

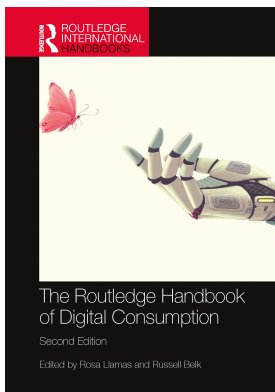
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PATIENT EXPERIENCE ASSEMBLAGES ON DIGITAL HEALTH PLATFORMS

Handan Vicdan and Nikhilesh Dholakia

The rise of platform organizations in healthcare

Platform organizations have come to dominate e-business in general, and especially social networking, e-commerce and e-service businesses. They emerge as spatially delimited on-line social environments, bringing together a network of diverse stakeholders in the market and digitally mediating as well as recodifying a social ecosystem into the relations of data and knowledge production via data tracking tools. Platforms combine technological, human, and organizational actors (Thomas et al. 2014) to create business models that rely on web community dynamics (Chanal and Caron-Fasan 2010) for producing new or challenging existing knowledge (Caliandro and Gandini 2017), thereby posing a series of opportunities and risks (Kitchin 2015) in a utopian/dystopian ambivalence. Such technologies enable distant and asynchronous monitoring of people not as discrete individuals but as assemblages of data (Darmody and Zwick 2020; Zwick and Denegri-Knott 2009), and gathering multiple stakeholders and facilitating multiple interactions via these assemblages shape the participatory (Gillespie 2010) and social nature (Van Dijck 2013) of these platforms. Platforms are popular, often more massive (in terms of number of participants) than the largest nation states, wield enormous sociopolitical-economic power, and they have thus become under intense scrutiny (Srnicsek 2016; Zuboff 2015, 2019). Many believe that regulatory ways to tame giant platform businesses are destined to fail and that commons-cooperative models are the only ways to make platforms responsible to society and to people (Kwet 2020; Scholz 2016).

Interestingly, though, the health-medical platforms often do have elements of cooperation and collective control among diverse industry actors, and the sustainability of these platforms depends solely on patients actively and voluntarily sharing their health data and contributing to medical knowledge production. Health platform organizations enable patients to actively manage their health and participate in alternative medical knowledge production (Kallinikos and Tempini 2014). With advanced technological tools, data management, and network capabilities on these platforms, patients connect to other patients and industry actors for health data generation, the effects of which go beyond merely conducting medical research and producing knowledge alternative to conventional medicine. We are witnessing the rising popularity of participatory medicine through these platforms where patients track and share their own and others' health data and collaborate with other healthcare industry

actors for big data generation and distribution in healthcare (Eysenbach 2008, 2009; Hesse et al. 2010). Such advances bring about potentialities for sociocultural, sociomaterial, and communal production of medicine and control of diseases in the healthcare system. These potentialities seem to be disruptive in terms of changing the dynamics of power relations in the healthcare market for controlling patient data and medical knowledge generation as well as raising questions concerning the power of the dominant expertise system in generating and acting on health data. With such shared and aggregated knowledge on digital health platforms, the foundations and practices of scientific medical “research” begin to transform as well (Kallinikos and Tempini 2014). Moreover, increased democratization of knowledge production via patient-generated medicine (Gibbon and Novas 2008) destabilizes hierarchies of knowledge production and dissemination (Indyk and Rier 1993; Rier and Indyk 2006).

The importance of participatory medicine was further accentuated during the 2020–2021 pandemic crisis. Indeed, platformization of Covid has tremendously helped with the management and control of the virus in situations where government efforts were insufficient to effectively track the spreading of the virus, and digital health platforms overtook the responsibility of virus tracking and data generation from governments (Vicdan 2020). For example, in order to speed up the tracking of the virus and discovery and development of the vaccine, digital health platforms enabled initiatives such as developing and refining Covid symptom tracker via collaboration of patients and healthcare providers to then use this self-tracking tool to report Covid symptoms and share and compare treatments received. Patient-generated data on digital health platforms is thus viewed as an effective solution to detection and monitoring of global sanitary crises (Knight 2020).

Performativity of patient experience assemblages via platforms

The growing complexity of consumer–producer–technology assemblages raises questions concerning how these assemblages emerge and change over time, and how their effects extend to broader intersecting sociomaterial assemblages. With such advancements, Hoffman and Novak (2018) justly ask: “how will consumer experience be enabled and constrained as a result of this complexity?” Similar concerns can be raised when it comes to healthcare, as patient experiences on platform organizations can be thought of as a multiplicity of assemblages constructed together with patients, platform communities, physicians, caregivers, pharmaceutical companies, state institutions, and public and private research institutions. These patient experience assemblages also consist of other non-human entities such as self-quantification and tracking tools as well as data aggregation and visualization tools, and interpretation processes. In a variety of ways, these complex relations produce various outcomes at ongoing and multiple levels of sociomaterial interaction.

Performativity as an analytical lens will be employed in studying patient experience assemblages as constitutive entanglement and interaction of humans and technologies (Kjellberg and Helgesson 2006; Orlikowski and Scott 2008) and articulating the sociomaterial outcomes of these assemblages (Barad 2003; Orlikowski 2007; Orlikowski and Scott 2008). Performativity is defined as not only a discursive process but as “happ[ening] through the political engineering of sociomaterial agencements” (Cabantous et al. 2016, 197) that work to support the realization of alternative organizing. In light of technological advances in healthcare, such as wearable devices, tracking tools, data aggregation tools, and the like, scholars call for a need to unearth the performativity¹ of different “sociomaterial” assemblages and their consequences, and the resulting change in power dynamics among actors that form these assemblages (Cecez-Kecmanovic et al. 2014; Orlikowski and Scott 2015).

Scholars in marketing and consumer research have predominantly studied the performativity of marketing tools/models (Kjellberg and Helgesson 2006; Mason et al. 2015) as well as how consumer-enacted performativities (Martin and Schouten 2014; Scaraboto 2015) shape markets. Performativities enacted by collaborative networks (Scaraboto 2015) inclusive of diverse market actors and exchange dynamics, more importantly rising platform organizations as alternative markets and organizational forms in healthcare, nevertheless received little attention. To address this gap, we articulate how patient experience assemblages are enacted by these platforms, and critically assess the performativities and counterperformativities of these assemblages unfolding at various levels. In doing so, we also elucidate the empowering and constraining outcomes of patient experience assemblages (Hoffman and Novak 2018) on actors involved in these assemblages as well as on the market dynamics for medical research and knowledge production.

Context

We focus on two digital health platforms as alternative markets and profit-generating “sociotechnical assemblages” (Gillespie 2018, 19), PatientsLikeMe (PLM) and Raremark, which we find as fruitful contexts to study how patient experience assemblages on these health platforms emerge and evolve, various interactions among human/non-human actors in these assemblages, and the outcomes of these assemblages at micro, meso, and macro levels. On these platforms, patients contribute to the generation of collective medical knowledge and clinical research together with other patients, pharmaceuticals, physicians/researchers, and government and medical research institutions. Hence, conventional medicine that views patients and healthcare actors as distant entities for producing medical knowledge and managing diseases is unarguably challenged. Patient experience assemblages on these platforms operate via different levels of interaction and involvement of multiple human (e.g., patients, physicians, caregivers, the platform operatives, pharmaceuticals, research institutions, and state regulatory bodies) and non-human (digital tracking tools such as disease symptom trackers, mood maps, doctor visit sheets, disease outcome measures, genetic and ancestry reports) actors, and their effects extend beyond the platforms, leading to new networks of patient experience.

For example, PLM as a Medicine 2.0 platform organization uses social media and networking technologies and (re)connects market actors to each other for medical research and knowledge generation, reinforces collaboration among these actors by combining patient-generated data and expert medicine in the design of medical research and advancement of medical knowledge, and enables proactive relations with healthcare actors in and beyond its platform. Founded in 2004, PLM seeks to democratize learning of and access to medical knowledge, and continues to increase the number of patient communities with diverse disease conditions (e.g., Multiple Sclerosis, Amyotrophic Lateral Sclerosis, mental health, women and men’s health issues, transplant communities) and collaborations with other healthcare market actors for patient data generation and medical research. To date, PLM has achieved a considerable impact on medical research, producing more than 100 research studies in peer-reviewed medical and scientific journals (<https://www.patientslikeme.com/about>).

Raremark is an online platform owned by Xperiome health-tech company, which aims to “crowdsource and organize the wisdom of experts: patients, parents, and caregivers who deeply understand what it’s like to live with a rare disease every day” and build a “library to catalog the lived experiences of rare diseases” (<https://raremark.com/about-raremark/>

about). It was founded on the idea of developing research networks of rare-disease patients and their caregivers and families. These research networks will then enable pharmaceuticals to have access to anonymized aggregate patient data to support clinical research and speed up the drug development and commercialization process, and test the effectiveness of new treatments. Furthermore, these research networks also aim to give visibility to and raise knowledge of rare diseases and inform industry actors about patient-generated data to deliver fast and innovative solutions and enable them to have access to a large rare-disease patient pool to recruit patients for clinical trials.

In the following section, we will articulate the patient experience assemblages enacted by these two digital health platforms, and their performativities and counterperformativities at various levels.

Micro-meso-macro level performativities of patient experience assemblages

Multiple level performativities of patient experience assemblages are generated in and beyond digital health platforms, which demonstrate the potential for shaping the practices of actors, organizations and their markets, and their relations in material and social terms (Callon 2008; Orlikowski and Scott 2008).

At the micro and meso levels, self-tracking tools designed by platforms in collaboration with patients and industry actors shape individual patient practices. For example, doctor visit sheets as data tracking tools on PLM platform are printed and used by patients in clinical settings where conventional patient-physician relationships are challenged and transformed, and error-reduced data flows are enabled. Such tools create new digital materialities and give patients alternative visibilities and reconfigure relations and practices in patient care (Jones 2014). Hence, the effects of such experience assemblages generated on the platform extend beyond the platform itself. Patient accounts emphasize the positive impact of these micro-experience assemblages created on the platform on the communication with their healthcare providers outside of the platform, hence enabling the emergence of new social relations between patients and doctors and improving clinical outcomes such as reducing the possibilities of wrong medical decisions in clinical settings. Consequently, platform-enabled patient experience assemblages are viewed as performative both in the new and alternative ways patients are visibilized to their healthcare providers and in the new relations and practices that emerge in other patient care contexts beyond the platform (Jones 2014).

Tracking tools help patients manage their well-being and also organize their relations with other patients on the platform. For example, self-tracking tools (e.g., disease diagnostic/prognostic tools, disease symptom meters, treatment and side effect tracking tools, lifestyle modification tools, and mood tracking tools) enable patients to gain deeper insights of themselves and others (Moore and Robinson 2015), and such practices are enactments of a dynamic sociomaterial arrangement (Bode and Kristensen 2016). Different forms of self-tracking, regardless of their pushed or voluntary nature, yield better health and well-being outcomes for the society, for the commons (Lupton 2016). Through such reflexive assemblages, patient care becomes a shared decision and liability in and beyond the platforms. Self and collective quantification and tracking of health data, and monitoring of disease progression and treatment via tracking tools bring about the potentialities of increased awareness of embodied ill-self and disease literacy. For example, in Raremark, rare-disease patients often lack the literacy and knowledge concerning their conditions and are unable to obtain a complete outlook of their diseases. Because of this illiteracy, patients on this platform express and share

the feelings of loneliness of dealing with rare diseases. Diagnosis and treatment of such diseases take years due to disease illiteracy and lack of latest knowledge about rare diseases from healthcare providers as well. Increased awareness via continuous self-tracking also serves as a lifeline for patients experiencing acute disease episodes. Monitoring of one's and other's health data via tracking tools such as mood charts and disease symptom rating scales on these platforms allows for empathetic and adaptive relational exchanges, and patients relate to each other almost in an inter-corporeal way (Pullen and Rhodes 2014).

At the macro level, digital health platforms also serve as gateways for challenging conventional expert-driven medical research and knowledge production by bridging patients to other healthcare stakeholders on and via the platform. Pharmaceutical companies and research institutions track and recruit patients on these platforms for clinical trials. These institutions gain access to and analyze patient-reported data to not only validate patient-generated medical research on these platforms through clinical trials but also validate clinical trials and improve their trial protocol design. They often discover drug effectiveness, new drug side effects, and secondary uses of medications as well as new drug developments via patient-reported medical data. Patients use disease symptom meters, and the data produced as a result enable new treatment possibilities, which are then validated through collaboration with other research institutions. For example, research conducted on patient-generated data research in PLM is published in scientific journals (e.g., *Journal of Medical Internet Research*, *Patient Journal*, *Health and Quality of Life Outcomes Journal*, *Amyotrophic Lateral Sclerosis Journal*, *Epilepsy & Behavior Journal*), which demonstrates that conventional medicine can be informed by real-time real-world patient-generated medical knowledge. Platforms also enable patient-pharmaceutical co-creation and improvement of tracking tools to be used by patients to report their data. For example, in PLM, patients collaborate with pharmaceutical companies and healthcare providers to develop and validate comprehensive disease symptom rating scales that do not fit the given classifications of conventional medical knowledge (see Kallinikos and Tempini 2014). Furthermore, government institutions (e.g., Food and Drug Administration) also become a part of the patient experience assemblages. Using these platforms, patients can also report drug side effect data to government agencies, which allows for alternative monitoring of pharmaceuticals by state institutions, and gain increased access to government-activated clinical trials.

Similarly, Raremark partners with TriNetX global health research network, which serves to draw and map Raremark's rare-disease patient data. This, then, enables member pharmaceutical or biotech companies to send clinical trial opportunities using the platform's Trial Connect feature and connect them with patients to include them in clinical trials. Furthermore, Raremark's Xperiome platform aims to find the right rare-disease patients to take part in research studies, and help make rare disease treatments available faster. It serves as – “a patient powered knowledge platform” – including more than 100,000 users that are actively engaged in growing patient-generated knowledge using data from people with rare diseases and assisting the pharmaceutical industry and partner research institutions in crowdsourcing innovative and fast therapies. Machine learning and behavioral science are utilized on this platform in order to make sense of patient data (for example, by categorizing patient-reported data based on COM-B model²: capability, opportunity, motivation, and behavior) by partner companies, provide customized data to other patients and eventually increase health literacy and informed participation in medical research. Rare disease real world patient data then guides pharmaceutical researchers on this platform for gaining a complete outlook of living with a rare disease and developing new treatments accordingly. Xperiome platform also enables pharmaceutical companies and research institutions to recruit hard-to-reach rare disease patients for research studies that will help in assessing the impact of new

treatments and the potentials of new markets. Hence, macro-level performativities of patient experience assemblages indicate that clinical trials today have the opportunity to directly connect with patients through these platforms, and these platforms offer the potential to decentralize clinical trials in order to overcome barriers to rare disease patient participation in clinical trials, and challenge standard approaches to patient data collection by pharmaceuticals. Furthermore, drug development processes benefit from accelerated patient recruitment and randomized clinical research processes.

Counterperformativities of patient experience assemblages

Performativities of patient experience assemblages – and their risks – nevertheless remain but are incorporated into a multifaceted process, which makes it difficult to either denunciate or acclaim platform organizations' adverse effects in healthcare. Nonetheless, performative struggles (Callon 2007) or counterperformativities (Mackenzie 2007) of these assemblages and their destabilizing effects are equally important to shed light on, especially when patient care and vulnerability are involved.

First, data ownership poses further questions concerning who will be the responsible party for managing and protecting data. If data are owned by patient-citizens, will this responsibility be shirked by other stakeholders? Second, apart from data collection issues raised, data use issues need not be forgotten. It has been suggested that individual data points will provide value only if they are a part of an amassed and aggregated data pool and are put to use, because it is the use of such data that makes it actionable and produces outcomes (Couldry and Yu 2018). Indeed, exploring the rhetorical strategies used by digital health platforms, Van Dijck and Poell (2016) aptly argue that such rhetorical strategies include fuzzy concepts of open data and open research; yet, the questions remain concerning who owns the data, who gets access to it and uses it in what forms?

Although platform organizations multiply the scope and directionality of medical gaze, discriminatory, and exploitative effects of rhizomatic patient experience assemblages will only be circumvented through shared responsabilization. The liability for data generation and security has to be shared by all the stakeholders involved, aiming toward greater transparency in medical knowledge generation. Flyverbom (2019) addresses the issue of transparency as not only an information technology question but a matter of visibility management that entails a networked practice of disclosing and disguising data and design of digital infrastructures that afford new forms of visibility.

Micro and meso level performative struggles also occur, including data illiteracy, which causes non-democratic access to patient experience assemblages. Indeed, data literacy entails the ability to report, analyze, and make sense of data and reflect on the ramifications of datafication, all of which are important to reduce individual vulnerability against data use and security in digital society. Moreover, patients' lack of knowledge and skills to input and interpret health data may lead to patient exclusion from medical knowledge production. Tracking tools designed in collaboration with patients and other research institutions may not be inclusive enough to apprehend the complete aspects of patient disease experience, and algorithmic designers may fall short of understanding and interpreting the patient language in describing his/her experience (Tempini 2015).

Platforms may also create a “technology of the self” via self-tracking and quantification, which may also lead to manipulation of data by users. Their algorithmic capabilities then shift from serving as “codes of normalization” (Foucault 2004, p 38) to “codes of deviance” in order to game the system and make demands that cater to their self-interests in

clinical settings. Patient deliberate falsification or manipulation of data generated as well as algorithms designed to aggregate this data to then sell it to pharmaceuticals and research institutions exacerbate the vulnerability³ of medical knowledge generation and patient care, including the involved stakeholders. The dynamic and performative nature of algorithms renders translation and manipulation of data invisible to data subjects, leading to discrimination, social ordering, and data proprietorship (Zuboff 2015). Furthermore, despite these algorithms as well as data capturing and processing capabilities, judgment of data by human subjects is still essential for interpretation and application of our learnings to manage own and others' care, which is by no means free of bias (Gillespie 2017; Kitchin 2014). As such, platformization of patient bodies through self-quantification movement has been cited as a risk, as algorithms provide a digitally embodied self-information with such precision that it could change our relationship with our new datafied bodies (Pedersen 2020).

Such observations allow for nuancing West's (2019, 5) claim that "the value of the free and open network, the potentials of personalization, and the development of new forms of consumer power" are in fact narratives of power masking detrimental effects of control and information asymmetry. Indeed, platform organizations as data intermediaries not only "mediate" but also constitute and control our lives, controlling information flow and manipulating data (Gillespie 2017). They become new gatekeepers of information flow on how data are collected for whom and for what purpose, given meaning, used, and manipulated (Boyd and Crawford 2012; Gillespie 2017). Warnings (Boyd and Crawford 2012; Constantiou and Kallinikos 2014) have been issued on the "distributed and largely uncontested new expression of power" underlying big data (Zuboff 2015, 75). Hence, concerns proliferate regarding how such power is redistributed and exploited by online mastodons while escaping legal frames.

Scholars from critical management, marketing, and information systems draw attention to the ramifications of platformization as a dominant organizational form. In particular, Zuboff (2019) underlines the value extraction and profit-making motives of platforms via data, driven by the principles of surveillance capitalism. Data capturing, classification, delegation, and data sharing – while yielding many potentialities – bring forth issues related to these processes (Puntoni et al. 2021), such as racial inequalities (French and Monahan 2020) and socio-technical vulnerability perpetuated by the growing infodemic via digital platforms (Donovan 2020). Especially in healthcare, vulnerability of patients who seek information and share their data to find ailments to their diseases is imminent.

Creation of patient experience assemblages on digital health platforms, therefore, calls for collective and multidirectional responsabilization (from grassroots to institutional, from human to non-human) for extracting, classifying, delegating, and sharing data. This is essential to prevent data manipulation and security, to reclaim civil liberties, and to enable complete transparency regarding the use and sharing of private health data (Kitchin 2020) in the era of post-privacy economy (Weigend 2017). In contingencies such as healthcare and epidemics, "data philanthropy" (Tatevossian 2011) and "data commons" could help achieve societal well-being through datafication (Rifkin 2013) by online health platforms dedicated to advancing medical science via data assemblages generated through participatory medicine. In such contexts, the question remains, how far are we going to give up on control over our data to achieve societal well-being, and does calling it data commons make data ownership by citizens obsolete – as data are still amassed under wider control exerted by corporations? (Couldry and Yu 2018). Under neoliberal logic, patients are responsabilized to engage in self-tracking and care for themselves to then ultimately contribute to the well-being of the commons and generating social value (Couldry and Yu 2018). If so, will individual data rights be surrendered to the societal well-being? Does this make individual rights and

values of data transparency, data ownership, and data use irrelevant under this data commons rhetoric? Furthermore, it has been noted that although health platforms use a “collective well-being” rhetoric, only a few of these platforms aim to instill a broader social change in healthcare (Lupton 2014).

Concluding remarks

Exploring multiple levels of performativities and counterperformativities of patient experience assemblages exemplified earlier also enables us to reassess the power dynamics in generating alternative medical research and knowledge (Callon 2008, Orlikowski and Scott 2008).

For participatory health platforms to challenge and/or complement the conventional expert-based medical research process (Kallinikos and Tempini 2014), a key condition is the inclusion of multiple stakeholders in big data and knowledge generation, and enabling the multiplicity of gazing through convergent sociomaterial assemblages. Through multiplicity, problematization muddles its way through to affect the way knowledge is produced and utilized on and by patients. It is the performativity of particular sociomaterial assemblages – inclusive of human and non-human entities – that enables the tracing and producing of agency (Hansen and Flyverbom 2015). Such assemblages then lead to new forms of organizing relations between humans and technology for scientific research and knowledge production (Treem and Leonardi 2012). Exchange dynamics shift and extend beyond organizational boundaries (Majchrzak et al. 2013) via these assemblages, hence enabling an alternative institutional environment to produce new knowledge (Kitchin 2015) inclusive of multiple stakeholders, and shape and contest their practices (e.g., clinical practices and medical research, government regulation of the pharmaceutical market).

With participatory medicine and platform-enabled patient experience assemblages, we can instantly conceive these transformations in healthcare as a form of patient empowerment. Self-management of health (Fox and Ward 2006), patient control over his/her illness and participation in management of his/her care, and increased patient education during clinical encounters with healthcare providers are all considered forms of patient empowerment (Ouschan et al. 2000). As we move to patient-technology interactions (Lupton 2013) and assemblages enabled via platforms that gather multiple stakeholders, we witness the burgeoning complexity of relational exchanges among healthcare actors. These transformations challenge the paternalistic as well as consumerist and reactive accounts (Ouschan et al. 2000; Schneider-Kamp and Askegaard 2020) of patient empowerment while acknowledging patient connection to other healthcare actors, not just their physicians. Patient participation in medical decision making involves not only personal physicians and caregivers but also other patients, research institutions, and pharmaceuticals. Indeed, Kamp and Askegaard (2020) view this as a form of patient autonomy and increased opportunities for patient education that extend beyond patient-physician exchanges. We extend this debate on patient empowerment by exploring prosumer accounts of participatory medicine enabled via platforms, and how patient participation in medical knowledge generation influences the dominant market dynamics for medical research. Indeed, health platforms conceive of patients not as consumers but as stakeholders of research and knowledge generation networks.

Another important outcome of patient empowerment is gaining increased access to medical research via health platforms and the assemblages they create, which is crucial for research institutions and pharmaceuticals to maintain diverse participation in clinical research, especially with the impact of global pandemic such as Covid-19. Nevertheless, we also cautiously draw attention to the idea that datafication of health via these assemblages need not be

understood merely in polarized terms such as empowerment and disempowerment but also how individuals creatively act on their data guided by their values, the outcomes of which for example extend beyond the polarized discourses of autonomy and discipline (Sharon 2015). Datafication brings about new understandings and productions of social relationships established through our biological beings and becomings, “datasociality” in Ruckenstein and Schüll’s (2017) terms, that encompasses diverse enactments and negotiations of autonomy, solidarity, and authenticity (Sharon 2017).

Lastly, despite her critical stance on platformization and capitalism’s commodified surveillance logic for datafication of everyday life, Zuboff (2019) agrees that the digital revolution has transformed both the logic of accumulation and the logic of cooperation. Indeed, new forms of participation and cooperation will emerge as well as possibilities for resistance and change, to subvert the logic of accumulation. Of course, in hyper-digital marketplaces, there are also data-intensive processes afoot that employ consumers’ own data to nudge them into choices that consumers cannot assess in terms of their own welfare, lulling them into a feeling of being in autonomous control (Dholakia et al. 2020).

Rather than corporate-controlled health platforms, should we imagine increased public digital spaces to encourage people to openly share their health data and crowdsource their cures via making this data freely accessible to all? Or should we encourage new forms of datafication generated through data cooperatives? The political issue here of course extends beyond healthcare settings – it is a generic issue of contemporary platforms for sharing views and news, obtaining services (rooms to stay in, cars to rise in, etc.), reviewing and designing new products, and so on. Some (Kwet 2020; Scholz 2016) – a minority for now, but it could garner momentum and strength – are convinced that regulatory approaches to platforms would fail (or be “captured” and sidetracked by dominant corporate players). Truly cooperative and shared digital commons – also made feasible by emerging technologies – may remain the best bets for making platforms serve public rather than private interests.

Further reading

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Notes

- 1 The core tenet of performativity theory concerns the outcomes or effects produced by activities, practices, doings, and sayings by human and non-human entities, and how these outcomes (re) shape their practices (Orlikowski and Scott 2015).
- 2 Such models are applied in order to enable partner companies to listen to and focus on the needs of rare-disease patients and build relationships with them (<https://pharmaphorum.com/views-and-analysis/why-relationships-are-key-in-rare-disease-patient-engagement/>).
- 3 Kozinets and Gretzel (2021) draw attention to the challenge of organizations’ overreliance on changing AI applications that leads to their vulnerability and loss of control over decisions fed by AI data. Indeed, over-technologizing of marketing via AI exacerbates our insubstantial and far-fetched understanding of customer needs and wants.

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