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Not 'Just' Data: Participatory Data Governance for Health Data Infrastructures, a Decolonial Agenda for Data Justice

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Abstract

With the growing digitisation of healthcare services, health data infrastructures play a critical role in healthcare and medical research. Health data are relational in nature and can reproduce historical inequities and manifest colonial patterns, where Global North notions and agendas for healthcare and research are replicated. In this light, governance of health data infrastructures needs to be centred within the sociopolitical context of these infrastructures, promoting the data interests of communities, especially vulnerable and marginalised communities. However, current data protection frameworks that prioritise individual privacy rights are inadequate for addressing collective, context-dependent harms arising from data use. To address this governance gap, the article advocates for a shift from privacy-centric governance to a data justice approach, and seeks to layer data justice with a solidarity-based, decolonial approach. The theoretical and practical dimensions of this approach are explored through three key elements: constitutional, procedural and positional. Constitutional elements deal with the foundational principles or logic underlying the governance architecture of the health data infrastructures. Seen through a justice lens, these constitutional elements are geared towards acknowledging, preventing and mitigating inequities in healthcare and health data activities. Further, procedural elements are building blocks with the aim of embedding tangible mechanisms within governance architecture. Lastly, positionality is the connective tissue that weaves together the constitutional and procedural elements. It is understood as the inherently embodied nature of knowledge, knowledge creation and its processes. It brings forth the criticality of the situatedness of knowledge and power structures, and urges us to imagine governance that does not seek to escape perspective, but makes vantage points both explicit and answerable.

Keywords: Health data; collective rights; data justice; data solidarity; community data governance.

1. Introduction

The advent of digital technologies has fundamentally altered the way health and medical research is conducted, and how health services are accessed and implemented. Present-day innovations in health research, healthcare and diagnostics rely heavily on digital data. Sources of health data now also encompass data exhaust from digital health technologies, wearables and biosensors, as well as the digitisation of traditional data sources – existing healthcare systems and population-scale datasets. Today, data act both as inputs in the making of digital health interventions and medical research, and the primary exhaust from these systems – making data a critical artefact, and the lifeblood of health infrastructures. Accordingly, the use of health data for care, research and innovation is becoming much more structured and of a far larger scale. This has led to concerted efforts from governments, technology companies and international bodies to build health data infrastructures.[1] In particular, Global South countries such as India, Brazil and Nigeria are seeing a *digital revolution* in health.

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[1] Oderkirk, "Survey Results"; Cortez, "Conceptualizing a Data Infrastructure"; OECD, Towards an Integrated Health Information System in Korea; Airan, "Landscaping Infrastructures"; Bietti, "Data is infrastructure."

With these developments, health data can be read as infrastructural in nature, given the cyclical, critical and relational role such data play within advancements in medical research, healthcare and public communication. This is further exemplified by the emergence of health 'data banks', and other large-scale data repositories, where data serve as the pivotal base for innovation, research and population-scale explorations in health and medical developments. Thus, health data infrastructures can be understood as ecosystems of digital and non-digital systems, processes and organisations that facilitate the capture, use and sharing of health-related data.[2] These modular elements may range from consent forms and biosample storage units to cloud services, FAIR APIs[3] or wearable monitoring devices.[4] The increasing criticality of these digital ecosystems – in facilitating better health outcomes, innovation in treatment and care, research, technological advancement and mediating access to care and research – makes them infrastructure.[5]

We may imagine health data infrastructures as superstructures imposed on existing social contexts. As with any other traditional infrastructure, developing and sustaining digital infrastructure triggers externalities. Health data carry pertinent social linkages; existing societal faultlines manifest in the functioning and deployment of data infrastructure, resulting in exclusion and bias, lack of access to healthcare and unwarranted surveillance.[6] Historically, healthcare and medical research have been sites of the systemic exclusion and marginalisation of Indigenous and minority communities. This ranges from the exclusion of, and racialised medical experimentation on, Black populations to the exclusion of women and Indigenous groups from medical trials. In order to build digital health technologies, interventions or data-driven research in a manner that serves the public and societal good, it is necessary to deepen our understanding and identify means to resist, mitigate and reimagine these inheritances.

In light of these considerations, there is an emerging application of a justice lens to data governance at large, specifically in the health data ecosystem.[7] The past decade has seen significant strides towards reimagining data governance and the nature of data. As a response to capitalistic tendencies of big tech, growing authoritarian and technocratic regimes across the world and skewed geopolitical power dynamics prevalent within the global digital order,[8] efforts are being made to move away from understanding data as a disembodied commodity that can be used and interpreted in isolation or abstraction. Especially in the context of health, there is growing recognition of the power dynamics and the politics of knowledge creation, intertwined with the use of health-related data for a 'value-free scientific enterprise'.[9] The data justice school of thought contends with prioritising the interests of marginalised, oppressed and the most vulnerable groups when governing data. This is rooted in recognising the situatedness of the outcomes of datafication – where the data subject is embedded within historical, colonial, socio-political and cultural contexts, and is treated based on these group identity characteristics.

This article landscapes the discourse on data justice and participation in data governance to locate the relevance of political and social contexts within these theories, followed by a discussion on data colonialism, particularly in the Global South, and its prevalence in health data infrastructures. Next, we foreground data governance as a critical layer in understanding and mitigating power imbalances in health data infrastructures, and explore participation as it relates to decoloniality and data justice. The article then interrogates the potential and pitfalls of participatory governance theoretically and in practice, relying on schools of data justice, decoloniality and data solidarities.

This article relies on existing literature, as well as the authors' experiences in establishing participatory methods of data governance, and a series of interviews with experts and practitioners within databanks, biobanks and population-scale data repositories. It is intended to offer substantive theoretical bases toward a rights-based approach to health data relationalities (particularly from the perspective of the Global South), and prompt further scholarship, as well as proposing some practical pathways for participatory governance.

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[2] Cortez, "Conceptualizing a Data Infrastructure"; OECD, Towards an Integrated Health Information System in Korea; OECD, Towards an Integrated Health Information System in the Netherlands.
[3] Fair Process Framework, "Fair Process Framework."
[4] OECD, Health Data Governance for the Digital Age.
[5] Airan, "Landscaping Infrastructures for the Digital Ecosystem."
[6] Howe, "Ethical Challenges Posed by Big Data"; Davis, "Algorithmic Reparation."
[7] Dencik, "Exploring Data Justice"; Taylor, "What is Data Justice?"; Akbari, "The Politics of Data Justice."
[8] De Souza Siddharth, "Rebooting the Global Consensus."
[9] Shaw, "Health Data Justice."

2. Tracing Data Justice and Health

2.1 Relational and Assemblage Theory

Over the course of a few years, scholars across disciplines have variously analysed the nature of data, scoping it beyond its value-free technical understanding and envisioning scaffoldings for data capture and use, and looking critically at the legal and market structures dictating these. This theoretical evolution can be strongly demonstrated through the relational and assemblage theories of data, which highlight the situated nature of data – in its intrinsic nature, and in data governance architecture.

Relational theory provides a critical socio-legal lens, describing data as a ‘relational good’: data can be characterised as social relation between individuals, driving the social value and harm of data collection and use.[10] Further, data value is typically released only in conjunction or when merged with other data. Therefore, harms arising from data activities are not only limited to individuals, such as breaches of privacy, but also have collective and diffused harms, such as discrimination and bias.[11] Social structures influence data relations, which then influence the social value or harms arising from data activities.[12] We must account for the social structures that influence data relationalities, as they play a key role in the lived experiences of groups and individuals reflected in the dataset and how data use impacts them.

Assemblage theory provides a broad systems-level framework for capturing and evaluating the role of governmentalities and other conditions attached to data systems.[13] It highlights that data ecosystems are a way to sort and categorise populations forming sites of critical power struggle, and present-day data protection laws form an important part of data assemblage conditions. Assemblage theory helps articulate the social-political context in which health data ecosystems are created and function, further highlighting the role data laws and governance systems play in perpetuating these contexts.

Data governance cannot be neutral, and is deeply embedded in political, economic and social contexts. However, current regulatory frameworks limit themselves to individual privacy harms, failing to note the underlying relationalities of data. This mismatch creates an uneven playing field in data politics.

An Individualist Notion of Data Rights and Harms

Regulatory frameworks across various jurisdictions focus on protecting *individuals* from data harm, articulating data rights as atomisable and individualistic (typically including personal data, thus, personally identifiable health data).[14] Unfortunately, there are abundant instances where harm is caused to individuals or groups sharing certain characteristics, including gender, race, ethnicity, geographical area, consumption of certain goods or digital platforms use.[15] Individual privacy protections do little to prevent or redress collective and group harms from data activities synthesising multiple types of data sources, such as in social sciences research.[16] Further, collective harms may be directly related to a breach of the right to privacy (for example, mass surveillance, large-scale data breach) or may violate some other substantive rights, such as discrimination (bias, exclusion).

Moreover, data protection approaches so far are *ex-post*, where the protection or cause of action only activates when harm is or can be caused.[17] There is no positive articulation of data interests and rights, to emphasise the need for mechanisms of collective control over data, protecting groups from harm and ensuring data use aligns with their interests. Further, seen from the perspective of the existing geopolitical hegemonies perpetuated by digital platforms and data infrastructures (for example, access to redressal against big tech companies in Global South nations), major data-protection laws lack provisions for collective action around data harms affecting communities at large.[18] Those available are limited in imagination[19] and reach, in terms of just equitable distributions of social value of health data.

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[10] Viljoen, “A Relational Theory of Data Governance.”

[11] Graef, “Collective Data Harms.”

[12] Knight, “Challenging Racism.”

[13] Kitchin, “Assemblage Theory.”

[14] General Data Protection Regulation, 2016, articles 4(1), 22(3) read with recital 71 (European Union). See Ausloos, “How the GDPR Can Exacerbate Power Asymmetries”; Devakumar, “Racism, Xenophobia, and Discrimination”; Wilson, “In This Together”; Taylor, Group Privacy.

[15] Schaake, “The Data Delusion”; Weber, “Surfacing Collective Harms.”

[16] Weber, “Surfacing Collective Harms.”

[17] Wilson, “In This Together.”

[18] Ausloos, “The Case for Collective Action.”

[19] Hakkarainen, “Naming Something Collective”; Wörle, “Collective Data Protection Litigation.”

Data Harm as a Use-Trait, Not a Type-Trait

Critical to protecting collective interests is the basis on which data harms are understood. We argue that the basis (and thereby level) of protection must be a function of the context and nature of data use. However, the status quo so far has categorised harm and resultant protection based on sensitivity of data types.[20] Legal regimes across jurisdictions focus on sensitivity-based categorisation of data; distinctions between anonymised or non-identifiable (non-personal) data and personal data often form the basis for determining the level of protection. For example, under HIPAA, personal health information cannot be disclosed to entities other than the authorised entities without specific authorisation,[21] yet following HIPAA's de-identification process causes health datasets to lose HIPAA protection.[22]

Crucially, categorisation based on the sensitivity or types of data may be insufficient to capture the relational and contextual implications of data use, and consequently the possible harms arising from it.[23] Any understanding of ethical data governance must prioritise the manner in which data (whatever its nature) is being used. Given that data are a relational good, its value and impact are determined by how they are used, by whom and to what end. Yet, data-type distinctions of harm are unable to capture the dynamic nature of data sensitivity. The ability to draw sensitive inferences from personal and non-personal data has increased due to big data analytics tools; de-identification of data is ineffective for preserving individuals' privacy. Further, using de-identified non-personal data may cause other informational harms, such as mass surveillance or discrimination, normally affecting communities at large.

Therefore, regulatory categorisation of data based on sensitivity or data type leads to a critical exclusion of certain (and growing) types of harm. Understanding that 'sensitivity' is a data use-trait, not a type-trait (e.g. the analysis of a person's purchase history or social media use can be used to generate inferential information about their health, and therefore higher protections for medical records alone are insufficient) means protections afforded to data principals must uphold *how* data have been used, over *what* data have been used.

2.2 Data Justice Theory and Health Linkages

With growing recognition of the fundamental flaws in data protection legislation and the impact of data structures on communities, there has been a recent pivot towards data justice. Early iterations of data justice theory sought to apply social justice in the context of datafication, relying on existing notions of justice.[24] Taylor[25] draws from the capability approach, adopting a justice theory based on visibilisation, digital engagement/non-engagement and non-discrimination. This emphasises the development of capabilities through education, activism or legislations, to enable participation, inclusion and access, centring the data justice debate around people and communities as active actors within the data ecosystem.

However, these accounts of data justice overlook the politics of data justice, participation and collectivisation. Akbari[26] explores the idea of abnormal justice, and voice and exit theory: a data subject may have the choice to exit, or to participate and change the status quo. However, in dehumanising situations, access to humanitarian aid or medical benefits depends on participation, so walking away is not an option. Akbari argues that the politics of participation and solidarities are crucial to build pathways for data justice.

When considering alternatives to individualised approaches to health data governance, data solidarity stands out as a framework that prioritises collective ownership and data control. Particularly in the context of power imbalances, an individual set of data rights is limiting in addressing structural inequities that arise from/with datafication; instead, the costs and benefits of digital practices are born collectively and fairly.[27] When public interest from data use is defined exclusively or largely by profit-driven corporations, there are shifting goal posts between public interest and data as an economic good for societal progress. A data commons approach,[28] for instance, creates procedural and structural pathways for communities to collectively define social value and 'good' from data. These collective and solidarity-based approaches will frame our conceptualising of decoloniality in data governance.

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[20] Analysis of GDPR, California Consumer Protection Act, Kenya Data Protection Act, Digital Personal Data Protection Act.

[21] Ganesan, "Why India Should Think"; "10 Misunderstandings."

[22] Rothstein, "Is Deidentification Sufficient?"

[23] Solove, "Data is What Data Does"; Quinn, "The Difficulty of Defining Sensitive Data"; Mitchell, "Are Synthetic Health Data?"

[24] Dencik, "Exploring Data Justice."

[25] Taylor, "What is Data Justice?"

[26] Akbari, "The Politics of Data Justice."

[27] Prainsack, "Data Solidarity."

[28] Purtova, "Data as an Economic Good."

3. Health Data and Coloniality

Scholarship in and around the global digital rights movement has also seen the emergence of the term ‘data colonialism.’[29] Couldry and Mejias articulate the role of data, when viewed as mere ‘exhaust’ from human lives, as a resource that is ‘just there’, not dissimilar to natural resources that imperial powers considered open for extraction, and otherwise disembodied from the communities with natural and local relationships to them.[30] Data colonialism can also be understood through the lens of increasing global dependency on Western/imperial (typically US- or China-based) technology companies for digital platforms, cloud and compute power, and knowledge production from digital services.

This reality also complicates the distinction of Global North and Global South, through which historical coloniality typically has been understood. While useful in chalking imperially birthed power imbalances, the North–South distinction is often inadequate in the context of digital technologies. Global South geographies are heavily dependent upon digital superpowers – which lack the language, context and involvement of local communities. This form of power concentration and control over online experiences, privacy and contexts also sees disparate impacts on marginalised/disenfranchised communities within the Global North.[31] In Global South regions, digital colonialism can also be understood through an epistemic lens, where external, primarily Western ways of knowing, logics and contexts are embedded through digitisation into lives, services and lived outcomes.[32] In the case of digital technologies, there is little opportunity to evade extractive and simultaneously essential digital technologies, and communities in the Global South are compelled to adopt the epistemic universe of technology as it comes ‘by making tracking a permanent feature of life, expanding and deepening the basis on which human beings can exploit each other’.[33] The pervasive, networked and disembodied nature of digital technologies lends itself to a kind of sprawling coloniality – vast in reach, slippery to grasp, but profoundly apparent in its impact.

The legacy of health and medical research also houses numerous examples of medical colonialism as a core element of control. French colonial strategist Lyautey referred to medicine as ‘the most effective of our agents for penetration and pacification’.[34] The imposition of medical practices, healthcare systems and research on developing countries from wealthier, industrialised nations has led to an immense erosion of public confidence and trust in medical interventions coming from these countries.[35] In service of a syncretic approach to understanding coloniality in digital health infrastructure, we must consider the social faultlines inherited from coloniality in the Global South, and how they are replicated in digital health interventions today.[36] Global hegemonies are maintained, as most digital health technologies and health data infrastructures (software, hardware, networks) are under the control of technologically advanced countries – mostly situated in the Global North.[37] As identified by present scholarship, there is a pervasive presentation of digital health innovation as a one-shot solution for most public health issues in developing contexts. This carries risks – for example, there has been great emphasis by international bodies such as WHO on using electronic health records, which present many benefits for longitudinal patient care, but also result in data centralisation and concentration with big data analytics firms.[38] Such centralised control over technological resources increases the Global South’s dependencies and vulnerabilities to colonial power dynamics. Self-determination or sovereignty over the digital realm is limited at best, leading to exploitative/extractive research activities and even skewed prioritisation of research interests and social value.[39]

A digital health revolution, forged through advanced technologies and data infrastructure for longitudinal impact, ‘reinforces existing colonialism’.[40] Centralised control over digital platforms and data infrastructure coupled with epistemic hegemonies results in hermeneutical injustice through the suppression of local language, culture, knowledge and ideologies,[41] and prejudicial flaws in ways of thinking/interpreting social realities,[42] which manifest in deeper injustices and

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[29] Nothias, “An Intellectual History of Digital Colonialism.”
[30] Couldry, “Data Colonialism.”
[31] Mann, “(Big) Data and the North-in-South.”
[32] Kwet, “Digital Colonialism.”
[33] Couldry, “Data Colonialism.”
[34] Eichbaum, “Decolonizing Global Health Education.”
[35] Diplomatic Courier, “Overcoming the Dark History.”
[36] Kumar, “Decolonising Global Health Research.”
[37] Gray, “More Than Extraction”; Kwet, “Digital Colonialism.”
[38] Qato, “Reflections on ‘Decolonizing’ Big Data in Global Health.”
[39] Davis, “Algorithmic Reparation.”
[40] Sekalala, “Colonialism in the New Digital Health Agenda.”
[41] Causevic, “Whose Knowledge is Online?”
[42] Fricker, “Hermeneutical Injustice.”

disenfranchisement.[43] The use of (predominantly private sector-driven) digital technologies such as wearables for data collection in areas of limited internet access or high reluctance around digital technologies can result in datasets being skewed, benefiting a limited population, excluding the most vulnerable groups.[44] This mimics the historical colonial agenda of supplanting an epistemic superiority of Western medicine – empirical and material – over Indigenous medical practices – often spiritual and social. Currently, the lion's share of benefits from the appropriation of human biological and social information from the Global South remains skewed towards innovation and advancement of markets and institutions in the Global North.[45] As we interrogate how power operates through data, we may also focalise the knowledge-trait of data. Data is knowledge, but *value from data* depends upon how clearly this information is categorised and amenable for further use, analysis and knowledge production. Data is also relational – valuable when combined with other data. In the case of socially relevant or socially sourced data (*from* and *about* the lives of people), this relational trait is germane.

We may look to Foucault's articulation of the relationship between the possession, sharing and accumulation of knowledge and power: knowledge is a technology of power.[46] In the Foucauldian context of 'governmentality',[47] shaped in a colonial era, power is constructed by the accumulation of scientific knowledge, by direct force and coercion, and by creating knowledge about populations. Communities are categorised through this knowledge production, and the norms for how they may be understood and governed are constructed therein. Power operates indirectly, infrastructurally, where a vast network of decisions, entities and interests shapes knowledge – and eventually the field of possible actions. Thus, power is embedded infrastructurally.

Today, data infrastructures represent a similar apparatus. In the case of health and health-related data, bodies and their health-relevant criteria are digitally constructed – genetics, biomarkers, health behaviour, social risk factors. These define, implicitly or explicitly, what is normal, healthy, risky or deviant, and how interventions must be shaped, simultaneously digitally crystallising the systemic invisibility of the most disenfranchised communities. These data regimes do not merely reflect health disparities; they also help to construct them. By embedding racial, gendered and geographic categories into technical systems, health data infrastructures become both normative and disciplinary: guiding funding priorities, shaping research agendas, and influencing policy, often bypassing democratic oversight. Coloniality in health data infrastructures and activities risks solidifying existing postcolonial inequities, with a scale and endurance that were impossible before big data.

We may locate this risk and potential in some of the evolving large-scale data infrastructures being conceptualised and built around health data. Databanks serve as sites for the aggregation and curation of population-scale medically relevant health data. Databank access is often critical for scientific advancement,[48] and health data repositories represent some of the largest knowledge bases for scientists and researchers to test and generate hypotheses, verify evolving research, learn from ongoing clinical trials and assess longitudinal trends. The data lifecycle – various stages and decisions of a single datapoint – in a databank is vast. A varying number of stakeholders encompassing public and private are present across the databank data lifecycle, embedding a range of interests. Drawing upon an (anonymised) example from the authors' own work with a national-level health data repository, Figure 1 represents the governance architecture.

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[43] Petrakaki, "From 'Making up' Professionals."

[44] Liverani, "Assessing the Potential of Wearable Health Monitors."

[45] Longworth, Race After Technology.

[46] Foucault, Discipline and Punish.

[47] Foucault, The Birth of Biopolitics.

[48] "Quality" is a technical trait – data that are clean in formats, metadata markers and otherwise usable for analysis, rather than the notion of quality as a technical and apoliticised facet of data.

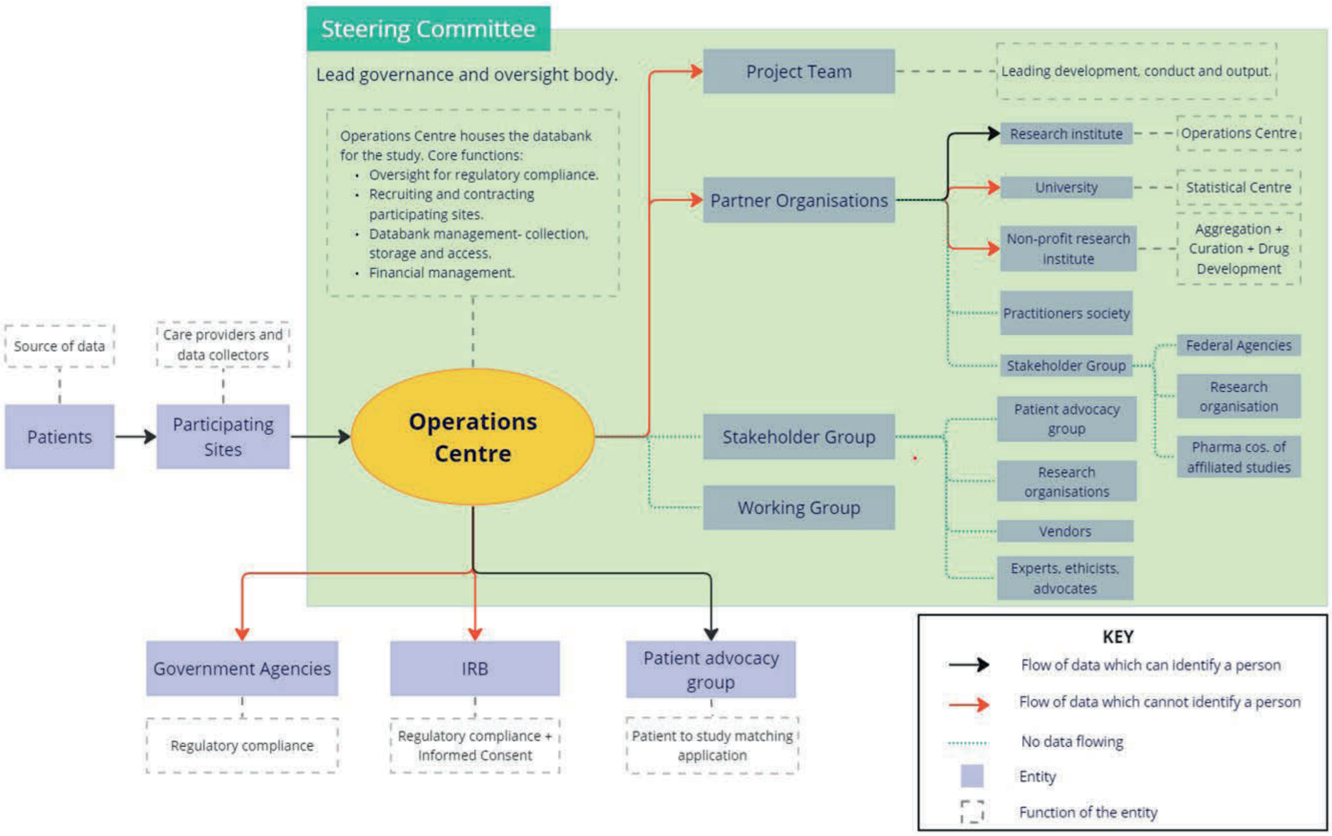

Figure 1. Databank data lifecycle

As with many data infrastructures, data governance in such a setup is diffused, with a lifecycle mediated by multiple stakeholders and varying interests. The Global South is seeing the swift entry of Western technologies (and their embedded data governance norms and structures); the path towards a more equitable and just data future is profoundly impacted by the perplexities of data governance itself. This determines: (1) how data are collected, embedding decisions around *what* is collected and *which* data are combined from various sources; (2) how data are *curated* (markers and metadata), affecting searchability and usage; and (3) data sharing, use, reuse and access by third parties. It is easy to imagine how an individual or a data community may be invisibilised through these necessary stages. Governance is critical to a social justice reading of coloniality in health data infrastructures.

4. Participation is Not a Silver Bullet

Given these concerns, it is important to consider what governance and decision-making architectures around data can look like through a decolonial agenda. Governmentality and market powers are now systemic, and shifting nodes of power towards people would require a tectonic shift in how data and its related resources are viewed. The existing scholarship has made significant strides in deepening ideas of postcoloniality in the global digital health agenda. The exploration of this article resides in an impactful micro layer of governance architectures: how can we envision decision-making within data infrastructures as a site for increased and meaningful agency for impacted communities? What would this entail in postcolonial contexts?

A data-justice approach focuses on building frameworks for fairly representing and treating people as a result of their use of technologies, premised on the need for a social justice agenda for communities, engagement with the technology and non-discrimination of individuals' and groups' datafication. It lays significant emphasis on visibilising the needs and concerns resulting from interaction with the technology.[49] Discrimination, surveillance or a lack of participation in data infrastructures need not be the necessary, accepted cost of the digital health revolution.[50] A digital health revolution that accepts the

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[49] Taylor, "What is Data Justice?"
[50] Taylor, "What is Data Justice?"

suppression of lived realities and intersectional social contexts is no revolution at all, but rather a stale reprise or further embedding of existing colonialities and inequities in the Global South.

A health data-justice approach denotes a framework where the needs of structurally marginalised and vulnerable communities are prioritised, and structural and institutional injustices are mitigated. The primary focus of such an approach would be to: (1) ensure meaningful participation in healthcare and public health; and (2) use health data to benefit marginalised and vulnerable communities and redress existing systemic faultlines.[51] This is hard to achieve through an exclusively atomised and individualistic approach to data rights, as data harms and the communities impacted by them are diffuse, with limited redressal mechanisms for community-level harms. Civic or community participation has often been heralded as a means to rebalance power in the data economy; there have also been globally located (though contextually varied) instantiations of participatory governance in data structures and infrastructures. However, the notion of participation in the context of digital colonialities is complex, with limited reach in building just ecosystems.

The idea that merely ‘including’ more people can wave away inequity has been identified by development scholars in participatory governance as delivering plain-faced moral licence for powerful institutions to intervene in the lives of others. Structurally, participatory approaches often reify existing norms and knowledge, acting as a means to enhance rather than question conformity, particularly in contexts of already-skewed power dynamics and gaps in epistemic access. Participatory approaches do not just carry the profound risk of not only crystallising control; by masquerading as democratic ‘empowerment’,[52] they make control less available to critique, while simultaneously embedding a self-governed conformity among disenfranchised groups.[53] So palpable have been the hazards and replications of control through participation that development scholars have termed the phenomenon a ‘tyranny of participation’. In the context of digital health and datafication, participatory efforts have been found to replicate the inherent alienation of coloniality, increasing the gulf between intervention and community. Knowledge systems are transplanted rather than co-created, and building upon them after interventions requires a seismic shift and relearning for communities – where the new paradigm for understanding medicine, bodies, health and data is alien, but has also become the only route.[54] Therein, coloniality is replicated and identities are transformed as well as self-governed by transplanted norms.

5. A Decolonial Agenda for Participation in Health Data Infrastructures

It appears, then, that the emancipatory potential of participatory governance structures hinges upon how well its politics are understood and translated to structural and textural means of implementation. We warn against the neoliberal compulsion to package redistribution of power into boilerplate, singular procedures (as with numerous participatory efforts): a reductive view of participation can fail on several fronts.[55]

These may relate first to the underlying and surrounding logics of participation: to what end is ‘empowerment’ geared, and in whose interests? A bottom line of profit (not public interest) impacts consensus around data decisions. This may include prevailing norms around data, health and social structures, deeply affecting the fundamental logic of data infrastructures (these underlaid and surrounding logics we term *constitutional* elements). Participation may also fail or be upheld meaningfully based on the practical elements of decision-making architecture. This includes an identification of which nodes of decision-making are critical sites for institutions of voice or agency, and on discussing *procedural justice* – urging a shift away from considering purely technical measures and bureaucratic setups, and instead using procedural mechanisms as a site to renegotiate power relations. Finally, participatory governance must recognise power dynamics and inherent politics around not only data, but interpersonal and social structures. A cognisance of varied, intersecting hierarchies among individuals and institutions requires a situated approach to participation (this connective mesh across the constitutional and procedural is *positional*). Further discussion leans upon feminist epistemologies of embodied knowledge, and prioritises them in a postcolonial context for participatory governance.

5.1 Constitutional Elements

These can be envisioned primarily as the foundational principles of the governance architecture, as well as surrounding logics within which data infrastructures exist. These are principles underlying the infrastructure itself: the desired goals and objectives, coupled with ecosystem-level prevailing narratives and norms that shape the logics of data and its use. These include

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[51] Shaw, “Health Data Justice.”

[52] Cornwall, “What Do Buzzwords Do?”

[53] Brear, “Structural Influences on Consent Decisions.”

[54] Petrakaki, “From ‘Making Up’ Professionals.”

[55] Fraser, “Abnormal Justice.”

sociocultural contexts, social norms, economic and market imperatives, conventional practices in medical ethics, and international policy/domestic legislations on data protection. These are *constitutional* elements, as they influence the critical decision-making in data infrastructure, directly influencing how knowledge is created through data, at large scale. For example, a consistent absence of gender-focused research for women's health as a priority (reflected from limited funding for women-specific research) has resulted in massive under-representation of women in datasets. This has consequently resulted in development and use of AI tools dealing with women's genealogical health that are severely problematic, with little to no real understanding of women's health, lacking the necessary peer review and oversight.[56] Prioritising a fundamental principle (such as gendered health research or prioritisation of healthcare needs of vulnerable groups) could have translated into better healthcare tools for women, rather than reducing access to healthcare. Thus, when thinking about participatory forms of data governance, it is critical to think about the constitutional elements of the governance architecture of a data infrastructure. Constitutional principles must:

- acknowledge existing inequities
- actively prevent/avoid reproduction of inequities, and
- ensure the needs of disadvantaged groups are prioritised.[57]

The present legislative environments, norms and narratives severely lack justice-oriented constitutional elements, demanding a reimagination of how norms are developed and enforced within health data infrastructures. Increasingly, there are instances of norm-building by non-state actors in the digital realm, in response to present data regimes that allow for exploitative and oppressive practices taking advantage of populations at large. Globally, CSOs have taken incredible strides towards pushing for counter-narratives and norms challenging 'the commodification of data and the economic and governmental configurations that arise from it'.[58] Big tech corporations and other stakeholders in the ecosystem, including supra-national organisations, back the well-established narrative that data must be a freely traded commodity during all parts of its lifecycle, but CSOs have played a critical role in pushing for relational and community-oriented approaches to data governance practices.[59] These movements present instances of bottom-up collective actions in the context of health data infrastructures. For instance, Māori principles for genomic research came as a response to extractive biocolonial activities and in order to exert sovereign control over their data, which they view as an extension of their bodies and community.[60] They emphasise community participation in research in many forms, to reclaim autonomy over their genomic data and exert sovereignty over health data.

Another example is found in the experience of data cooperatives, where the primary focus is on democratic control over data resources and prioritisation of collective interests of the community. A data cooperative in the climate justice space,[61] a communities-based fisheries monitoring cooperative in the Lakshadweep Islands in India, has aided the sustainable management of fishing activities. The project highlights the importance of communities in determining the method and purpose of data collection and use. Deep involvement of the fishing community in developing the data log-books and then managing fishing activities based on that information played a crucial role in achieving sustainable fisheries.[62] In these ways, collectivisation around data creates room for people to drive notions of value, uphold the role of public reasoning and institutional mechanisms to de-prioritise exclusively profit-driven motives from health data use.

5.2 Procedural Elements

While the constitutional element provides the broader principle context, *procedural elements* pertain to the embedded, tangible mechanisms within governance architecture. Accordingly, while the constitutional element works at the larger level of decolonial participation in data governance, the procedural element is instructive in how to do it. Drawing from the authors' own experience in helping health data infrastructures build participatory data governance frameworks, and conversations with experts across different jurisdictions, cultures and communities, we observe that the procedural element plays a critical role in realising people-centric governance mechanisms.

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[56] Algorithm Watch, "(When) will AI Improve Women's Health?"

[57] Sekalala, "Colonialism in the New Digital Health Agenda"; Akbari, "The Politics of Data Justice."

[58] De Souza Siddharth, "Rebooting the Global Consensus."

[59] De Souza Siddharth, "Rebooting the Global Consensus"; Dutta, "Our Data, Ourselves."

[60] Beaton, "Engaging Māori"; Te Mata Ira, Guidelines.

[61] Gadsden, "Amazonian Tribe."

[62] "Fish for the Future."

Critically, it lays emphasis on: (1) awareness of asymmetrical power relations governing interactions; (2) actively including voices of the marginalised and oppressed; and (3) challenging epistemic assumptions underlying procedures that have long denied the knowledge-systems and social realities of the marginalised.[63]

Accordingly, representation of impacted groups within the decision-making process is an important process (Figure 2). 'Representation' refers to inclusion of the impacted communities (patients, subjects and often caregivers) across various stages of data and research lifecycle. It involves proportionate representation of demographic indicators such as sex, gender, race, ethnicity and other socioeconomic factors in the groups participating in the decision-making processes. In the case of a health data bank, representation means inclusion of data contributors – that is, patients – in various decision-making functions, including data collection and access, ethics review, research agenda and output development. The rights-holder must be included within existing structures of 'stakeholder' participation. Participatory data governance entails the inclusion of representative groups in key data decision points: from initial involvement in data access and use guidelines to sustained Lived Experience groups[64] that contribute to data-related deliberations over time.

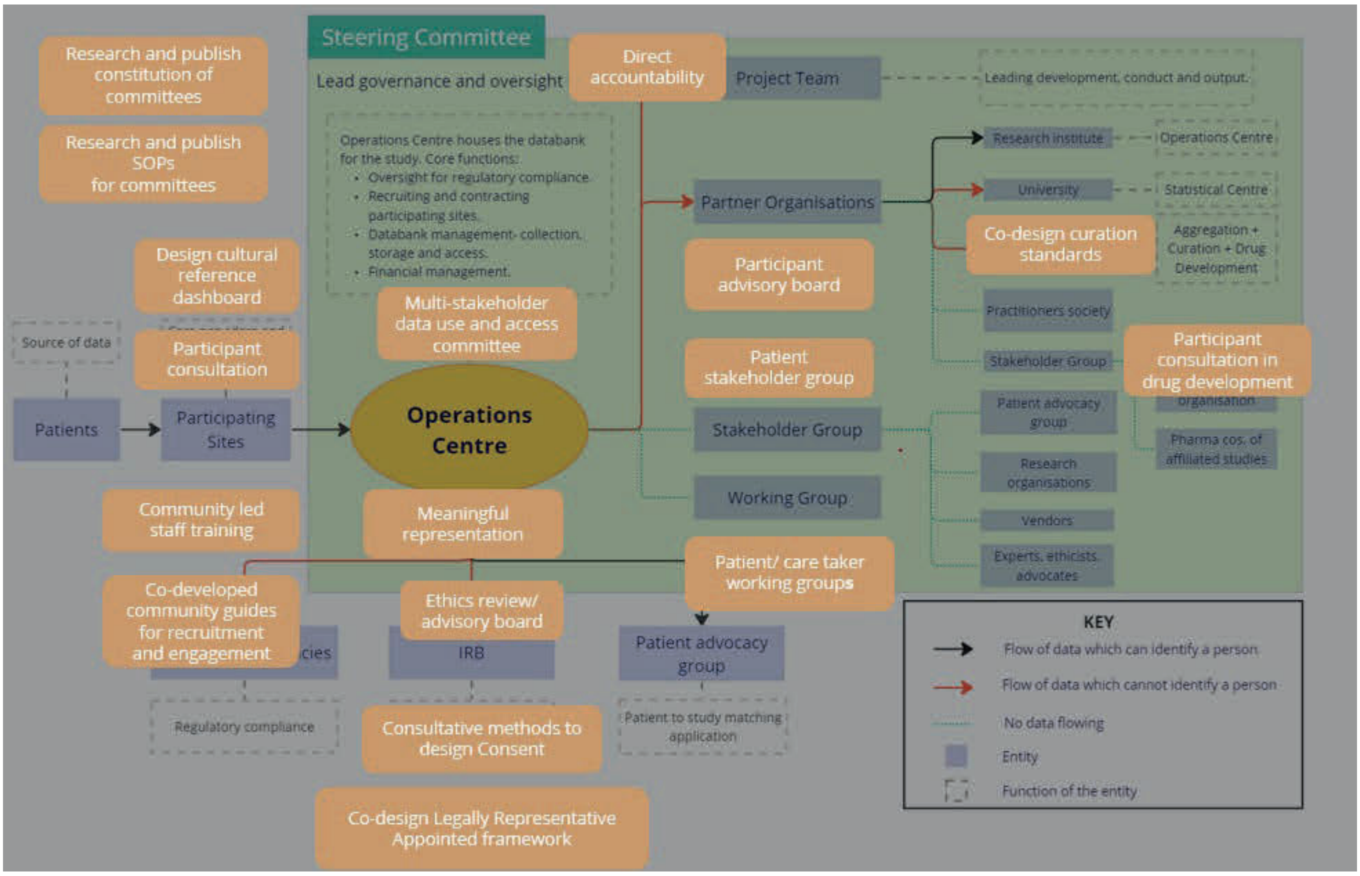

Figure 2. Representation of impacted groups within the decision-making process

Moreover, representation must not be limited to a simplistic inclusion of various demographics in the participating group. It is crucial to recognise the social-cultural realities afflicting these intersectional identities. Positionality is an instructive modality to understand the 'effectiveness' of representation. A participatory process must serve to acknowledge the 'multiple, changing and different identities of individuals'[65] within the group. It must reveal the realities of everyday oppressions and actively mitigate them, creating an enabling environment for different identities to experience the process of engagement in research, making the processes more inclusive for these identities.[66] This includes the removal of epistemic, accessibility, cultural and

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[63] Ohlsson, "Radical Justice."

[64] Groups with the lived experience of a health condition, who may or may not have directly contributed to the data.

[65] Cooke, Participation; Reynolds, "Conceptualising and Constructing 'Diversity'"; Hearn, Theories of Difference.

[66] Reynolds, "Conceptualising and Constructing 'Diversity"; Hearn, Theories of Difference."

resource barriers that impact how various individuals with a range of identities participate in research and decision-making.[67] For example, including women from each demographic may still not capture the delicate power relations within the group, or the impact of intersectional identities such as race, class or caste on their choices. Nor will superimposing successful participatory mechanisms from significantly distinct environments work. For example, a citizen assembly that may have worked in the New York City will not necessarily work in a refugee camp in Malawi,[68] most prominently because of the dehumanisation of migrants, for whom retaining the most basic rights and dignity depends on giving up their data.[69] In such situations, developing a representative participatory mechanism is a complex and iterative process.

Accountability is also a crucial pathway to data justice, providing a means to place responsibility, build trust and mitigate power dynamics. Traditionally, accountability is characterised as a *retrospective* mechanism of governance. A narrow interpretation of the concept renders a negative connotation, limiting its ambit to the transgression (and consequence) rather than an explanation.[70] This perspective places onus on the data contributor, who may not be in position to question due to power imbalances, and accountability is reduced to a bureaucratic barrier or a policy checkbox.

In public governance debates, the key elements of accountability are: (1) information provision; (2) debate; and (3) the possibility of consequences for actions. A broad interpretation of accountability would include a prospective obligation of explanation and deliberation. Crucially, in public governance theory, prospective accountability is associated with a representative legislature and strong democratic processes.[71] These principles can be associated with the decision-making processes and governance structure of a health databank, to embed reflexive and deliberative accountability measures.

Prospective accountability entails integrating stakeholders within the functioning of a databank, including decision-making bodies and various stages of the data lifecycle, through creating patient advisory boards or multi-stakeholder decision-making bodies, with clear, accessible and timely information on agendas, decision motivations and related factors.[72] Such bodies can contribute to different functional areas, such as co-developing informed consent, data-sharing policies, recruitment standards or participating in decision-making processes. The Native Biodata Consortium[73] is a non-profit health research institute and bio-repository run by native American researchers and the tribal members, and its governance structure is instructive in building prospective accountability. Since day one, tribal members have decided on key questions such as research agenda and community benefit, culturally consistent research practices, and databank structure and function. Moreover, the physical presence of the biobank office on tribal lands and easy access to the researchers at the biobank further humanises the relationship between the community and the researchers, strengthening trust.

5.3 Positionality

If constitutional elements and fundamental procedural logics are underlaid across governance structures, *positionality* is the connective tissue. Positionality is understood here as the inherently embodied nature of knowledge, knowledge creation and its processes. The preceding discussion on coloniality and governmentality has demonstrated how data infrastructures often universalise particular logics of knowledge and power, and participation often invites inclusion, compelling communities to speak in registers set elsewhere, upon different, bureaucratic or misaligned interests. Yet in order for participation to be embodied, or even to be understood critically, the different nodes and actors of participatory governance must be read as situated with their social and power locations and identity – not a disembodied and supposedly 'universal' perspective.[74]

This situatedness is especially relevant to the discourse on decoloniality in participatory governance. So-called 'local knowledge' (e.g. multilateral interventions in developing regions, analysed astutely by David Mosse),[75] even when developed through participatory themes, is in large part shaped by the projections and ambitions of the 'professional', the intervening party coming with built-in consensus. Cooke[76] also shows how participatory development processes are influenced on an interpersonal level by the real, imagined or implied presence of others. Here too, power becomes somewhat intangible, and can easily morph participatory efforts into compliance parades, with knowledge production removed from participating communities.

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[67] Breuer, "Using Theory of Change."
[68] Verhulst, "Operationalizing Digital Self-Determination."
[69] Akbari, "The Politics of Data Justice."
[70] Bovens, "Accountability and Constitutional Law."
[71] Kapur, "The Indian Parliament"; Bamforth, "Accountability of and to the Legislature."
[72] Cucciniello, "25 Years of Transparency Research."
[73] Native BioData Consortium, Home Page.
[74] Haraway, "Situated Knowledges."
[75] Cooke, Participation.
[76] Cooke, Participation.

In digital health infrastructures within colonial contexts, *positionality* urges us to imagine governance that does not seek to escape perspective, but makes vantage points both explicit and answerable. Positionality is a distinct element in the decolonial agenda – data governance cannot be considered an apolitical and technical measure. In data lifecycles, as seen in the preceding discussions around a Foucauldian understanding, power is not a fence between where it 'is' and 'is not', but something that circulates. In order for power to circulate towards communities and impacted groups, governance would first have to be seen through these power relations, and then reordered to build new ones. For participatory measures, this means community or collective agency cannot either be 'achieved' as an absolute, or 'completed' as a linear path. Instead, it must be cyclical and reflexive.

Measures around representation, accountability and transparency are limited most heavily by their embedded hierarchies, uneven norm-building and immediately imperceptible but longitudinally harmful replications of power imbalances. It is hard to imagine a version of participatory governance that can support the goals of decolonial data justice without also embedding a deeply political and situationally relevant slicing of governance itself. In participatory- and justice-based governance, accountability and transparency are not 'trust-acquiring' activities, but rather 'trust based'. Trust entails active recognition and exploration of culturally significant concepts and ideas within the affected community, and consequently meaningful incorporation into decision-making, data utilisation and harm conceptions. In engaging the Māori community in the collection and classification of genome data, for instance, priority was given to understanding and encompassing cultural context and significance, from the first stages of data collection, highlighting a trust-building and trust-based process toward contextually-sensitive collection and use of health data at a collective level.[77]

Accountability has often been seen as a superficial exercise in transparency, lacking responsibility and answerability. A *situated* approach would instead place accountability not just in tandem with responsibility, but be cognisant of power differentials. Jasanoff's call for 'technologies of humility' demands institutionalising practices that foreground uncertainty, distributional risk and vulnerability, rather than concealing procedure behind the language of technical inevitability.[78]

Positionality also demands community authority over how knowledge is defined and mobilised, and how knowledge use is directed – specifically, by whom. For instance, Open Humans[79] enables direct and granular control over data use, access and use purpose for data subjects – both individually and collectively through a platform and open-source notebooks, allowing patients or data subjects to review data requests, deliberate collectively and approve/disapprove of data use in certain contexts. While it is difficult to ascribe a notion as lofty as situated epistemology to one or another platform type or governance structure, there are many promising examples of how rights-holders can meaningfully exercise agency and authority over data.

The discussion around procedural justice foregrounds some of the structural pathways towards collective and participatory governance, but it is important to note that they cannot be read without constitutional and positional facets of participation. Participatory procedures can only be as effective as they are positional in their endeavours – crucial in the effort to reduce the potential for participation-washing. It is still to be fully explored whether it is possible to longitudinally routinise positionality, collectivisation and situated approaches into governance architectures; however, looking to examples of indigenous data sovereignty, data cooperative structures and more, the outlook is promising. It must be a reflexive, iterative, context-specific process – and thus the road to developing decolonial participatory governance around large health data infrastructures is uncertain. It will require the support and scaffolding of meaningful legal and regulatory environments that prioritise collective agency, alongside acknowledging the relational nature of data in how it plays upon skewed power hierarchies.

6. Conclusion

While participation has seen deep imperfection, there may still be vast areas of digital health infrastructures where it holds real potential to rebalance power. We have endeavoured to deepen how this may be understood and analysed in line with a decolonial, data-justice framework. In asking *how* participation can be meaningful, it is equally important to ask *where* participation can be meaningful. There are regimes where data governance (participative and collective, or otherwise) simply cannot overcome fundamentally dehumanising logics – such as when these constitutional elements are predicated upon power imbalances to a dehumanising degree (e.g. data-sharing is the cost of immediate care, relief from distress, asylum, etc.). Participation presents a strong starting point and, to be meaningful, must be read across its constitutional, procedural and positional elements.

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[77] Beaton, "Engaging Māori."

[78] Jasanoff, "Technologies of Humility."

[79] Greshake, "Open Humans."

In decolonial data justice, can *choice* exist?[80] Henkel and Strittat note that when '"empowering" participants "to take part in the modern sector of developing societies", empowerment is then tantamount, in Foucauldian terms, to subjection'. Instead of a paternalised 'transfer of power', where empowerment is offered and power is given, we look toward agency. We ask not 'How much power?', but 'Power for what?' Participation and collective governance, while they can aid and even be forms of resilience, do not make the role of resistance redundant. Increasingly greater scholarship is necessary regarding how we may gauge success in the aftermath of participation, trust-building and agency around data infrastructures.

We and many others have identified that, in the realm of data justice, there is no silver bullet to redirect or remove growing power asymmetries. Our body of knowledge, as well as practice, must be reflexive, attuned and strengthened over time, with a variety of locally unique and iterative practices to build pathways to resist data colonialism. The broader endeavour – to turn a rusty wheel of colonialities reprised in the digital economy – requires strengthened global digital rights movements, solidarity and shifts in political will around how health data infrastructures are designed, toward decolonial and equitable health data infrastructures.

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[80] Hirschman, Exit, Voice, and Loyalty.

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