



Counting, Debunking, Making, Witnessing, Shielding: What Critical Data Studies Can Learn from Data Activism During the Pandemic

Stefania Milan

INTRODUCTION

The more than 70 per cent of the Peruvian labour force employed in the informal economy has been severely impacted by the lockdown imposed to curb COVID-19 diffusion. But government efforts to deploy algorithms to aid in the distribution of welfare subsidies relied on official yet inaccurate databases and technology designed with other purposes in mind—repeatedly failing to reach vulnerable households. As Cerna Aragon has warned, “[I]n a state that barely knows its population”, “the technocratic asset of a rigorous algorithmic system brought woe for those in need. These technologies, by design and implementation, render some people invisible” (2021, p. 123). In India the biometric welfare system has

S. Milan (✉)

University of Amsterdam, Amsterdam, Netherlands

e-mail: s.milan@uva.nl

© The Author(s) 2022

A. Hepp et al. (eds.), *New Perspectives in Critical Data Studies*,
Transforming Communications – Studies in Cross-Media Research,
https://doi.org/10.1007/978-3-030-96180-0_19

445

come to a standstill due to pandemic-induced hygiene rules (Masiero, 2021), platform delivery workers in Barcelona (Spain) face a number of lose-lose dilemmas between survival and safety (Vieira, 2020), and in Ghana the government exploited the emergency to pass permanent legislation increasing state control over the national telecommunication system (Oduro-Marfo, 2020). Evidently, the COVID-19 crisis has exposed the open wounds of “the first pandemic of the datafied society” (Milan & Di Salvo, 2020), with the most vulnerable individuals and communities often paying the highest price. It has also laid bare how data power, understood as the variety of “problematic consequences of widespread datafication” (Kennedy & Hill, 2016, p. 775), evolves under the pressures of the pandemic, in ways that might undermine citizen agency even further.

The pandemic has considerably changed our lifestyles while also having effects on the information domain. We can identify as many as five significant adjustments. First, many of our daily activities have moved online and now unfold through a myriad of old and new e-commerce platforms, cloud computing, and videoconferencing facilities, exposing our tremendous dependence on for-profit digital infrastructures. Second, the increase in personal insecurity—for example, unemployment, poor access to health care, reduced mobility, and the suspension of school activities—has augmented social inequalities. It has paved the way for new forms of invisibility and exclusion to emerge, often propelled by algorithmic decision-making as in the case of Peru. Third, the uncertainties surrounding the virus as well as its related corrective measures have contributed to rising doubts among the populace, accelerating the spread of conspiracy theories and anti-scientific attitudes. Fourth, the techno-solutionism associated with the pandemic—see, for example, the governmental faith in contact tracing apps—has uncovered the tension between privacy and safety, and between individual and collective rights, often presented as irreconcilable dichotomies. Last but not least, the extended lockdowns have curbed the ability to mobilise social movements and other forms of aggregation in the public sphere, relegating the formation and expression of political opinion to the web.

Against this backdrop, data activism has stood out as a solid response to many of these problems, further consolidating its role within the social movement ecosystem. Emerging within the civil society realm, data activism embraces initiatives and mobilisations that take a critical approach to information and software and seek to marshal them for the social good—be it protecting online dissent and people’s privacy, “translating” numbers

into accessible stories, making the state more transparent, or mobilising for data justice. As we shall see, data activists have sought to meet the information and care needs of the citizenry during the pandemic. They have helped the general public to make sense of the tensions associated with the “governance by indicators” (Davis et al., 2012) that have characterised the government response to the crisis across the world. Among others, they have contributed to generate knowledge and alternative narratives of the emergency. Conversing with critical data studies and the sociology of social movements, this chapter analyses the evolution of data activism under the pressure of the first pandemic of the datafied society. In particular, it explores how citizens, advocates, and variably skilled users have engaged with data and technology in the wake of the COVID-19 crisis, surveying emerging practices of data activism as well as the challenges activists are likely to face in the post-pandemic world. It also derives lessons learnt that might inform critical data studies as the discipline further consolidates its role as interpreter of the datafied society.

The chapter is organised as follows. It starts by identifying two major shifts in data power that have been significantly accelerated by the global health crisis, namely the shift from state to corporate data infrastructure, and from private control over one’s own data to the monopoly of digital platforms. It is in this complex environment that data activists intervene. The chapter then reviews the burgeoning literature on data activism, positioning the role of data activists as an emerging counterpower intercepting the above-mentioned shifts in data power. Next, five main tactics adopted by data activists during the pandemic are identified and described, followed by an analysis of three questions that data activists will have to face in the post-pandemic world. Finally, the chapter concludes by reflecting on new perspectives in critical data studies opened up by the evolution of data activism. The analysis is based on news sources and participant observation data assembled since early 2020, and with examples collected in the framework of the *COVID-19 from the margins* blog and book project (Milan et al., 2021).

TWO SHIFTS OF DATA POWER

As the world battled the COVID-19 pandemic with its corollary of insecurity and fear, power-holders and laypersons alike nurture hopes for “silver bullet” solutions such as smart applications that might help to win over the virus. Data have become a fundamental ingredient of any reporting on

disease diffusion, betraying a positivist belief on the power of information to solve the most pressing problems of our times, on the grounds that “with enough data, the numbers speak for themselves” (Anderson, 2008). But these developments are not free of contradictions. Meanwhile, an “epic battle against coronavirus misinformation” (Ball & Maxmen, 2020) goes hand in hand with the normalisation of large-scale surveillance, putting civil societies under strain. These tensions are typical of what has been termed “surveillance capitalism”, a system of power and trade grounded on the transformation of human actions and interactions into data points which can be quantified, analysed, and monetised (Zuboff, 2019). They have, however, been considerably amplified by the pandemic.

Since the inception of the COVID-19 crisis, the tech industry has assumed an ever more important role in providing crucial technical solutions to daily needs and activities. As a result, it has seen its profit margins rise massively, strengthening its quasi-monopoly in sectors like e-commerce, cloud computing, and content streaming. By way of example, Amazon doubled its revenues in the first quarter of 2020 (Faulkner, 2020), while the returns of Azure, Microsoft’s cloud computing services, have increased by 48 per cent since the global explosion of the pandemic (Tilley, 2020). In the meantime, governments increasingly look at the possibilities offered by digital services in the response to the virus, verging on a one-size-fits-all techno-solutionism (Milan, 2020). The launch of questionable “immunity passports” based on “global” digital standards have raised concerns amongst privacy advocates and medical experts alike (Voo et al., 2020). State sovereignty appears increasingly at risk as many strategic infrastructures such as health care data or border control technology move into corporate hands (Latonero & Kift, 2018; Charitsis, 2019), while many human beings such as undocumented migrants are “invisibilized” by exclusionary data infrastructure and policies (Pelizza et al., 2021) In other words, data power—that is, the power of data actors and structures as well as the power exerted by data on social life—is rapidly evolving, not necessarily in the direction of progress or social justice.

Data power is shifting in two, worrying directions. On the one hand, state functions, prerogatives, and infrastructures are slowly but steadily moving towards the corporate world. This comes at a high cost: state oversight and sovereignty lose ground, while state powers (e.g., in the realm of repression and control) are augmented. Think, for example, of the involvement in the operations of the United States Immigration and Customs Enforcement agency of Palantir Technologies, a Silicon Valley

company specialised in case management and data software. The partnership resulted in a “cruel new era of data-driven deportation”, allowing authorities to cross-reference datasets more efficiently with the goal of identifying and expatriating migrants living illegally within national borders (Bedoya, 2020). On the other hand, we observe a shift from individual control over private information such as political preferences and biographical and biomedical data away from individuals themselves and into the grey area of corporate data infrastructure. For instance, in many countries, digital identity systems centralise medical and tax information in a single domain, often permeable to disparate state agencies and their commercial data management partners; biometrical systems track potential recipients of state welfare in countries as diverse as India and Colombia (cf. López, 2020).

To be sure, the two shifts in data power we have identified are the result of a complex process of rethinking access to information in the digital age—the so-called computational turn (Berry, 2012)—which started over half a century ago while the pandemic has played a part in dramatically accelerating. Tech solutions and functionalities such as location tracking (e.g., in contact tracing applications) and remote video surveillance (the infamous “proctoring” in university exams, see Maalsen & Dowling, 2020) have been introduced to facilitate activities otherwise paused by the rapid diffusion of the severe acute respiratory syndrome coronavirus 2. These developments have resulted in the fast-tracked legitimisation of large-scale data surveillance, with seemingly no end in sight. “Largely without public debate—and absent any new safeguards, we’ve become even more dependent on a technological ecosystem that is notoriously insecure, poorly regulated, highly invasive and prone to serial abuse”, cautioned Canadian cybersecurity scholar Ronald J. Deibert (2020).

In addition, the imperative to identify solutions as fast as possible, typical of emergency situations like a global pandemic (cf. Calhoun, 2010), has encouraged governments to rely on ad hoc groups of experts as the central feature of crisis governance. “Task forces”, “scientific councils”, crisis managers, and special advisors have become a central cog in the machine of the problem-solving infrastructure—but at a high price in terms of democratic oversight. These technocrats are usually removed from existing mechanisms of democratic accountability, such as elections, and criteria for their selection are rarely made transparent. These moves have the added value of deflecting attention from broader systemic failures (such as the continued budget cuts affecting public health care systems in

Western Europe since the 1990s) and are expected to increase citizen confidence in their governments. However, this strategy seems to have achieved mixed results, as the increasing frequency of anti-lockdown or no-vax protests across the globe seem to signal (cf. Schradie, 2020). It is in this complex scenario that data activists operate.

DATA ACTIVISM AS AN ALTERNATIVE TO DOMINANT DATA POWER

Surveillance capitalism has long been met by growing user concern about the aggressive intermediation of the industry, including social media platforms (Brown, 2020a). Also, state snooping, perpetrated, for example, through “smart city” projects, has been increasingly countered by grassroots resistance and attempts to create viable alternatives (Lynch, 2020). Over time, datafication and surveillance have become a target of contentious politics, permeating the agenda of social movements worldwide: think, for example, of Hong Kong pro-democracy protesters taking down “smart lampposts” suspected to deploy facial recognition technology (*Hong Kong: Anti-Surveillance Protesters Tear down “smart” Lamp-Post*, 2019). Revealing our dependence on the tech industry, the COVID-19 pandemic has registered a renewed interest in questions of data power.

As civil society’s response to datafication, data activism is simultaneously a by-product of the datafied society and one of its most fascinating manifestations. Broadly speaking, it questions the role of data and data infrastructure (such as datasets, dashboards, apps, monitoring devices) in promoting or undermining social justice. It comprises a range of autonomous and rebellious actions that leverage technology and information to exert social change and to promote citizen agency and data justice.¹ It represents a practical counterpower to data power as described above, in that it systematically seeks to keep in check and to offset the consequences of a ubiquitous surveillance capitalism, while trying to exploit technological innovation for the social good.

¹Data activism subsumes under the same label a number of distinct politically engaged identities, including but not limited to digital rights activism (cf. Maréchal, 2015), civic hacking (Schrock, 2016), transparency activism (Rajão & Jarke, 2018), and counting. While not all of these groups might identify themselves under the sphere of “data activism”, they share a similar understanding of the role data and data infrastructure play in promoting justice and change.

Data activism is characterised by a distinctive action repertoire which focuses on the role of information and software in producing (or preventing) social change. Social movement scholars have characterised action repertoires as “sites of contestation in which bodies, symbols, identities, practices, and discourses are used to pursue or prevent changes in institutionalized power relations” (Taylor & van Dyke, 2004, p. 268). An action repertoire may embrace a number of distinct tactics, that is to say “alternative means of acting together on shared interest” in order to “make a statement of some kind” (Tilly, 1983, pp. 463–464). It is worth noting that tactics are not neutral means; rather, they “represent important routines, emotionally and morally salient in these people’s lives. Just as their ideologies do, their activities express protestors’ political identities and moral visions” (Jasper, 1997, p. 237).

If we look at tactical preferences of data activists as they fight a variety of manifestations of data power—most notably mass surveillance and the poor transparency practices of public administrations—we can identify at the bare minimum two ideal types of data activism (Milan & Gutierrez, 2015; Milan & van der Velden, 2016). These ideal types reflect distinct interpretations of the role of information in society, but share an overall “data justice” (Dencik et al., 2019) agenda. As is often the case with ideal types, there are not necessarily clear-cut boundaries between the two. However, they represent two distinct tactical preferences which typically reflect diverse identities. We can understand the two ideal types as positioned along the continuum of citizen engagement with data.

At one end of the spectrum, we find re-active data activism, which voices concerns over the social costs of “big data” and artificial intelligence technology in matters of surveillance and repression and exposes the consequent depletion of political agency. Examples of re-active data activism include the development of software able to offset privacy risks (Gürses et al., 2016), the promotion of security training to encourage human rights defenders to encrypt their communications (Daskal, 2018), and the forging of alternative imaginaries in an attempt to make sense of the complexity of our digital environment (Kazansky & Milan, 2021). In summary, re-active data activists seek to thwart the diffusion of “surveillance realism”, whereby citizens can no longer imagine a society without mass surveillance (Dencik, 2018).

At the opposite end of the spectrum, pro-active data activists see information in all its present denominations as a key currency in the fight for progressive social change (Gutierrez, 2018). They may, for example, use

publicly available data or access to information requests to audit the state (Torres, 2019). They engage in data-based storytelling to support public journalism or advocacy goals (Baack, 2018). They might browse the internet to collect evidence of human rights violations (Deutch & Habal, 2018) and gather publicly available data to be used in a court of law (Heller et al., 2012).

Focusing on the role of data as mediators of social action is another way of approaching data activism, as proposed by Beraldo and Milan (2019). Broadly understood, data can indicate what is at stake in an instance of collective action, that is to say data become issues and/or objects of political struggle in their own right. The mobilisation against the dismantlement of evidence-based environmental governance by the Trump administration (United States, 2016) is a case in point: over 175 US volunteers, including technologists and activists, embarked to archive vulnerable federal data corroborating climate change and environmental injustice, in an act of “data resistance” (Vera et al., 2018). But data can also become part of a movement’s action repertoire, turning into a modular tool for political struggle mobilised alongside “traditional” tactics such as street protest, campaigning, or civil disobedience. Think for instance of Amnesty International’s Decoders project, re-interpreting for the digital age the established tactic of “witnessing” as a way to generate evidence of human rights violations. Witnessing injustices with data means gathering evidence of historical abuses from newly digitised documents, and collecting proof of online abuse through the classification of data from the microblogging platform Twitter (Gray, 2019).

A second important distinction advanced by Beraldo and Milan (2019) concerns data activism as an individual practice versus data activism as collective action *strictu sensu*. Like earlier forms of activism focusing on media and technology, such as open-source software development (Coleman, 2013) or anti-copyright actions (Postigo, 2012), data activism unfolds into a myriad of individual practices such as encryption or access to information requests. These individual practices, however, assume meaning and exert impact only in relation to a broader community of acting individuals. Encrypting one’s digital communications is a typical example: it is implemented by individual users, but it can only work when at least two people exchange encryption keys. Similar to what has been observed about other social movements, “there is protest even when it is not part of an organized movement” (Jasper, 1997, p. 5). Rather, activism results in

(shared, recurrent) practices questioning or critically deploying data infrastructures.

The next section surveys how data activist tactics have been deployed during the pandemic by data activists often in collaboration with others, including volunteer citizens, in the hope of exploiting the potential of information to offset the social costs of the COVID-19 crisis.

DATA ACTIVIST TACTICS DURING THE COVID-19 PANDEMIC

We have seen how the first global health scare of the datafied society has exposed fundamental tensions between privacy and safety, and between civil liberties and public health (see also Kitchin, 2020). In the increasing complexity of our digital ecosystem, where previously offline activities and forms of social aggregation have resorted to the digital realm, data activists have positioned themselves as the “interpreters” of these tensions to the benefit of the citizenry at large. A number of initiatives have materialised across the globe to help mitigate the impact of the pandemic, for example, producing “alternative” knowledge about virus diffusion, monitoring state measures, or building health care aids to counter the scarcity of medical devices. To make sense of the variety of grassroots initiatives that emerged during the pandemic, we can distinguish five focal approaches that are implemented by data activists or inspired by and derived from data activism and neighbouring communities of practice, such as the hacker movement (see, e.g., Jordan, 2016; Maxigas, 2012): counting, debunking, making, witnessing, and shielding, which I explore below. Interestingly, these tactics are more generally available to civil society actors in the pursuit of a collective response to the socio-economic crisis brought about by the pandemic.

Counting

Quantification is particularly alluring in uncertain times like a pandemic. This is because indicators and “numbers convey an aura of objective truth and scientific authority” (Merry, 2016, p. 1). Predictably, numbers have been at the core of the governmental and journalistic narrative of the pandemic. However, criticism emerged about partial data, non-transparent governments, and poorly reported figures, revealing the ways in which

new “data gaps” currently haunt marginal communities and less resourced countries in the Global South (Milan & Treré, 2021). The archetypical data activist tactic of counting has been employed in many corners of the globe to produce “alternative” evidence about the pandemic. In Indonesia, to counter the absence of reliable official statistics on virus diffusion and the inability of the government to provide testing kits, citizens teamed up to collectively generate an alternative dataset by registering online suspected unreported cases in their neighbourhoods. Digital “information hubs” emerged to improve data transparency and help raise awareness among the citizenry (Nadzir, 2020). In Brazil, data activism proved “essential to challenge the [coronavirus-denying] state narrative about the pandemic and to prevent more deaths from COVID-19”. Data activists “assumed governmental functions” by providing reliable figures to substantiate decisions. In particular, the activist group Brasil.IO independently collected data on COVID-19 cases and deaths, often manually compiling datasets and tabulating hundreds of local epidemiological bulletins. It also made available open-source software to empower others to scrape the datasets to fit their needs and run their own analyses (Füßy, 2021).

Debunking

No matter how seductive, numbers and indicators, anthropologist Sally E. Merry reminds us, are deeply affected by “the extensive interpretative work that goes into their construction” (2016, p. 1). But data activists can help interpret data in view of generating “alternative data epistemologies” to help non-experts interpret complex realities described through data (Milan & van der Velden, 2016). This skillset was put to good use during the pandemic when individuals and groups promoted initiatives oriented towards opening up the data vaults of public institutions, enhancing transparency and advancing independent investigations. They also spearheaded projects designed to mediate data for larger, lay audiences. In South Africa, a Johannesburg-based data journalism team aptly called the Media Hack Collective launched an independent national COVID-19 data visualisation dashboard with the goal of complementing the official narrative by making data available to the public (Odendaal, 2021). “Data silences”, meaning the lack of data on marginal communities such as migrants, have been countered by national advocacy and campaigning initiatives. In Scotland, the non-governmental organisation Coalition for Racial Equality

and Rights protested the poor data available regarding the impact of COVID-19 on minority populations living within national borders (Daly, 2021). Further, across the globe, activists have been calling for pandemic data to be released in an “open” format as a key step towards publicly informed evidence-based policymaking (Zingales, 2021).

Making

On account of the virus’ sudden mass diffusion and the scarcity of medical equipment to protect caregivers or support declining respiratory functions, data activists have intervened by mobilising their “maker” skills. Although the maker and the data activism communities differ substantively (with the former being highly curated and removed from the grassroots, as illustrated by Hepp, 2020), the two share an “ethos of creativity, experimental and experiential learning, and sharing” (Davies, 2017, p. 171). During the pandemic this ethos has been applied to do-it-yourself (DIY) digital fabrication as well as to open hardware/software development (cf. Söderberg & Delfanti, 2015). For instance, data activists and professionals alike have attempted to produce DIY responses to the shortage of personal protective equipment (Richterich, 2020). In Lombardia, the Italian region that was most severely hit by COVID-19, a coalition of citizens, makers, and local administrations teamed up to transform consumer snorkelling masks into respirators for hospitals facing equipment shortages. Using a 3D printer made available by a local school to manufacture adaptors and fittings, the group not only began producing the makeshift respirators but also made the design available for noncommercial use (Morandi, 2020). Similarly, the Kenyan Ushahidi open-source mapping software, particularly popular among data activists since its launch, has been deployed to various ends including geolocating local needs and resources in quarantined Spain, ensuring food and medicine supplies are distributed to vulnerable communities in Italy, and documenting the outbreak in Nigeria, with over 200 grassroots mapping projects started in mid-March 2020 alone (Lungati, 2020).

Witnessing

The *SARS-CoV-2* virus was first identified in mainland China—a country plagued by pervasive information censorship. The first public reports of the virus’ aggressiveness and its diffusion in the urban area of Wuhan, in

the populous Hubei region, were met by government attempts to filter social media such as Sina Weibo in attempts to covering up the outbreak (Brown, 2020b). Chinese data activists, however, sought to preserve the memory of the communities affected by the pandemic. Evading the prevailing internet censorship by using Western services that still escape censorship, such as the software repository GitHub, they rallied volunteers in a collective documentation project, giving birth to alternative media projects involving citizens as well as journalists (Merini, 2021). “Witnessing” through data in the pandemic comprised collecting evidence to act, giving voice to marginalised groups, and enabling collective memory to counter mainstream narratives denying the pandemic or other social problems exacerbated by the lockdowns, such as the increased incidence of domestic violence. In Mexico, when the lockdown prevented feminist groups from taking to the streets while President Andrés Manuel López Obrador denied the increase of domestic violence within quarantined families, women mobilised on social media *en masse* using the hashtag #NosotrasTenemosOtrosDatos (“we have other data”) in their demands for transparency in the identification and release of official figures (Villaseñor, 2021).

Shielding

In times of COVID-19, thermal facial recognition technology is regularly deployed to regulate access to public space such as airports (Kitchin, 2020). In China first, and later across the European Union, citizens were required to scan QR codes when accessing public space to verify their infection or vaccination status (see, e.g., Zhao, 2020). Once rolled out during crisis situations, however, these technologies often stay in place (see also Deibert, 2020). In the attempt to navigate the tension between privacy and public health, data activists have raised their voice against biometric mass surveillance presented as the necessary deterrent against virus diffusion, in the hope to “shield” the citizenry from unnecessary privacy breaches. Contact tracing apps are a case in point: they have been variably met with resistance across the world, which resulted in generally low adoption rates in most Western countries. In the Netherlands, a coalition formed by the non-governmental organisations such as Bits of Freedom, Waag, Platform Burgerrechten, and Amnesty International analysed the government plans for a contact tracing app, identifying ten principles to ensure that it would safeguard individual freedoms and rights, social

security and cohesion, and pressed the government to respect these principles—with some success (VeiligTegenCorona.nl, 2020). In the European Union, a wide coalition of civil society organisations launched the “Reclaim Your Face” campaign in October 2020, which maintained that facial recognition technology is “Secretive. Unlawful. Inhumane” (ReclaimYourFace, 2020). They also launched a European Citizens’ Initiative in early 2021, with the aim of gathering 1 million signatures across Europe and petition the European Union for a new law on the issue.

All things considered, data activism tactics have proved crucial in mitigating the negative effects of the pandemic on the citizenry. They have expanded the toolbox available to civil society actors so that they might get to grips with data power in all its denominations, be them of an informational or an infrastructural nature. But what does the future bear for data activism? The following section delves into this question and reflects on the open challenges data activism might face in the post-pandemic world.

DATA ACTIVISM RELOADED: OPEN QUESTIONS FOR THE POST-PANDEMIC WORLD

Notwithstanding the popularity of data activism tactics during the pandemic, there are at least three open questions that activists might have to face in the coming years if they are to maintain their active role as the interpreters of and as a counterforce to dominant data power.

The first challenge has to do with infrastructure and the ambiguous attitude displayed by data activists when it comes to distinguishing ideals from practice. Today, social movements rely on commercial infrastructure to mobilise, organise, and campaign. They reach their potential audiences on commercial social media services such as Facebook, Instagram, or Twitter; they petition on Google Forms; and they organise gatherings on Zoom or Microsoft Teams. Contrary to their predecessors of the 1970–1990s, who postulated the value of autonomy and self-determination in the realm of communication infrastructure (see, amongst others, Couldry & Curran, 2003; Downing, 2001; Milan, 2013), contemporary movements seem to have given up their role of critics of capitalism and surveillance capitalism in particular. Data activists, too, embody contradictory positions surrounding the role of corporate digital infrastructure: on the one hand, they embody a fierce critique of platforms and other commercial services, but on the other hand, they fail to embrace or promote radical practices of self-organisation online. In other words, their critique

of data power does not adequately translate into an equally critical technical practice. However, the time might be ripe for significant change to happen. The change in privacy policy of the chat application WhatsApp in early 2021 has been followed by a surge in Signal and Telegram users, two privacy-friendly alternatives, forcing the company to address user concerns (Statt, 2021)—revealing that users are increasingly sensitive to matters of data power and thirsty for alternatives.

The second open question data activists might have to address in the near future concerns the impending forms of “data poverty” (Milan & Tréré, 2020) that the pandemic has revealed. Data poverty has to do with the invisibility of certain social groups and communities along the lines of the pandemic’s digital governance. As the Peruvian example made apparent, vulnerable categories must be visible to the state to benefit from welfare support, with privacy concerns being somewhat of a luxury in extreme poverty situations. Because today “data is tied to peoples’ visibility, survival, and care”, data poverty exposes visibility as “a sine qua non condition of existence” in the datafied society, which “gets to the bottom of what it means to be human” (2020, p. 2). But data activists have long assumed that the human right to privacy is (and should be) of primary concern to everyone, indirectly disregarding the fact that “being visible” might sometimes be more important. Re-negotiating this potential clash of values and priorities, re-assessing the question of privilege in relation to questions of data power, and branching out to other social groups whose top concerns have not (yet) emerged in the realm of digital rights, could be transformative when it comes to societal understanding of the perils of mass surveillance.

The third major challenge that data activists are likely to face in the post-pandemic world calls into question the multifaceted problem of digital literacy. Digital literacy is still relatively low in society: in 2019, 54 per cent of the European Union population had low or basic digital skills (Eurostat, 2019). But digital literacy encounters other types of specialised knowledge, in times in which people are increasingly critical of scientific knowledge or might simply be willing to trade privacy and data protection for a return to “normality”. Understanding the risks of discrimination associated with immunity passports rolled out on a global or regional scale, for example, requires an appreciation of the technicalities of technology standards alongside the explanatory value of serological tests or vaccines. Data activists should identify the promotion of digital (data) literacy at large scale as a fundamental condition of survival for their progressive

agenda. Furthermore, any efforts in support of digital literacy should not underestimate the current breadth of the digital divide (Van Dijk, 2020), considering that only 53 per cent of the world's population has "some" access to the internet (International Telecommunication Union, 2019).

WHAT PATH FOR CRITICAL DATA STUDIES?

This chapter has analysed data activism during the era of the COVID-19 pandemic, including tactics and outstanding issues, with a view of establishing the critical lessons the field of critical data studies might learn in the years to come. It has exposed how the COVID-19 pandemic has hastened a process of data power's centralisation, with two main shifts exacerbated by the global health crisis: state functions are increasingly delegated to the tech industry and key personal information is stored on corporate platforms. In this complex scenario, data activists represent a counterforce to predominant data power dynamics. Data activism has adopted five main tactics—counting, debunking, making, witnessing, and shielding—to mitigate the social impact of the crisis, contributing to raise awareness within civil society of the role played by information and software in contemporary societies. However, three open questions have the potential to jeopardise the advancement of data activism's agenda in the post-pandemic world: the inconsistent critique of infrastructure, the increase of data poverty and the related tension between privacy and visibility, digital literacy and the digital divide.

What can these observations on data activism tell us about critical data studies' prospects going forward? What new perspectives emerge to future-proof the discipline in a post-pandemic world? Still in its infancy, the interdisciplinary field of critical data studies has been at the forefront of the critical analysis of the relationship between data (and data infrastructures) and society. Scholars have foregrounded everyday forms of engagement with data (Kennedy, 2018), technical practice (e.g., Evans et al., 2020), and data practices (e.g., Neff et al., 2017), as well as the role of the state (e.g., Dillon et al., 2019) and industry (Couldry & Mejias, 2018). But we can identify at least two interconnected blind spots in the sprawling agenda of critical data scholars—and scrutinising the blind spots of data activism can help bring them into focus.

First, the datafied society is a deeply unequal society, where access, knowledge, infrastructures (cf. digital divide), and rights are not evenly distributed. Critical data studies should embrace an explicit (in)equality

agenda in its normative analysis of the consequences of datafication. Incorporating perspectives from de- and postcolonial studies (e.g., van Schie et al., 2020), for example, might help to close the gap, overcoming the use of notions such as colonialism as mere evocative metaphors. Second, in a world where privacy is still a luxury for many and data literacy largely a mirage, the field should engage with a critique of data universalism, that is, the tendency to interpret data practices and infrastructure through Western lenses, values, and lifestyles (Milan & Treré, 2019). Although data activism, to name just one social phenomenon of concern to critical data studies, appears in various sociocultural contexts, as testified by the examples illustrating this chapter, the bulk of the discipline is still disproportionately white and “Western”. Calls for “decolonizing” the discipline (e.g., Arora, 2019) or attempts to inject critical race and intersectionality perspectives (e.g., Ruberg & Ruelos, 2020) certainly move in the right direction. However, the field should be mindful of the risks connected to the “depoliticized languages of de-westernizing, internationalizing, and decolonizing” (Dutta, 2020, p. 228) and ought to simultaneously engage with the metalevel of institutional politics that interrogates “the politics of what counts as knowledge and how such counting is carried out within hegemonic structures” (Dutta, 2020, p. 233). Whether data activism and critical data studies will stand the test of time will depend on how seriously and skilfully these challenges will be addressed. Funding This project has received funding from the European Research Council (ERC) under the European Union’s Horizon 2020 research and innovation programme (grant agreement No. 639379-DATACTIVE; <https://data-activism.net>).

REFERENCES

- Anderson, C. (2008). The end of theory: The data deluge makes the scientific method obsolete. *Wired*. <https://www.wired.com/2008/06/pb-theory/>
- Arora, P. (2019). Decolonizing privacy studies. *Television & New Media*, 20(4), 366–378. <https://doi.org/10.1177/1527476418806092>
- Baack, S. (2018). Practically engaged. The entanglements between data journalism and civic tech. *Digital Journalism*, 6(6), 673–692. <https://doi.org/10.1080/21670811.2017.1375382>
- Ball, P., & Maxmen, A. (2020). The epic battle against coronavirus misinformation and conspiracy theories. *Nature*. <https://www.nature.com/articles/d41586-020-01452-z>

- Bedoya, A. M. (2020). The cruel new era of data-driven deportation. *Slate*. <https://slate.com/technology/2020/09/palantir-ice-deportation-immigrant-surveillance-big-data.html>
- Beraldo, D., & Milan, S. (2019, July/December). From data politics to the contentious politics of data. *Big Data & Society*, 1–11. <https://doi.org/10.1177/2053951719885967>
- Berry, D. M. (2012). Introduction: Understanding the digital humanities. In D. M. Berry (Ed.), *Understanding digital humanities* (pp. 1–20). Palgrave Macmillan.
- Brown, A. J. (2020a). “Should I stay or should I leave?”: Exploring (dis)continued Facebook use after the Cambridge Analytica scandal. *Social Media + Society*, 6(1). <https://doi.org/10.1177/2056305120913884>
- Brown, L. (2020b). Fighting for Covid information: Meet the people who are ensuring that even those in the most censored environments receive accurate information on the pandemic. *Index on Censorship*, 49(4), 102–104. <https://doi.org/10.1177/0306422020981289>
- Calhoun, C. (2010). *The idea of emergency: Humanitarian action and global (dis)order*. Zone Books.
- Cerna Aragon, D. (2021). On not being visible to the state: The case of Peru. In S. Milan, E. Treré, & S. Masiero (Eds.), *COVID-19 from the margins: Pandemic invisibilities, policies and resistance in the datafied society*. Institute of Network Cultures.
- Charitsis, V. (2019). Survival of the (data) fit: Self-surveillance, corporate wellness, and the platformization of healthcare. *Surveillance & Society*, 17(1/2). <https://doi.org/10.24908/ss.v17i1/2.12942>
- Coleman, G. (2013). *Coding freedom: The ethics and aesthetics of hacking*. Princeton University Press.
- Couldry, N., & Curran, J. (Eds.). (2003). *Contesting media power: Alternative media in a networked world*. Rowman & Littlefield.
- Couldry, N., & Mejias, U. A. (2018). Data colonialism: Rethinking big data’s relation to the contemporary subject. *Television & New Media*, 20(4), 336–349. <https://doi.org/10.1177/1527476418796632>
- Daly, A. (2021). COVID-19 data on the fringes: The Scottish story. In S. Milan, E. Treré, & S. Masiero (Eds.), *COVID-19 from the margins. Pandemic invisibilities, policies and resistance in the datafied society*. Institute of Network Cultures.
- Daskal, E. (2018). Let’s be careful out there ...: How digital rights advocates educate citizens in the digital age. *Information, Communication & Society*, 21(2), 241–256. <https://doi.org/10.1080/1369118X.2016.1271903>
- Davies, S. R. (2017). Characterizing hacking: Mundane engagement in US hacker and makerspaces. *Science, Technology, & Human Values*, 43(2), 171–197. <https://doi.org/10.1177/0162243917703464>

- Davis, K. E., Fisher, A., Kingsbury, B., & Merry, S. E. (Eds.). (2012). *Governance by indicators: Global power through quantification and rankings*. Oxford University Press.
- Deibert, R. J. (2020). The pandemic has made us even more dependent on a highly invasive technological ecosystem. *The Globe and Mail*. <https://www.theglobeandmail.com/opinion/article-the-pandemic-has-made-us-even-more-dependent-on-a-highly-invasive/>
- Dencik, L. (2018). Surveillance realism and the politics of imagination: Is there no alternative? *Krisis: Journal for Contemporary Philosophy*, 1, 31–43.
- Dencik, L., Hintz, A., & Cable, J. (2019). Towards data justice: Bridging anti-surveillance and social justice activism. In D. Bigo, E. Isin, & E. Ruppert (Eds.), *Data politics. Worlds, subjects, rights* (pp. 167–185). Routledge.
- Deutch, J., & Habal, H. (2018). The Syrian archive: A methodological case study of open-source investigation of state crime using video evidence from social media platforms. *State Crime*, 7(1), 46–76.
- Dillon, L., Lave, R., Mansfield, B., Wylie, S., Shapiro, N., Chan, A. S., & Murphy, M. (2019). Situating data in a Trumpian era: The environmental data and governance initiative. *Annals of the American Association of Geographers*, 109(2), 545–555. <https://doi.org/10.1080/24694452.2018.1511410>
- Downing, J. D. H. (2001). *Radical media: Rebellious communication and social movements*. Sage.
- Dutta, M. J. (2020). Whiteness, internationalization, and erasure: Decolonizing futures from the Global South. *Communication and Critical/Cultural Studies*, 17(2), 228–235. <https://doi.org/10.1080/14791420.2020.1770825>
- Eurostat. (2019). *Individuals' level of digital skills*. <https://appsso.eurostat.ec.europa.eu/nui/submitViewTableAction.do>
- Evans, S. W., Leese, M., & Rychnovská, D. (2020). Science, technology, security: Towards critical collaboration. *Social Studies of Science*. <https://doi.org/10.1177/0306312720953515>
- Faulkner, C. (2020). Amazon doubled its profit during a pandemic. *The Verge*. <https://www.theverge.com/2020/7/30/21348368/amazon-q2-2020-earnings-covid-19-coronavirus-jeff-bezos>
- Füssy, P. (2021). Liberating COVID-19 data with volunteers in Brazil. In S. Milan, E. Treré, & S. Masiero (Eds.), *COVID-19 from the margins. Pandemic invisibilities, policies and resistance in the datafied society*. Institute of Network Cultures.
- Gray, J. (2019). Data witnessing: Attending to injustice with data in Amnesty International's Decoders project. *Information, Communication & Society*, 971–991. <https://doi.org/10.1080/1369118X.2019.1573915>
- Gürses, S., Kundnani, A., & van Hoboken, J. (2016). Crypto and empire: The contradictions of counter-surveillance advocacy. *Media, Culture & Society*, 38(4), 576–590.

- Gutierrez, M. (2018). *Data activism and social change*. Palgrave Macmillan.
- Heller, C., Pezzani, L., & Studio, S. (2012). *Forensic oceanography. Report on the "left-to-die boat"*. Goldsmiths, University of London. <https://content.forensic-architecture.org/wp-content/uploads/2019/06/FO-report.pdf>
- Hepp, A. (2020). The fragility of curating a pioneer community: Deep mediatization and the spread of the quantified self and maker movements. *International Journal of Cultural Studies*. <https://doi.org/10.1177/1367877920922867>
- Hong Kong: Anti-surveillance protesters tear down "smart" lamp-post. (2019, August 26). <https://www.theguardian.com/world/video/2019/aug/26/hong-kong-anti-surveillance-protesters-tear-down-smart-lamp-post-video>
- International Telecommunication Union. (2019). *Individuals using the internet, 2015–2019*. <https://www.itu.int/en/ITU-D/Statistics/Pages/stat/default.aspx>
- Jasper, J. M. (1997). *The Art of moral protest: Culture, biography, and creativity in social movements*. Chicago University Press.
- Jordan, T. (2016). A genealogy of hacking. *Convergence*, 23(5), 528–544. <https://doi.org/10.1177/1354856516640710>
- Kazansky, B., & Milan, S. (2021). Bodies not templates: Contesting mainstream algorithmic imaginaries. *New Media & Society*, 23(2), 363–381. <https://doi.org/10.1177/1461444820929316>
- Kennedy, H. (2018). Living with data: Aligning data studies and data activism through a focus on everyday experiences of datification. *Krisis: Journal for Contemporary Philosophy*, 1. <http://krisis.eu/living-with-data/>
- Kennedy, H., & Hill, R. L. (2016). The pleasure and pain of visualizing data in times of data power. *Television & New Media*, 18(8), 769–782. <https://doi.org/10.1177/1527476416667823>
- Kitchin, R. (2020). Civil liberties or public health, or civil liberties and public health? Using surveillance technologies to tackle the spread of COVID-19. *Space and Polity*, 1–20. <https://doi.org/10.1080/13562576.2020.1770587>
- Latonero, M., & Kift, P. (2018). On digital passages and borders: Refugees and the new infrastructure for movement and control. *Social Media + Society*, 4(1). <https://doi.org/10.1177/2056305118764432>
- López, J. (2020). *Experimentando con la pobreza: El Sisbén y los proyectos de analítica de datos*. Fundación Karisma. <https://web.karisma.org.co/wp-content/uploads/download-manager-files/Experimentando%20con%20la%20pobreza.pdf>
- Lungati, A. O. (2020). *Ushahidi in the era of COVID 19*. Ushahidi. <https://www.ushahidi.com/blog/2020/03/30/ushahidi-in-the-era-of-covid-19>
- Lynch, C. R. (2020). Contesting digital futures: Urban politics, alternative economies, and the movement for technological sovereignty in Barcelona. *Antipode*, 52(3), 660–680. <https://doi.org/10.1111/anti.12522>

- Maalsen, S., & Dowling, R. (2020). Covid-19 and the accelerating smart home. *Big Data & Society*, 7(2). <https://doi.org/10.1177/2053951720938073>
- Maréchal, N. (2015). Ranking digital rights: Human rights, the internet and the fifth estate. *International Journal of Communication*, 9, 3440–3449.
- Masiero, S. (2021). *Beyond touchscreens: The perils of biometric social welfare in lockdown. COVID-19 from the margins: Pandemic invisibilities, policies and resistance in the datafied society*. Institute of Network Cultures.
- Maxigas. (2012, June). Hacklabs and hackerspaces – Tracing two genealogies. *Journal of Peer Production*, 2. <http://peerproduction.net/issues/issue-2/peer-reviewed-papers/hacklabs-and-hackerspaces/>
- Merini, K. (2021). In memory of Covid-19 in China: Forms of digital resistance towards censorship. In S. Milan, E. Treré, & S. Masiero (Eds.), *COVID-19 from the margins. Pandemic invisibilities, policies and resistance in the datafied society*. Institute of Network Cultures.
- Merry, S. E. (2016). *The seductions of quantification: Measuring human rights, gender violence, and sex trafficking*. University of Chicago Press.
- Milan, S. (2013). *Social movements and their technologies: Wiring social change*. Palgrave Macmillan.
- Milan, S. (2020, July–December). Techno-solutionism and the standard human in the making of the COVID-19 pandemic. *Big Data & Society*, 1–7. <https://doi.org/10.1177/2053951720966781>
- Milan, S., & Di Salvo, P. (2020, June 8). Four invisible enemies in the first pandemic of a “datafied society”. *Open Democracy*. <https://www.opendemocracy.net/en/can-europe-make-it/four-invisible-enemies-in-the-first-pandemic-of-a-datafied-society/>
- Milan, S., & Gutierrez, M. (2015). Citizens’ media meets big data: The emergence of data activism. *Mediaciones*, 14, 120–133. <https://doi.org/10.26620/uniminuto.mediaciones.11.14.2015.120-133>
- Milan, S., & Treré, E. (2019). Big data from the south(s): Beyond data universalism. *Television & New Media*, 20(4), 319–335. <https://doi.org/10.1177/1527476419837739>
- Milan, S., & Treré, E. (2020, July–September). The rise of the data poor: The COVID-19 pandemic seen from the margins. *Social Media + Society*, 1–5. <https://doi.org/10.1177/2056305120948233>
- Milan, S., & Treré, E. (2021). A widening data divide: COVID-19 in the Global South. In S. Milan, E. Treré, & S. Masiero (Eds.), *COVID-19 from the margins: Pandemic invisibilities, policies and resistance in the datafied society*. Institute of Network Cultures.

- Milan, S., & van der Velden, L. (2016). The alternative epistemologies of data activism. *Digital Culture & Society*, 2, 57–74. <https://doi.org/10.14361/dcs-2016-0205>
- Milan, S., Treré, E., & Masiero, S. (2021). *COVID-19 from the margins: Pandemic invisibilities, policies and resistance in the datafied society*. Institute of Network Cultures.
- Morandi, R. (2020). La “officina” che assembla respiratori con le maschere Decathlon. *VareseNews*. <https://www.varesenews.it/2020/04/la-officina-assembla-respiratori-le-maschere-decathlon/917394/>
- Nadzir, I. (2020). Data activism and COVID-19 in Indonesia. *Jurnal Kependudukan Indonesia*. <https://doi.org/10.14203/jki.v0i0.578>
- Neff, G., Tanweer, A., Fiore-Gartland, B., & Osburn, L. (2017). Critique and contribute: A practice-based framework for improving critical data studies and data science. *Big Data*, 5(2), 85–97. <https://doi.org/10.1089/big.2016.0050>
- Odendaal, A. (2021). The trouble of visualizing COVID-19 during a nation-wide lockdown in South Africa. In S. Milan, E. Treré, & S. Masiero (Eds.), *COVID-19 from the margins. Pandemic invisibilities, policies and resistance in the datafied society*. Institute of Network Cultures.
- Oduro-Marfo, S. (2020). Ghana. Transient crisis, permanent registries. In L. Taylor, G. Sharma, A. Martin, & S. Jameson (Eds.), *Data justice and COVID-19: Global perspectives*. Meatspace Press.
- Pelizza, A., Milan, S., & Lausberg, Y. (2021). Undocumented migrants in COVID-19 counting: Rethinking the data-(in)visibility nexus. *Data & Policy*, 3, e18. <https://doi.org/10.1017/dap.2021.19>
- Postigo, H. (2012). *The digital rights movement: The role of technology in subverting digital copyright*. MIT Press.
- Rajão, R., & Jarke, J. (2018). The materiality of data transparency and the (re) configuration of environmental activism in the Brazilian Amazon. *Social Movement Studies*, 17(3), 318–332. <https://doi.org/10.1080/14742837.2018.1459297>
- ReclaimYourFace. (2020). *The problem. Secretive, Unlawful, Inhumane*. <https://reclaimyourface.eu/the-problem/>
- Richterich, A. (2020). When open source design is vital: Critical making of DIY healthcare equipment during the COVID-19 pandemic. *Health Sociology Review*, 29(2), 158–167. <https://doi.org/10.1080/14461242.2020.1784772>
- Ruberg, B., & Ruelos, S. (2020). Data for queer lives: How LGBTQ gender and sexuality identities challenge norms of demographics. *Big Data & Society*, 7(1). <https://doi.org/10.1177/2053951720933286>

- Schradie, J. (2020). "Give me liberty or give me Covid-19": Anti-lockdown protesters were never Trump puppets. *Communication and the Public*, 5(3–4), 126–128. <https://doi.org/10.1177/2057047320969433>
- Schrock, A. R. (2016). Civic hacking as data activism and advocacy: A history from publicity to open government data. *New Media & Society*, 18(4), 581–599. <https://doi.org/10.1177/1461444816629469>
- Söderberg, J., & Delfanti, A. (2015). Hacking hacked! The life cycles of digital innovation. *Science, Technology & Human Values*, 40(5), 793–798. <https://doi.org/10.1177/0162243915595091>
- Statt, N. (2021, January 12). WhatsApp clarifies it's not giving all your data to Facebook after surge in Signal and Telegram users. *The Verge*. <https://www.theverge.com/2021/1/12/22226792/whatsapp-privacy-policy-response-signal-telegram-controversy-clarification>
- Taylor, V., & van Dyke, N. (2004). "Get up, stand up": Tactical repertoires of social movements. In D. A. Snow, S. A. Soule, & H. Kriesi (Eds.), *The Blackwell companion to social movements*. Blackwell.
- Tilley, A. (2020, October 27). Microsoft's earnings continue to ride pandemic-fueled demand for cloud videogaming. *The Wall Street Journal*. <https://www.wsj.com/articles/microsofts-earnings-continue-to-ride-pandemic-fueled-demand-for-cloud-videogaming-11603831078>
- Tilly, C. (1983). Speaking your mind without election, surveys, and social movements. *The Public Opinion Quarterly*, 47(4), 461–478.
- Torres, G. (2019). Institutional resistance to transparency: The quest for public Sector Information in Mexico. *Journal of Resistance Studies*, 5(2), 68–96.
- Van Dijk, J. (2020). *The digital divide*. Polity Press.
- van Schie, G., Smit, A., & López Coombs, N. (2020). Racing through the Dutch Governmental data assemblage: A postcolonial data studies approach. *Global Perspectives*, 1(12779). <https://doi.org/10.1525/gp.2020.12779>
- VeiligTegenCorona.nl. (2020, April 8). *Bescherm onze gezondheid, maar bescherm ook onze rechten*. <https://www.veiligtegencorona.nl>
- Vera, L. A., Dillon, L., Wylie, S., Ohayon, J. L., Lemelin, A., Brown, P., Sellers, C., Walker, D., & The Environmental Data and Governance Initiative. (2018). Data resistance: A social movement organizational autoethnography of the environmental data and governance initiative. *Mobilization: An International Quarterly*, 23(4), 511–529. <https://doi.org/10.17813/1086-671X-24-4-511>
- Vieira, T. (2020). The lose-lose dilemmas of Barcelona's platform delivery workers in the age of COVID-19. *Social Sciences & Humanities Open*, 2(1), 100059. <https://doi.org/10.1016/j.ssaho.2020.100059>
- Villaseñor, T. (2021). La otra epidemia: Los feminicidios que no se cuentan. In S. Milan & Treré, e., Masiero, S. (Eds.), *COVID-19 from the margins. Pandemic invisibilities, policies and resistance in the datafied society*. Institute of Network Cultures.

- Voo, T. C., Clapham, H., & Tam, C. C. (2020). Ethical implementation of immunity passports during the COVID-19 pandemic. *The Journal of Infectious Diseases*, 222(5), 715–718. <https://doi.org/10.1093/infdis/jiaa352>
- Zhao, Y. (2020, October 16). When health code becomes health gradient: Safety or social control? *COVID-19 from the margins*. <https://data-activism.net/2020/10/bigdatasur-covid-when-health-code-becomes-health-gradient-safety-or-social-control-2/>
- Zingales, N. (2021). A Brazilian cautionary tale on pandemic negationism: Open data is an essential safeguard for evidence-based policy-making. In S. Milan & Tréré, e., Masiero, S. (Eds.), *COVID-19 from the margins. Pandemic invisibilities, policies and resistance in the datafied society*. Institute of Network Cultures.
- Zuboff, S. (2019). *The age of surveillance capitalism*. Profile Books.

Open Access This chapter is licensed under the terms of the Creative Commons Attribution 4.0 International License (<http://creativecommons.org/licenses/by/4.0/>), which permits use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence and indicate if changes were made.

The images or other third party material in this chapter are included in the chapter's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the chapter's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder.

