be created.

So, what do healthcare activists aim to achieve? Specific goals can of course vary dramatically, and this book’s chapters provide a small snapshot into this variety. Yet, I argue that by and large all of the healthcare activists presented in these pages have a guiding vision of what I will call the “collective good”—a vision of what is “moral” or “right.” In this volume, these visions include advocating for improved testing technology, creating awareness about genetic predispositions to breast cancer, protesting egregious pharmaceutical pricing practices, and “hacking” proprietary medical devices. Much of the time, while representing a powerful driver, what “good” exactly it is that activists are aiming to defend remains implicit in the practices they engage in, and it may be left to the analyst to explicate it. In addition, a particular definition of the collective good may be unique to a particular grouping, and one that may or may not correspond to others’ definitions – a vision of a particular “collective” good may thus not necessarily a “common” or a “public” one. Even in the same activist grouping there are likely to be fractional divisions as to the definition of the collective good and how to achieve this, as Stendahl and Geiger (2020) demonstrate through the example of a “flanked” diabetes 1 patient movement (see also Gottlieb in this volume, Chapter 8).

In some cases, the notion of the collective good is actively foregrounded, and in those cases it is frequently confounded with homonyms such as the common or public good. For instance, at the time of writing this introduction, in late 2020, the distribution and rollout of Covid-19 vaccinations were planned. Aware of the potential inequalities in access depending on where in the world one lived, healthcare activists called for any Covid-19 vaccine to become a “global public good,” available and affordable to every last citizen of the planet. The phrase was soon adopted by public officials including United Nations Secretary-General Antonio Guterres and World Health Organization Director-General Dr Tedros Adhanom Ghebreyesus, though often what exactly was meant with it remained unclear.<sup>3</sup> A public good, according to Paul Samuelson’s (1954) classic definition, is a good that is non-rivalrous (one person’s consumption of the good does not subtract from another’s) and non-excludable, meaning that a person cannot feasibly be prevented from access to the good. The public good, then, truly is the property of all; it is the most collective of all goods. Yet, as Samuelson himself readily admitted, “pure” public goods are in fact relatively rare cases—examples often mentioned are clean air, the light from a lighthouse, or national defense—and the difference between public and private goods may in fact be one of degree rather than binary opposition. From that perspective, vaccines, treatments, ventilator access, or hospital beds may be objects of public costs or expenditure. However, because they are at least partly rivalrous and excludable, and in fact often supplied through normal market mechanisms, they could never be true public goods. By contrast, the herd immunity created through widespread vaccination rollouts would be a public good, as would a notion of healthcare and wellbeing for all (see Love 2020).

In fact, in many cases calls for the “public good” by activists or public figures are a shorthand to signal the need for more, or more targeted, public or civic involvement in biomedical markets—as in the orphan drug reimbursement cases that Rabeharisoa and Doganova (Chapter 3) and Moran and Mountford (Chapter 4) consider. In these cases, activists advocate for different versions and visions of what I call the “collective good”—goods where individual and communal (or private and public) value and economic and moral reasoning are intrinsically intertwined. The term collective good, which I put forward in this volume, points to the entanglements and overlaps between “rights” and “goods” from a moral philosophical perspective (Hummel and Braun 2020). It also highlights that the way collective goods are construed depends on how the community advocating for it is defined (Widdows and Cordell 2011), and of course on the practices that a particular community engages in and the values it holds. Though we do not adopt her terminology, Elinor Ostrom’s related term of a “common



pool good” also reminds us that there is in fact a “commons” and thus a degree of collective ownership, control, or governance associated with a collective good (Ostrom and Ostrom 2015; Prainsack 2019).

As a working assumption for this volume, I thus postulate that the collective good in healthcare activism becomes shaped and defined in the activists’ practices – specifically by the discursive and/or embodied negotiations over the collective value of biomedical products and services through which a collective seeks to gain a certain level of control over the economic ordering and governance of that good. This definition de-emphasizes the question of property rights, which is at the forefront of both economic and legal definitions of notions of the public or the common good. Instead, it highlights the more active and dynamic nature of a good that is always under negotiation, but where this negotiation necessarily and at least partly relates to the economic organization of that good (including its innovation, valuation, and distribution). It also leaves space both for cases where this “good” is a material one that can have property rights attached (a “people’s vaccine,” for instance, where patent rights are held as a collective property), and more conceptual notions of what is “good” for a given collective, as for instance in the attempts to safeguard public innovation spaces in biomedical research.

### 3. Multiple Concerns—Multiple Goods?

A number of theoretical frameworks may help conceptualize the struggles for the collective good in and around healthcare markets. McLoughlin et al. (2017) and Sharon (2018) for instance utilize Boltanski and Thévenot’s framework of orders of worth (1991/2006)<sup>4</sup> to illustrate how healthcare is answerable to arguments belonging to different justificatory regimes. Boltanski and Thévenot (2006) point toward the fact that individuals bring a shared sense of what is good or worthy to any public dispute, and they present six broad orders that social actors fall back on when constructing judgments and evaluations of other actors, objects, or a situation (the market; the industrial; the domestic; the civic; the inspired; and fame). While these six orders are coherent spheres of evaluation in and of themselves, Boltanski and Thévenot emphasize that they can and often do co-exist in the same social context. In fact, they may be selectively and pragmatically mobilized by actors to justify or contest certain valuations or judgments (Boltanski and Thévenot 2000). These orders can thus be deployed flexibly to cope with tensions and conflicts in evolving situations. Most of the

time, compromises can be found between orders, but there may also be situations where these orders are irreconcilable and a common moral ground may not be established. McLoughlin et al. (2017) for instance detect clashes in healthcare between four orders of worth: the domestic (care for the sick), the civic (citizens' rights and voice), the industrial (healthcare as an efficient socio-technical system), and the market (patients-as-consumers; price as the ultimate arbiter). Sharon (2018) identifies a similar conflict when large multinational technology firms such as Google or Apple move into health research. Rather than pitching an "amoral" market worth against a (more) moral civic register, she argues that different conceptions of the collective good are negotiated through several justificatory regimes, each with their own articulation of what is moral (in her case the market, the civic, the industrial, the project, and a "vitalist" one).

While we do not follow Boltanski and Thévenot's orders of worth framework explicitly in this volume, we take from their analyses the need to understand the "market" element of healthcare not necessarily in opposition to but in continuous interaction and exchange with other ways of seeing and judging what is moral or "good" for a given collective. Thus, rather than drawing any simple dichotomies between "markets" and "morals," these moralities and ways of conceptualizing the collective good are often overlaid. For instance, many EU healthcare policies are arguably driven by the belief that market competition is a central force for innovation and over the longer term lead to societal benefits, yet they also acknowledge the need to steer the market's creation of the collective good through public engagement and regulation (Geiger 2020).

Emphasizing how markets can in fact benefit through taking account of diverse conceptions of the collective good, my colleagues and I have previously argued that healthcare could be conceived as a "concerned" market—markets where multiple actors' values and concerns clash (Geiger et al. 2014). Such markets can never be represented through a single perspective of "what is good." Nor indeed is there one view of when such a market's workings need to change in the interest of the collective good, or one way to change them. Rather, these markets are deeply contested by a great diversity of actors with equally diverse perspectives and value measures, all grappling to frame and engage in economic and non-economic exchanges where multiple value registers meet. These clashes of values and morals force a level of reflexivity onto the market and open up the possibility that these clashes can be publicly articulated and negotiated. Callon et al. (2009) have proposed the use of hybrid forums as reflective spaces of physical or virtual encounter in which heterogeneous actors—

concerned publics, experts, politicians—collectively define the problems in which they are all implicated and search for solutions. Other forms of deliberative democracy have also been invoked in healthcare (Davies et al. 2006; see also Prainsack and Wagenaar in this volume). The question of how to build these hybrid forums to voice multiple conceptions and definitions of the collective good is a recurring theme in several of the book's chapters, for instance in Galasso and Geiger's conceptual piece on patient and public involvement (Chapter 2), but also in Lindén's description of cervical cancer activists (Chapter 6) and in Rabeharisoa and Doganova's tracing of orphan disease patients' pricing battles through evidence-based activism (Chapter 3).

#### 4. Hearing Multiple Voices

There can be immediate pragmatic effects of opening up the negotiation of the collective good in healthcare markets to multiple voices. As mentioned above, during the Covid-19 pandemic an often maligned pharmaceutical industry has arguably received a considerable image boost by being heralded by some as our only potential savior to free society from a lengthy period of personal restrictions and economic hardship (e.g. Lowry 2020). For many, tinkering with the way the pharmaceutical market is structured became almost unthinkable, as became obvious during the lengthy negotiations at the World Trade Organization over a patent waiver for Covid19 vaccines. At the same time, the pandemic did provide an opportunity to question and reflect on some of the industry's "sacred cows" (Scholz and Smith 2020): private governance of R&D processes even when these are partly publicly funded, intellectual property protection, and profit-maximizing pricing strategies. Though these practices had been standard industry practice for decades and criticized myriad times before the pandemic, they were now openly debated as jeopardizing the collective good, defined as broad and affordable access to coronavirus medications and/or vaccines, rapid innovation, and open sharing of scientific insights. Just as the pharmaceutical industry was elevated from a position of commercial supplier to the public health sector to a central societal actor, the crisis also foregrounded some of its typically invisible market practices and made them subject to public debate—as practices that must contribute not just to shareholders' bottom line but also (and perhaps predominantly) to the collective good. Opening up these debates had immediate consequences in some cases. For instance, following controversies over the price point at which the Covid-19 medication candidate

remdesivir would be made available in different countries, the pharmaceutical maker Gilead's chief executive officer Daniel O'Day felt compelled to publish an open letter responding to criticism that Gilead may be profiteering from its invention at the expense of global health concerns.<sup>5</sup> The letter stated that the company was fully aware of its responsibilities "to ensure price is in no way a hindrance to ensuring rapid and broad treatment," and that it would price remdesivir below what it would normally charge for a treatment of its kind.<sup>6</sup>

Beyond these (relatively rare) immediate effects, providing space for multiple conceptions of the collective good in healthcare is also vital in the long run. As Moran and Mountford argue in Chapter 4 of this volume, marketization is a process where the market's logics, values, institutions, and culture obliterate or at least weaken alternative conceptions of public life and social exchange.<sup>7</sup> Brown (2015, 31) explains this with reference to Michel Foucault's work: "neoliberal rationality disseminates the model of the market to all domains and activities—even where money is not at issue—and configures human beings exhaustively as market actors, always, only, and everywhere as *homo economicus*." Marketization, in this sense, can lead to a point where the market logic is used implicitly or explicitly to value and evaluate persons, situations, events, choices, or encounters in such terms as return on investment, efficiency, competition, or human capital, to the detriment of other alternative moralities or values. Thus, even a fully public healthcare system can be heavily marketized in its logics and its practices, and individuals contribute to this marketization by becoming "invested" in this rationality. Activists do not—and perhaps cannot—automatically stand outside this market logic, but importantly they attempt to insert their conceptions of the collective good into the market's governance structures. Indeed, Rabeharisoa and Doganova argue that their rare disease patient groups are deeply involved with the pharmaceutical market—not as dupes or hostages, but as active participants and shaping forces, bringing vital evidence and knowledge into the market. Of course, this also means that these activists may in fact walk a moral tightrope. On the one hand, by engaging with "the market" and its moralities, there is a constant risk of cooptation: that becoming conversant with the logic of the market and engage in dialogue to stem its excesses or rectify its overflows means adopting its rationality, thus cementing the market as a preeminent institution responsible for providing the collective good. In the extreme, this includes the risk of biomedical companies doing just enough 'good' in order to "neutralize dissent" (Ismail and Kamat 2018, 569). One example of such neutralization of patient dissent are Compassionate Use patient programs, where a proportion of a drug manufacturer's medicines is allocated free of charge or at very low cost to patients

in need, which may silence broader, systemic calls for a reform of the pharmaceutical pricing model in the face of often egregious medication prices.<sup>8</sup> On the other hand, attempting to find compromises between the logic of the market and those emanating from different perspectives may often be the only route to achieve change in a world where alternatives to the neoliberal order have become almost unthinkable.

## 5. Marketized and Personalized—Medical Science and the Collective Good

Up to this point we have ignored a central issue in our argument: that healthcare's morals and markets are always intrinsically linked to the evolution of scientific and clinical practice. Dynamics and shifts in these practices may both influence conceptions of the collective good and the economic orders through which biomedical innovations reach patients (Clarke et al. 2003). Though often seen as different spheres, the scientific and the economic orders are thus better conceived as non-identical twins, as they typically emanate from the same (ideological) stock. Jasanoff and colleagues famously proposed in 2004 that “the ways in which we know and represent the world . . . are inseparable from the way in which we choose to live with it.” In short, science, society, and its markets are co-produced: the types of technologies and techniques that dominate a scientific domain at any one moment also presuppose and/or cement certain economic and social orderings.

Two scientific shifts have in recent times most heavily influenced conceptions of the collective good in healthcare and simultaneously created widespread changes in biomedical markets: the move toward precision or “personalized” medicine through advances in molecular and genomic medicine, and, relatedly, a broader “datafication” of individuals’ health and other personal traces (Hoeyer et al. 2019). Often subsumed under the label of data-driven medicine, both of these techno-scientific developments have become pet targets of public and economic policy over the past ten years. President Barack Obama famously heralded the dawn of a new healthcare age characterized by both processes when launching one of the leading initiatives on precision medicine, “All of Us,” which would assist in tailoring healthcare “to individuals’ lifestyles, genes, environment and preferences” (White House 2015). While undoubtedly promising important innovations, these scientific developments have been heavily shaped by private companies, including some of the largest and most powerful corporate entities in the world (‘Big Tech’ and ‘Big Pharma’), who have quickly outpaced all but a handful of large public institutions in their push toward precision medicine. This is an almost necessary economic consequence of a simple scientific fact: data-

driven medicine relies on an unprecedented scale of data access, collection, storage, and analysis at a time where the digital and pharmaceutical domains have witnessed unprecedented corporate concentration of power (Hogle 2016). Thus, if the future collective good in healthcare is cast in terms of data-driven medicine, then it is almost inevitable that this good will be channeled through market orders dominated by large, private organizations. Critics of neoliberalism see this future scale- and data-driven biomedical marketplace as reducing the patient, and often the healthcare provider, to “knowledge-producing machines” or “subroutines” (Nik-Khah 2018). These would feed a marketplace where knowledge is generated and accumulated “not to create more knowledge available for all, but instead the right kind of knowledge selected for its usefulness to (because demanded by) well-heeled patrons” (2018, 94). Thus, many critical voices argue that the personalization and datafication of biomedicine leads to an increase in private goods rather than collective ones, even if it is individuals’ and collectives’ data that feed this particular medical economy (Hummel and Braun 2020; Geiger and Gross 2021). This may even be the case when private corporations cooperate with public bodies in so-called public–private partnership arrangements, such as public–private genomics initiatives where the private entity gains property rights over large and publicly sourced accumulations of individuals’ DNA data (Galasso and Geiger 2021). Of course, such partnerships are purportedly always forged in the service of keeping the precarious balance between economic and collective concerns. Yet, in many cases, it remains unclear whether the potential future value to the public truly balances out the costs of the partnerships in terms of governments handing decision-making power and property rights to private entities (Powles and Hodson 2017). At the very least, in charging private entities with public innovation goals, governments risk further consolidating the hegemony of the market’s morals—and with it, arguably cementing the belief that only the market can deliver the collective good. To put it simply, the more sophisticated and “bigger” medical science becomes, the more challenging it will be to argue against the fact that the private market is the only thinkable place where the collective good can be shaped.

## 6. Defending the Collective Good in the Age of “Me” Medicine

The increasing power and influence of private “big data” or “big science” entities on innovation trajectories and decision making in healthcare is an important factor in explaining some of the current activist struggles described within this volume, and it is one that Prainsack and Wagenaar critically discuss in their concluding Chapter 9. Yet, the move to

ever more costly and data-intensive medical sciences also has subtler consequences on the assembling of collective voices in healthcare. In discussing precision medicine and genomic sciences, Dickenson (2013) famously diagnosed the move from a “we” medicine to a “me” medicine. Dickenson sees neoliberalism’s traces in personalized biomedical approaches acting to push individualist thinking in healthcare and weaken communitarian views, especially in the persistent rhetoric affirming individual choice in healthcare as an absolute value. While autonomy and a right to decision making in healthcare contexts are generally recognized as essential, pushing this autonomy rhetorically into the notion of choice, as often framed by the biomedical industry, turns it into de facto consumerism: where healthcare products and organizational structures become increasingly marketized or market-like, Dickenson argues, the patient assumes the default position of individual consumer. Even if one does not buy into a “consumerist” interpretation of current healthcare models, the ever narrower stratification of disease categories and associated illness groups makes the assembly of truly collective voices a difficult undertaking—the more “personalized” healthcare gets, the more fragmented the collectively concerned voices may become (though see Prainsack 2018).

The often lauded “unprecedented” ability for data analysis and ever more minute stratification of patient and illness categories does not only distract from a communal view of healthcare to the advantage of an individualistic one. This ability also turns the responsibility for (ill) health away from fate or bad luck toward putting patients “in charge” of their own destiny as (neoliberal) entrepreneurs of the self, as Cheded and Hopkinson powerfully illustrate in their Chapter 7. Rather than encouraging a solidaristic or even activist perspective of tackling the root causes of many diseases, which may at least partly lie in socio-economic factors rather than individual ones, this prevention paradigm leads more typically to the responsabilization of individuals as “proto” patients who assiduously track individual risks and acceptable behaviors. Needless to say, in this healthcare universe, there is little space nor really any need for collective action—the market endogenizes all possible points of friction in the rhetorical trajectory from patient empowerment to fully individualized consumer choice (Mold 2015). Or, as Brown (2015, 38) puts it, “the subject is at once in charge of itself, responsible for itself, yet an instrumentalizable and potentially dispensable element of the whole. In this regard, the liberal democratic social contract is turning inside out.” In this future scenario, the collective good is, at best, an aggregate of individual entitlements rather than a communitarian goal that would drive collective action. Regarding recent events, it

remains to be seen whether Covid-19 and the associated government actions will trigger a (re)turn to collective responsibility and an awareness that true “collective goods” require collective involvement and governance.

Of course, the tension between individual freedom and collective good is nothing new. Neither is the fact that the collective good is always precarious, often disputed, and prone to capture by other actors (Boyle 2003). The boundaries between the invisible hand of the market, as governor of private goods, and the more visible one of the public actor, who represents society as shepherd of the collective good and shaper of the private one, have long been shown to be porous. And, as argued previously, many healthcare activists have in fact been engaging with and embedding their own conceptions of the collective good into the fabric of the biomedical industry. Market actors, meanwhile, have started counting on these patient groups for their “ethical citizenship” (Rose and Novas 2005). As mentioned before, what used to be seen as “hostile worlds”—those of private firms and those of civil society and activists, so acutely opposed for instance in the early days of AIDS activism (Epstein 1996)—have arguably become more and more entangled with the biomedicalization of healthcare (Clarke et al. 2003; Rabeharisoa 2003). And where this entanglement is missing, organizations often actively strive to create or regain it, as in Galasso and Geiger’s discussion of patient and public involvement practices in genomics initiatives in Chapter 2. Where activists’ conceptions of the collective good become enmeshed in the economic functioning of the market, activists are no longer “problematic” for that market—they are in fact needed to bolster the market’s moral fabric. The problematic parties are the ones who refuse to make themselves calculable in this entangled “concerned market” frame. In current times, the most visible, vocal, and controversial of such “problematic” persons are the anti-vaccination activists and Covid skeptics who protest against what they see as big business/big government “dictating” individual responsibility for the greater good. In a sense, these particular “activists” have taken individualization to its ultimate degree and turned it against what they see as a state/market cabal that forces a notion of collective good onto them.

We can thus draw an idealized continuum from “invited activism,” which directly serves to inject a certain level of moral legitimacy into market-based institutions, to “tolerated activism” by health activists who recognize the market and work to make it more moral by innovating, improving, or taming it, all the way to “deviant activists” who refuse to reconcile their moral worlds with those of the market and prefer to keep them “hostile.” Importantly, this is not to say that all activists or patient representatives working within market-based



institutions are either “pro”-market, captured, or unaware of the tightrope they are balancing. Most are very aware of the difficulties of working within a market-based system but choose to do so consciously to achieve their collective good objectives. This broad and idealized categorization also does not mean that “tolerated” activism cannot still take the form of “spectacular political protest and opposition” (Wehling et al. 2014, 240). We see such opposition in Moran and Mountford’s Chapter 4 in the case of parents demonstrating in front of the Irish parliament for reimbursement of their children’s specialty medicines; even if these demonstrations came to benefit the pharmaceutical industry that charged “economically inefficient” prices in the first place. But it is to say that healthcare activism is perhaps at its most provoking when it rejects a market-driven formulation of the collective good altogether.<sup>9</sup>

Let me summarize this introduction’s argument before moving on to present the book’s individual contributions: We live in an era where the collective good in healthcare is defined through diverse concerns but often channeled through “the market”—both as an institution and as an overarching logic of economic ordering and governance. As we move further and further into the realm of data-driven or precision medicine, this market logic is likely to occupy an increasingly central role in providing, steering, and governing the collective good in healthcare on behalf of the community. As this happens, space for negotiating and debating a truly collective good through multiple voices may shrink, but the entanglement of activist voice and market through “invited” or “tolerated” activism may also act to keep collective good concerns alive in an increasingly privatized and individualized market realm. And, as Prainsack and Wagenaar in their Chapter 9 so powerfully argue, with the devastations wrought by the Covid-19 pandemic there comes the hope that civil society, and governments will in fact emerge with a common realization of just how necessary it is to defend and uphold the collective good in healthcare.

The contributors in this book volume and I are far from naively claiming that “all” healthcare activism is inherently good or justified, or that activists’ definitions of the collective good are always morally superior (or indeed much different) from that of other stakeholders. Yet, acknowledging multiple concerns, even if some of these may be contested (as in the current case of Covid-19 vaccination skeptics) serves an important societal and moral function. In their “archeological” work of deconstructing naturalized processes, science and technology studies scholars often pose counterfactual questions. What would society look like if certain publics weren’t around; what would happen, and who (if anyone) would fill the gap? Let’s

adopt this thought experiment: if “invited” activists, who are for instance involved in specific organizations’ patient engagement initiatives, did not exist, these organizations would be devoid of valuable learning opportunities, and the activists themselves would be without designated forums to help govern the good produced by these organizations. If “tolerated” activists such as patient groups fighting for access to medicines or inclusion in clinical trials were to disappear, the market as a whole and its governance would risk becoming unmoored from collective good considerations that are outside their immediate sight. Though perhaps the least “heard” or acknowledged, “deviant” activists also fulfill an important purpose, in continually reminding us that the current economic organization of healthcare is but one of many possible ways of governing the collective good, and that “other worlds” are in fact conceivable (Roelvink 2015).

## 7. This Book’s Contributions

While not all of the following chapters touch on all of the issues raised above, together they present a vivid array of civil society, patient groups, and other voices struggling to define and defend the collective good in the era of marketized, personalized, and datafied healthcare. In positioning themselves in relation to these dynamics, the activist and advocate groups we will encounter over the course of the next eight chapters at times adopt the vocabulary and tools proffered by the market, but in doing so inevitably contribute to shaping its meaning and form. As Moran and Mountford (Chapter 4) show us, for instance, engaging directly with market concerns such as pricing both expands the activists’ remit and puts them at risk of being captured by “the market”; claiming a position of “empowerment,” vis-à-vis regulators and commercial actors, as the T1D hackers in Gottlieb’s account (Chapter 8), also runs the danger of being “uber compliant” to a neoliberal discourse. Thus, in the round, the individual chapters demonstrate that activists cannot ever fully escape the market in healthcare and its broader economic and institutional dynamics—but also highlight the significant role they play by defining and defending their own conceptions of the collective good vis-à-vis market-based organizations.

Several of the chapters in this volume engage with the notion of invited activism, pinpointing the opportunities but also potential difficulties patient groups face in being “welcomed” into the market’s structure. Leading into this issue conceptually in Chapter 2, Ilaria Galasso and Susi Geiger present a contribution that acts as a counterintuitive to those chapters that focus more on “uninvited” activism. Utilizing Hirschmann’s classic distinction between voice, exit,

and loyalty, they argue that in most cases healthcare represents a classic “no exit” situation: while (limited) choice may exist as to providers or specific products and services, the decision not to engage at all with the healthcare market typically doesn’t arise. On the contrary, much healthcare activism, as described by other chapters in this volume and epitomized by the HIV/AIDS movement in the 1980s, can be characterized as health access movements, to use Brown and Zavestoski’s (2004) distinction. These movements typically fight for their constituents to gain entry into healthcare markets or to create a market around their illness in the first place, often working with policy makers, researchers, and pharmaceutical firms to make these markets happen. Of course, health access movements are not automatically pro-market advocates, to the contrary. The PXE community briefly described by Rabeharisoa and Doganova in their chapter for instance was careful to implement market governance mechanisms that would allow sharing of the intellectual property created in their collaborations with scientists and drugs firms, thus introducing an important collective good concern into market-based R&D processes.

The dynamics around access in precision medicine initiatives are different. Precision medicine initiatives are reliant on patient and public volunteering of the “raw materials” for the development of future biomedical markets. As Galasso and Geiger point out, for individuals who are unable to expect immediate returns from precision medicine initiatives in the form of immediately available products or services, the “costs” of contributing to these initiatives by donating their data or genetic samples often outweigh potential gains. As a consequence, “exit” or opt-out—refusing to participate—is by far easier than exercising voice to shape these initiatives for collective good concerns, which is almost absent from these initiatives. To avoid becoming more and more removed from the concerns of their stakeholders, many of these initiatives thus recreate voice and “invite” activism in the shape of patient and public involvement. Importantly, the lengths some of these organizations go through to institute these initiatives indirectly highlight the vital role that patient and public voices play in keeping biomedical markets and market practices imbued with collective good concerns.

Where Galasso and Geiger ask why certain healthcare organizations actively seek to engage with activist patients, Vololona Rabeharisoa and Liliana Doganova, in their Chapter 3, pose the reverse question: Why and how do patient organizations engage with the biomedical market? The authors locate the current struggles around intellectual property rights and prices of medicines in the context of an evolving “war on disease.” “War on disease” highlights the

epistemic role that patient organizations have adopted since the 1980s, which has in recent years extended into (co-)producing “market” knowledge—specifically knowledge around the value, costs, and pricing of economic entities. Through evidence-based activism, patient organizations, in the authors’ account, are active actors within the markets they have helped create: “these patient organizations do not reject the market as a way to access drugs. Quite the contrary: For them, caring about the market is part and parcel of caring about the patients.” Rabeharisoa and Doganova paint a brief historical arc of the development of patient movements from the advent of “experiential” knowledge in the 1940s and 1950s, through pursuing identity objectives in the 1960s, to a foregrounding of patient organizations’ epistemic role in the 1980s to what Rabeharisoa et al. (2014) have coined “evidence-based activism.” “War on disease” at this point shifted the very contours of which knowledge is seen as relevant and legitimate in the first place—and this soon included market knowledge. Thus, the rare disease patient organizations engage with economic entities such as cost, price, or value for money not as a reaction against market forces, but as a series of situated responses to difficulties in accessing medicines and establishing a “fair price” in a market that they have actively contributed to create.

The issue of a “fair price” and the clash of market and civic logics to arrive at such an elusive entity also stands at the center of Gillian Moran and Nicola Mountford’s Chapter 4, who continue the context of rare disease patient groups encountered in Chapter 3. The authors zoom in on two specific social media campaigns, set in the aftermath of negative reimbursement decisions by the Irish health technology assessment unit (the National Centre for Pharmacoeconomics). Their chapter elucidates the mechanisms through which patient communities oppose and eventually manage to reverse government decisions for the orphan drugs Orkambi and Spinraza. While social media are often accused of creating a “shout loudest” culture, Moran and Mountford demonstrate that through careful enrolment of other—previously “unconcerned”—actors and media, the campaigns systematically promulgate a valuation logic that stands apart from the economic valuations cemented by extant market governance practices. A tension arises from their chapter, of particular relevance to the volume’s overall concern: on the one hand, by forcing the government’s hand to reimburse highly expensive medications, the activities of the two patient communities arguably played directly into the hands of the pharmaceutical industry. The quick succession of both cases, only a year apart, further begs the question of whether these “spectacular” protestations can have any longer-term impact on the system itself. At the same

time, campaigns such as #YesOrkambi and #SpinrazaNow are vital to reiterate the broader concerns of actors who uphold a civic logic in the face of marketized economic evaluation processes—hopefully to the ultimate benefit of all those patient voices who may be less visible or audible but suffer no less from a purely market-driven conception of the collective good.

In Chapter 5, Klaus Hoeyer and Henriette Langstrup lead us into a consideration of what it means for the collective good to be continuously negotiated by introducing us to a healthcare system that has become “datafied.” Hoeyer and Langstrup present us with a case where public activism is relatively muted. This is unsurprising, perhaps, as the case they are considering—the digitalization of Danish healthcare infrastructures—is strongly characterized by collaborative governance mechanisms and full of the “invited” spaces that Galasso and Geiger reflect on in their chapter. In fact, the Danish government goes to great lengths to make sundhed.dk, the online portal giving access to the public health data infrastructure, as useful and “empowering” to individuals as possible. Yet, dissenting voices do come to the fore in moments of breakdown or “ruination,” as the authors put it. They show that “failure” does not just happen in markets but in processes of public organizing too; however, they also demonstrate that these moments of breakdown open up a cycle that can lead from ruination to repair (and to further promise). Hoeyer and Langstrup discuss the moral ambiguity of state-sanctioned empowerment where patients and other stakeholders who are engaged in various forms of activism attempt to affect public digital data infrastructures. They also show how activists-turned-collaborators in the datafication project became “agents of repair” in their own right. Their focus on the never-ending work of “infrastructuring” also emphasizes the epistemological ambiguity of these attempts to affect and govern data flows as collective goods: what exactly this collective good is and how it can be arrived at is always and forever a contested issue.

Lisa Lindén continues the focus on “epistemic politics” through participation in healthcare governance in Chapter 6—though in contrast to Hoeyer and Langstrup’s mostly “invited” Danish activists, Lindén’s Swedish gynecological cancer activists (the “GCG”) have to fight for a seat at the table. Similar to Rabeharisoa and Doganova’s rare disease patients, they gain this seat through evidence-based activism—even if, as Lindén shows, this knowledge can still be highly contested. This evidence is then used by the activists to occupy a broad set of patient advocacy roles, including those of “initiators,” “controllers,” and “influencers.” Thus, the policy change process is “policed” by the advocates at every step, but these roles,

explains Lindén, can only be understood in dynamic relation to other actors, including policy makers and (presumably, though not explicitly mentioned) biomedical industry. Her account shows how defining the collective good is indeed a collective and embodied achievement “enacted in and through practices, rather than being an abstract construction based on general ethical or political principles.” The activities of patient groups, in this reading, can thus never be divorced from the dynamics in the larger socio-material assemblages in which they take place.

This point is also brought into stark relief by Mohammed Cheded and Gillian Hopkinson’s Chapter 7 on breast cancer patients’ roles and the dynamics of individualization and collectivism that different narratives of these roles create. Cheded and Hopkinson describe two alternative breast cancer social movement narratives across the three illness phases of pre-cancer, illness, and post-illness. The mainstream narrative formats a role of the responsabilized, heteronormative biosocial citizen whose fate is intrinsically linked to accepting, adhering to, and promoting the biomedical explanation of their illness. As becomes apparent throughout Cheded and Hopkinson’s account, in the shadows of this narrative lurks a significant level of governmentality of the individual patient, partly driven by market forces that keep a shadowy existence in the funding drives, the pink ribbon campaigns, and the consumerist tools that help survivors restore their former selves in line with this narrative. As the authors mention, breast cancer is the top pharmaceutical investment therapeutic category—though it is not the biggest global killer—and is typically seen as a highly “lucrative” disease area by the industry itself.<sup>10</sup> It is telling that the biomedical (and other) markets are at once nowhere and everywhere in this narrative—where a faulty gene is the narrative’s “villain,” the “heroes” are those industries that work to detect, predict, and fight this villain. As Cheded and Hopkinson point out, the alternative to this mainstream narrative, proffered by “deviant” activists in the vocabulary used above, proposes a much more critical, non-normative, and non-market-compliant reading of the collective good in breast cancer activism. This narrative includes marginalized voices, those who have fallen victim to environmental harms caused by polluting industries, and those who are unable or unwilling to fit the molds offered by mainstream biomedical discourse. Cheded and Hopkinson’s account powerfully demonstrates how efforts to generalize an illness experience into commercially driven activist roles end up individualizing patients and in particular alienating those who do not recognize themselves in these narratives—those who don’t feel “pink” enough, perhaps.

The penultimate Chapter 8, by Samantha Gottlieb, returns to this neoliberal shaping of the notion of patient empowerment and the challenges that activists face when reclaiming this notion. Gottlieb charts the balancing acts that type 1 diabetes “hackers” perform by working at the very boundaries of the medical device market and regulation when creating unregulated or “hacked” closed-loop insulin pumps and meters. Interestingly, Gottlieb notes that the very hackers who are spearheading a movement that could be emblematic for patient collectives reclaiming their agency from large biomedical firms in fact often have close ties to the medical device industry. Being at once inside and outside the market, for these advocates, is not mutually exclusive. Neither is being simultaneously uber-compliant (by taking on the neoliberal mantle of self-management) and non-compliant (by performing their own non-market version of being an empowered patient).

Gottlieb closes her contribution with an important reflection, which in many ways permeates other chapters too: though mostly born from desperation and necessity, patient activism that addresses market misfires all too often remains the purview of health-, economically, and digitally literate individuals—at least, this is the kind of activism that has been traced in the pages of this volume. I suggest that one explanation for this fact is an error of omission: that we as researchers tend to gravitate to those voices we most readily hear and see in public discourse; or indeed those in which we may recognize ourselves most closely. While this volume undoubtedly holds important insights into current dynamics of this type of healthcare activism, we should not forget that there are many more marginalized, unheard, or actively silenced patient and activist collectives, most of whom will forever remain “uninvited” by dominant institutions. It should be our future task as researchers to make those marginal voices stronger and provide a space for their conceptions of the collective good to be seen and heard. In an era where, for better or worse, biomedical markets need to concern everyone who comes in touch with healthcare, we should ensure that these markets also show concern for everyone, regardless of how far their individual and collective voices carry.

This call for an encompassing form of solidarity in healthcare and a renewed role for both state and civil society—and, I would add, activist researchers—in a post-Covid-19 world is made loud and clear by Barbara Prainsack and Hendrik Wagenaar in their concluding Chapter 9. Reflecting on recent and potential future changes caused by the Covid-19 pandemic on societies’ “moral landscapes,” the authors argue that the time has come to re-think the role of “the state” and its relation to civil society, within and beyond the context of the Covid-19 crisis. Prainsack and Wagenaar thus complete the arc drawn in this volume; an

arc reaching from this introductory chapter's warning about the hegemony of a market logic in contemporary healthcare across the numerous entanglements between state, market, and civil society that the subsequent chapters demonstrate, to their own diagnosis that the ideology of public choice economics has failed the most vulnerable in this pandemic crisis, but that there are ways to remediate this state of affairs. As they point out, many states have shown a level of innovativeness and assertiveness during the pandemic that have arguably been missing from preceding decades' deference to the market as chief healthcare innovator. Thus, where authors such as Mariana Mazzucato see a renewed role for the state as entrepreneur, Prainsack and Wagenaar call for it to reassert its role as social innovator. Yet, they are also clear in stating that this cannot be done without the collaboration of grassroots civil society. Thus, their chapter offers a hopeful ending to this book volume: beyond the devastation it has caused, maybe the current pandemic has opened up a window to rethink the collective good in healthcare beyond any facile juxtaposition of markets and morals.

I hope that this volume will demonstrate to its readers just how powerful a shaper and defender of the collective good healthcare activism is. Again, this is not a naïve stance to say that all healthcare activism is necessarily or intrinsically good. But by concerning themselves with and caring about the way healthcare is organized, activism opens up current biomedical structures, logics, and institutions for debate. By caring about, pushing for, and driving innovation in the market and the state, healthcare activists—be they patients, concerned publics, or experts—are an indispensable part of our fabric of the economic ordering of modern healthcare. Caring, in Puig de la Bellacasa's (2017, 12) sense, is always a speculative and political undertaking; it is fundamentally disruptive, seeking that which can be "as good as possible" by opening up "reconfigurations engaged with troubled presences." And even though, just like the healthcare activists we observe in this volume, as researchers we may sometimes play into and help consolidate existing economic power structures, caring about healthcare and the shape it takes is what this book volume is all about. Let it stir up a "troubled presence" in the moral and economic analysis of contemporary healthcare.

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1 See Carrier and Miller (1998) or Callon (1998) for extended critiques of this “abstraction” and the role that such economic thought has played in shaping really existing markets.

2 [https://global-response.europa.eu/index\\_en](https://global-response.europa.eu/index_en).

3 WHO Coronavirus Briefing 12 June 2020.

4 Boltanski and Thévenot (2006) point toward the fact that individuals bring a sense of what is good or worthy to any dispute, and they present six broad orders that social actors fall back on when constructing judgments and evaluations of other actors, objects, or a situation. These include: the market (where objects are evaluated from the angle of profit maximization and competition); the industrial (emphasizing science, productivity, and instrumental relationships); the domestic (which considers attachment, hierarchy, and honesty); the civic (valuing civic solidarity, the collective, and delegation); the inspired (emphasizing charisma, creation, and uniqueness); and an order of worth based on fame (reputation, public opinion, and success). While these six orders are coherent spheres of evaluation in and of themselves, Boltanski and Thévenot emphasize that they can and often do co-exist in the same social context. In fact, they may be selectively and pragmatically mobilized by actors to justify or contest certain valuations or judgments in different situations (. Orders can thus be deployed to cope with tensions and conflicts in dynamic situations.

5 E.g. <https://www.channelnewsasia.com/news/world/covid-19-coronavirus-gilead-price-drug-public-good-profit-12,709,990>.

6 <https://stories.gilead.com/articles/an-open-letter-from-daniel-oday-june-29>. The letter also emphasized that the relatively unusual pricing decision taken—to set a standard per patient price for developed countries—balanced out public good consideration with a long-term “public good” of continuing investment in R&D.

7 For a narrower definition of marketization see for instance Birch and Siemiatycki (2016).

8 On a sidenote, the fact that the allocation of these medicine programs is often done through a lottery system is often considered less than moral by the patients involved.

9 We may note in passing that such “alternative economies” are not as far-fetched or without precedent as one may think. In France, for instance, a large part of the pharmaceutical industry was under public ownership until the early 1970s (Bourgeron and Geiger 2020).

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10 Phamaprojects Research Report, "Pharma R&D Annual Review 2019,"  
<https://pharmaintelligence.informa.com/~media/informa-shop-window/pharma/2019/files/whitepapers/pharma-rd-review-2019-whitepaper.pdf>, and QY Research Report 2020, "Global Breast Cancer Treatment Drugs Market,"  
<https://startupng.com.ng/uncategorized/123440/global-breast-cancer-treatment-drugs-marketlucrative-regions-for-the-manufacturers-in-2020-abbvie-abbott-bristol-myers-squibb/>.