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Solidarity-based data governance

To date, most of the approaches seeking to protect the interests of data subjects and to mitigate the power asymmetries between people on the one hand, and powerful corporate data users on the other, have focused on strengthening control over data use at the individual level. While this is clearly important, it is also necessary to strengthen collective forms of responsibility, oversight, and also ownership of data. Importantly, this needs to go beyond approaches that merely strengthen group rights, where groups are considered a sum of individuals (e.g. data cooperative approaches that foster exclusive or even elitist forms of in-group solidarity). Instead, it is necessary to acknowledge and accommodate the relational nature of people and of data. This requires nothing less than (a) a new way of thinking of data subjects and of data that is underpinned by a relational ontology, and (b) an explicit commitment to solidarity and justice.

We have developed a programme of solidarity-based data governance in recent years that seeks to reach that goal. Being informed by work on relational autonomy and other approaches that consider people's relationships to their human, natural, and artefactual environments as shaping their interests and subject positions (e.g. Mackenzie & Stoljar 2000), this programme has three main pillars:

The first one is to facilitate data use that is in the public interest. At present, it is often much easier for for-profit enterprises to use even sensitive personal data than it is for non-profit organisations, universities, public hospitals, and other entities whose main goal is the creation of public value. This situation needs to be remedied.

The second pillar of solidarity-based data governance consists of the strengthening of instruments of collective responsibilities for harms that may emerge from data use. Specifically, we have suggested the introduction of Harm Mitigation Bodies (McMahon et al. 2020) that would provide unbureaucratic, low-threshold support for people who have plausibly been harmed by data use but have no access to legal remedies.

The third pillar of solidarity-based data governance seeks to strengthen mechanisms of benefit sharing to ensure that some of the profits that emerge from commercial data use come back to the public domain, which has enabled the data use via the data work of patients and other citizens, public infrastructures, etc.

Importantly, our approach gives equal value to justice and solidarity. It considers the two as necessary complements of each other. Solidarity – understood as a practice by which people support others with whom they are bound together through a shared goal or other characteristic – is not only necessary to realise justice, but also to understand what justice is and should be.

References:

Mackenzie, C. and Stoljar, N. eds., 2000. *Relational autonomy: Feminist perspectives on autonomy, agency, and the social self*. Oxford University Press.

McMahon, A., Buyx, A. and Prainsack, B., 2020. Big data governance needs more collective responsibility: the role of harm mitigation in the governance of data use in medicine and beyond. *Medical Law Review*, 28(1), pp.155-182.

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