

Advancing data justice in public health and beyond

Lina Dencik

Cardiff University, UK

DencikL@cardiff.ac.uk

In their analysis of HIV surveillance in the context of cluster detection and response, Molldrem and Smith (2020) propose a framework for 'HIV data justice' as a way to advance a 'bioethics of the oppressed'. Such a framework makes explicit the politics of data that underpin contemporary prevention programs in public health, largely enabled by the digitization and linkage of clinical, research, and public health data infrastructures. Of concern are not only issues of consent, privacy and a possibility of refusal, but also the lack of shared understandings of how data should be interpreted and used. In particular, Molldrem and Smith point to the lack of engagement with affected communities and the active marginalization of those already precariously positioned in relation to HIV medical care.

In highlighting such issues, Molldrem and Smith engage with the broader field of data justice, applying key debates to the question of HIV surveillance. Whilst still nascent, data justice is rapidly emerging as an approach that situates data explicitly in relation to questions of power, politics, inclusion and interests, as well as established notions of ethics, autonomy, trust, accountability, governance and citizenship (Dencik et al. 2019a). In particular, as a concept, it often denotes an analysis of data that pays particular attention to structural inequalities, highlighting the unevenness in implications and experiences of data across different groups and communities in society. This has, in some interpretations, led to new articulations of principles to underpin data governance that can better account for such inequalities (Heeks 2017; Taylor 2017), or practices in the handling of data that make asymmetries in the representation and power of data explicit (Johnson 2018). Others have foregrounded issues of justice in the design process and the conditions within which data infrastructures are developed, calling for participatory practices that actively involve impacted

communities and seek to empower rather than oppress marginalized groups (Costanza-Chock 2020).

A key aspect of data justice is therefore to shift the framing and understanding of what is at stake with the increased collection and use of data across society in such a way that foreground concerns with social justice (Dencik et al. 2018). As a starting point, this raises the issue of what voices and experiences need to be centered in any such debate and challenges the current constitution of the decision-making table. In line with Gangadharan and Niklas' (2019) notion of 'decentering' technology as a way of situating it within systemic forms of oppression, the harms that emerge from data processes need to be articulated by those who are predominantly impacted and those who understand the history of such oppression. That is, issues pertaining to data need to be integrated into a broader social justice agenda, one in which definitions of problems and solutions may not actually be about data. Indeed, as Mollidrem and Smith also point out in their study of HIV surveillance, in any advancement of data processes there must be space to question the premise and to assert refusal.

Holding on to such politicized understandings of data infrastructures, including in public health, have become particularly pertinent in light of the Covid-19 pandemic. Whilst responses to the crisis emerging from the pandemic have emphasized the continued relevance of the (welfare) state in countries around the world, interventions have notably also elevated the role of technology companies and data infrastructures (Dencik & Kaun 2020). The big data analytics company Palantir has been in talks with a number of governments, including the UK, Germany and France, to provide data infrastructure for health services as the pandemic evolves and Google and Apple announced a joint venture to develop infrastructure for contact-tracing apps that determine if an individual has been in close proximity of someone Covid-19 positive (Fouquet and Torsoli 2020; Kelion 2020). Meanwhile, the EU Commission requested metadata from large mobile phone carriers, including German Telekom and Orange, to calculate mobility patterns and track the spread of the coronavirus across Europe (Scott, Cerulus & Kayali, 2020).

These developments raise pressing questions about the nature and normalization of surveillance, the place of data protection regulation, and the role of private companies in the provision of healthcare. More broadly, they put into sharp focus contentious implications for democratic governance and public institutions. As has been widely argued in Science and Technology Studies, Critical Data Studies and related fields, data infrastructures cannot be abstracted from the wider social context in which they are developed and deployed, and are contingent on an amalgamation of different actors, interests and political and economic models that shape their affordances. As these infrastructures become embedded in society they therefore also create conditions for what is possible and how we should understand both problems and solutions. In other words, they are premised on a particular set of epistemological and ontological assumptions that have ideological implications (Van Dijck 2014). We therefore need to consider the ways in which the turn to data collection and use across social and public life reconfigures our imaginaries and practices in such a way that makes us increasingly dependent on these computational infrastructures. That is, the issue is not only what data about us is collected and how it is used, but also one of a fundamental transition of power and a new mode of governance (Dencik et al. 2019b).

Such dynamics should give us pause in our rush to implement novel technologies in not only the practice of public health, but across society. As our dependency on data infrastructures grow, the challenge of interrogating and overturning the politics of data inherent in these technologies become evermore difficult. This matters, as Molldrem and Smith point out, because the rapid rolling out and scaling up of data infrastructures can have concrete harms on people's lives. For a data justice approach, it is not sufficient to override such concerns in the name of efficiency and they cannot simply be addressed by individual consent. Instead, data justice relies on the empowerment of impacted communities to effectively engage with decision-making that have consequences for their lives and for technologies to be explicitly tied to a vision of society that is more just. Pursuing such an approach has rarely been more pressing.

References

Costanza-Chock, S. (2020) *Design Justice: Community-Led Practices to Build the Worlds We Need*. MIT Press.

Dencik, L., Jansen, F. and Metcalfe, P. (2018). A conceptual framework for approaching social justice in an age of datafication. DATAJUSTICE project. Retrieved from: <https://datajusticeproject.net/2018/08/30/a-conceptual-framework-for-approaching-social-justice-in-an-age-of-datafication/>

Dencik, L., Redden, J., Hintz, A. & Warne, H. (2019b) The 'golden view': data-driven governance in the scoring society. *Internet Policy Review*, 8(2): n.p.

Dencik, L., Hintz, A., Redden, J. & Treré, E. (2019b). Exploring data justice: conceptions, applications and directions. *Information, Communication and Society* 22(7): 873-881.

Dencik, L. & Kaun, A. (2020) Introduction: Datafication and the Welfare State. *Global Perspectives*, 1(1): [10.1525/gp.2020.12912](https://doi.org/10.1525/gp.2020.12912)

Fouquet, H. & Torsoli, A. (2020) Palantir in talks with Germany, France for virus-fighting tool. *Bloomberg*, April 1. Retrieved from: <https://www.bloomberg.com/news/articles/2020-04-01/palantir-in-talks-with-germany-france-for-virus-fighting-tool>

Gangadharan, S. P., Niklas, J. (2019). "Decentering Technology in Discourse on Discrimination." *Information, Communication & Society* 22 (7): 882–99.

Heeks, R. (2017). A structural model and manifesto for data justice for international development. *Development Informatics Working Paper Series*, No. 69.

Johnson, J. A. (2018). *Toward information justice*. Cham, Switzerland: Springer International Publishing.

Kelion, L. (2020) Coronavirus: Apple and Google to team-up to contact trace Covid-19. *BBC News*, April 10. Retrieved from: <https://www.bbc.co.uk/news/technology-52246319>

Molldrem, S. & Smith, A K J (2020) Reassessing the Ethics of Molecular HIV Surveillance in the Era of Cluster Detection and Response: Toward HIV Data Justice. *American Journal of Bioethics*

Scott, M., Cerulus, L., & Kayali, L. (2020). Commission tells carriers to hand over mobile data in coronavirus fight. *Politico* 3/25/2020. Retrieved from: <https://www.politico.eu/article/european-commission-mobile-phone-data-thierry-breton-coronavirus-covid19/>

Taylor, L. (2017). What is data justice? The case for connecting digital rights and freedoms globally. *Big Data & Society*, 4(2), 1–14.
doi: 10.1177/2053951717736335

Van Dijck, J. (2014). Datafication, dataism and dataveillance: Big data between scientific paradigm and ideology. *Surveillance & Society*, 12 (2), 197–208.