IT for Change
25 YEARS

Health for All Now!
People's Health Movement

Public Health in the Age of Data Digital Infrastructures and the Production of Dependency

Lessons from the UK and Brazil

Joyce Souza Maldonado
Matheus Falcão
Lauren Paremoer

Acknowledgements

This report is part of a research collaboration between IT for Change (ITfC) and the People's Health Movement (PHM) under the Centering Equity and Justice in Global Data Governance project, a collaborative initiative anchored by IT for Change, with support from the Fair Green and Global Alliance (FGG) and the Centre for Global Digital Justice (CGDJ). The project aims to advance sector-specific, contextually grounded data justice principles rooted in Global South perspectives, developed in collaboration with progressive civil society organisations and people's movements. Through this engagement, the project examines the impacts of digitalisation and datafication in critical domains — including public health, biodiversity, food sovereignty, and climate change mitigation and adaptation — to articulate justice-oriented approaches to data governance.

About IT for Change

Founded in 2000, IT for Change is a Southern NGO rooted in feminist principles and committed to advancing digital justice through the democratization of digital technologies. It holds Special Consultative Status with the United Nations Economic and Social Council (ECOSOC).

About the People's Health Movement

The People's Health Movement is a global network bringing together grassroots health activists, civil society organisations and academic institutions from around the world, particularly from low and middle income countries. They currently have a presence in around 70 countries.

About the Fair Green and Global Alliance

Fair, Green and Global Alliance is a consortium of eight global organisations whose goal is to expand civil society voices to make trade and global supply chains just and fair in Global South contexts.

About the Centre for Global Digital Justice

The Centre for Global Digital Justice (CGDJ) is a policy resource center that aims to further Global South visions of digital governance and technological innovation.

Credits

Authors: Joyce Souza Maldonado, with contributions from Matheus Falcão and Lauren Paremoer (PHM)
Research framework: Anita Gurumurthy and Nandini Chami
Editorial Review: Merrin Muhammed Ashraf, Amoha Sharma (CGDJ), and Anita Gurumurthy
Copyediting and Proofreading: Sadaf Wani
Illustrations and Publication Design: Harikrishnan B

All other contributors are affiliated with IT for Change.

Disclaimer

Copyright

Publication Enquiries

For publication-related enquiries, please contact: comms@itforchange.net

License

Contents

Executive Summary

This report offers a critical and comparative examination of the digitalisation of public health systems under contemporary neoliberal and data-driven paradigms. It explores how data infrastructures, algorithmic systems, and techno-solutionist narratives are reshaping healthcare governance, and evaluates the consequences for equity, sovereignty, and democratic participation.

Structure of the Report

The report is organised into eight core sections:

1. **Contextualisation** outlines the global transition from public to digital health, discussing how processes of datafication, artificial intelligence, and “smart” technologies have been embraced by governments and international organisations, often under narratives of innovation and cost-efficiency. It also analyses how these narratives mask the deepening of structural inequalities, surveillance, and the erosion of public systems.
2. **Objectives and Methodology** present the normative foundations and qualitative methods used, including document analysis, snowball sampling, and anonymised interviews with stakeholders in the UK and Brazil. The study adopts a critical lens grounded in social justice, the right to health, and digital sovereignty.
3. **Analytical Framework** introduces a conceptual model for ethical digital health systems. It proposes a flowchart that maps the ecosystem through four interrelated macro-dimensions:

    - Foundations and National Structure
    - Data Governance and Management
    - Operations and Practice
    - Impact, Evaluation and Global Justice

    This framework serves both as a diagnostic and normative tool to assess existing policies and to propose alternative strategies.

4. **Case Study: Keep Our NHS Public (UK)** documents the mobilisation of a British coalition resisting the privatisation and commodification of health data in the National Health Service (NHS). It highlights concerns over contracts with US tech giants like Palantir, the lack of transparency, and the increasing role of algorithmic decision-making in clinical settings. While successful in public awareness-raising, the movement faces challenges in influencing official policy.

5. **Case Study: Coalizão Direitos na Rede (Brazil)** presents a proactive civil society initiative that developed an ‘Agenda for Digital Health in Brazil’ based on public values, participatory governance, and technological sovereignty. It calls for open-source infrastructure, data protection, decentralised connectivity, and strong citizen participation. Although still gaining traction, the initiative has already shaped debates and influenced institutional dialogues.
6. **Comparative Analysis** draws contrasts between reactive and proactive civil society strategies in each context. It shows how both countries experience similar trends of opaque public-private partnerships, digital exclusion, and weak institutional accountability, yet differ in their levels of mobilisation, agenda-setting capacity, and alignment with constitutional health rights.
7. **Key Findings** assess the material impacts of digital health expansion on economic, social, and cultural rights. These include violations of the right to privacy, participation, equality, and the universality of care. The report denounces the role of techno-solutionism in bypassing democratic deliberation and displacing the public ethos of care with market logic.
8. **Conclusion and Strategic Recommendations** argue for a shift toward ethical digital health systems grounded in territorial justice, democratic governance, participatory regulation, and collective care. The report calls for global and local strategies to reclaim public health from data extractivism and corporate capture.

Key Findings

- **Digital health is not neutral**, it is shaped by power asymmetries, corporate interests, and neoliberal rationalities that prioritise efficiency and scalability over justice and care.
- **Multilateral organisations promote techno-solutionist frameworks** that encourage partnerships with transnational corporations, deepening dependency in peripheral countries and weakening public sovereignty.
- **Health data is increasingly treated as a commodity**, leading to financialisation, surveillance, and exclusionary practices—particularly in regions with poor digital infrastructure.
- **Algorithmic systems are being deployed without transparency**, risking biased decision-making, the undermining of clinical judgement, and the amplification of inequalities related to race, class, gender, and geography.
- **Civil society plays a crucial role** in resisting harmful digitalisation trends and proposing ethical alternatives. However, their influence remains limited by institutional inertia, lack of enforceable regulatory frameworks, and the dominance of corporate narratives.

- **The right to health is at risk** when digital infrastructures are shaped without transparency, consent, or citizen participation. Without public control, digital health may reinforce injustice rather than remedy it.

Contributions of the Report

- Proposes a **multi-layered analytical framework** for evaluating digital health systems through ethical and rights-based lenses.
- Offers **empirical insights from the UK and Brazil**, providing grounded examples of both harms and resistance.
- Bridges the debate between **health, technology, and human rights**, connecting discussions on digital governance with broader struggles for economic, social, and cultural rights.
- Articulates **policy pathways and strategic priorities** for reclaiming digital health as a public, participatory, and sovereign domain.

Contextualisation: The Struggle for Health in the Century of Data

The Digital Turn in Public Health

The development of digital health has become one of the most significant and complex transformations in the field of public policy in the 21st century, particularly in terms of the organisation of public health systems and the reconfiguration of relations between the state, the market, civil society, and digital technologies. Understanding the foundations and directions of this transition is essential for analysing its potential, risks, and the disputes it entails.

In this context, this report presents a critical overview of the digitalisation of public health, drawing on international guidelines and strategies, as well as case studies. These highlight how public health is being transformed into digital health across national contexts, particularly in both developed and economically dependent countries, often referred to as developing, peripheral nations or the Global South.

Datafication, Algorithmic Systems, and Big Data Ideologies

This context is marked by a profound transformation arising from the way data-driven technologies have begun to shape the economy, politics, and social relations. The digital technological revolution, which began in the late 20th century and intensified throughout the 21st century, has been catalysed by advances in computational systems and their infrastructures, coupled with increased data transmission capacity and network connectivity. These developments have enabled not only the creation of digital infrastructures and technologies for transmitting, storing, and processing data, but also the widespread dissemination of individual electronic devices.

These technologies fundamentally operate through the mass and continuous collection of data and its processing via algorithmic systems. The data captured by this technological machinery encompass an ever-expanding range of dimensions—from personal information, location records, and consumption patterns, to interactions on social media and even physiological and emotional indicators.

This data collection and processing have increasingly been structured through platforms and artificial intelligence (AI) systems. In the field of health, this process has been used to enable the development of increasingly data-driven solutions.

Although the transformation of actions and information into quantifiable data is not a new phenomenon, recent decades have witnessed a significant shift. Positivist perspectives, which argue that quantified data can solve previously intractable problems, have placed data collection, processing, and classification at the heart of public policy and business models. This has directly impacted the health sector—for instance, in the management of healthcare services, the formulation of medical diagnoses, the assessment of both individual and population-level health risks (including blurring the lines between population and individual information), and the construction of both basic and specialised models of care and attention.

Some scholars[1] have warned about ‘boundary transgressions’—situations in which professionals from one domain, such as technology, exercise undue influence over decisions traditionally made by health professionals. For instance, algorithmic outputs developed by private companies are used to guide clinical diagnoses or treatment decisions, sometimes without full oversight by medical staff.

Digital Health and the Neoliberal Shift

The process, known as datafication, has advanced in the health sector fuelled by a strong belief in the potential of big data technologies, which are seen as capable of generating economic benefits—such as cost reduction—and social gains, such as predictive analyses for more efficient public health systems.

This belief, referred to as the ideology of dataism, is promoted by so-called “big data fundamentalists”, who claim that it is possible to objectively quantify human behaviour and forms of sociability collected through digital technologies and later processed and classified. While this view is often supported by compelling examples of big data applications in solving specific problems, it frequently attributes an almost absolute role to quantification, treating it as the key to resolving humanity’s longstanding challenges. In practice, however, this has not materialised, as the deployment of big data solutions often faces structural barriers such as fragmented health systems, lack of contextualised data, opaque governance, and profit-driven implementation models.[2]

---

[1] See Evelyn Z. Brodkin, “Reflections on Street-Level Bureaucracy: Past, Present, and Future,” Public Administration Review 72, no. 6 (2012): 940–49., which explores how bureaucratic and professional discretion are transformed under external managerial pressures. On the role of AI ethics in safeguarding clinical decision-making from undue technological influence, see David Leslie, Understanding Artificial Intelligence Ethics and Safety: A Guide for the Responsible Design and Implementation of AI Systems in the Public Sector (London: Alan Turing Institute, 2020). For legal perspectives on the use of private algorithmic tools in public governance, including health care, see Teresa Scassa, “Administrative Law and the Governance of Automated Decision-Making: A Critical Look at Canada’s Directive on Automated Decision-Making,” Canadian Journal of Administrative Law & Practice 33, no. 2 (2020): 221–46.

[2] On critiques of dataism and the limits of quantification, see Shoshana Zuboff, The Age of Surveillance Capitalism (New York: PublicAffairs, 2019); Salomé Viljoen, “A Relational Theory of Data Governance,” Yale Law Journal 131, no. 2 (2021): 573–654. https://www.yalelawjournal.org/pdf/131.2_Viljoen_1n12myx5.pdf; and Anita Gurumurthy and Nandini Chami, “Beyond Data Bodies: New Directions for a Feminist Theory of Data Sovereignty,” Data Governance Network Working Paper No. 24 (January 2022), which advances a feminist relational ontology and emphasizes the need for collective and contextualised governance of health-related data. https://www.researchnet.net/publication/358552418_Beyond_data_bodies_New_directions_for_a_feminist_theory_of_data_sovereignty

These dynamics align closely with neoliberal rationalities that increasingly permeate public health. Neoliberalism finds in digital technologies—especially self-monitoring tools designed for profit extraction—a powerful mechanism for deepening its logic within healthcare. Through data collection and algorithmic processing, individuals are transformed into markets: they are fed fragmented information about how to manage their health, taking on both responsibility and blame for their outcomes. This market-oriented rationality disregards the complexity of health science and the collective determinants of wellbeing, instead imposing a framework in which each person must adapt to maintain and enhance their social and economic capital.

Discourses of Innovation and the Expansion of Smart Technologies

Excessive valorisation of data has influenced the guidelines and strategies of international organisations in both health and economic sectors, further driving the datafication processes. The World Economic Forum (WEF), for instance, characterises the rise of data-driven digital technologies as the Fourth Industrial Revolution, claiming that there is a particularly disruptive potential in the health sector through the creation of the so-called "quantified self".[3]

In this so-called Fourth Industrial Revolution, the health field has become increasingly associated with the integration of digital technologies. Initially conceived under the label of e-health (or electronic health),[4] the focus was on digitalisation of institutions and processes within the sector. However, with the strengthening of digital infrastructures and the advancement of technologies such as artificial intelligence, algorithms, big data, and mobile and wearable devices, the concept has evolved into digital health—encompassing not only institutional changes but also ways in which individuals are expected to manage their own health.

---

[3] Klaus Schwab, The Fourth Industrial Revolution (Geneva: World Economic Forum, 2016); World Economic Forum, Shaping the Future of Health and Healthcare (Geneva: World Economic Forum, 2016).

[4] The World Health Organization's approach to technology in health evolved from early initiatives focused on eHealth and mHealth toward a broader, integrated concept of Digital Health. This transition is reflected in a series of WHA resolutions and strategic documents. World Health Assembly, Resolution WHA58.28: eHealth (Geneva: World Health Organization, 2005), https://apps.who.int/gb/ebwha/pdf_files/WHA58/WHA58_28-en.pdf.marked the first formal endorsement of eHealth, calling on Member States to develop national eHealth strategies. Subsequently, World Health Assembly, Resolution WHA66.24: eHealth Standardization and Interoperability (Geneva: World Health Organization, 2013),https://apps.who.int/gb/ebwha/pdf_files/wha66/A66_R24-en.pdf addressed the growing use of mobile and wireless technologies for health (mHealth). The shift to a more holistic vision occurred with the World Health Assembly, Resolution WHA71.7: Digital Health (Geneva: World Health Organization, 2018),https://www.who.int/publications/i/item/10665-279505 which formally adopted the term 'digital health' and urged Member States to integrate digital technologies into their health systems. This culminated in the endorsement of the World Health Organization, Global Strategy on Digital Health 2020–2025 (Geneva: World Health Organization, 2021) which provides a framework for digital transformation in health systems, emphasizing governance and interoperability, for free flow of data.

This new paradigm, although it incorporates population health management and a health science that proposes an analysis beyond the clinical—taking into account issues such as gender, race, and class—has also strongly promoted the idea of individual self-management of health, meaning that the patient takes an active role in engaging with digital devices and sharing their personal health information. This self-management is encouraged by public policies, government programmes, institutional campaigns, and private sector interests.[5]

This is a concerning scenario, as it erodes the conception of public and collective health[6] and its promotion as a duty of the state, instead shifting responsibility onto individuals. These individuals are then held accountable for the risks of their choices, without "imposing" such costs on the state or society—particularly in economic terms.

Smart Health Solutions and the Persistence of Inequality

This rationality is intensified by hegemonic discourses that present digitalisation as inherently progressive, efficient, and innovative—framing digital health as a necessary evolution for modern care systems.[7] Building on earlier trends of datafication, these discourses have enabled the proliferation of so-called "smart" health technologies that extend surveillance over bodies and behaviours. Rather than challenging existing inequalities, such tools often reinforce a logic of individual responsibility, in which people are continuously encouraged to monitor and optimise their health as a form of capital. In this scenario, the promise of innovation obscures systemic disparities, risks to privacy, and the erosion of collective knowledge and public health practices.

Multilateral Optimism and the Role of International Organisations

Even in the face of concerns around the rapid digitalisation of healthcare and its implications, the dominant narratives that sustain its expansion continue to highlight primarily its economic and social benefits.

---

[5] Deborah Lupton, The Quantified Self: A Sociology of Self-Tracking (Cambridge: Polity Press, 2016).

[6] In Brazilian literature, collective health (saúde coletiva) refers to a distinct epistemological and political field that emerged in opposition to the more traditional, technocratic notion of public health. While public health has often been associated with state-centred, biomedical, and epidemiological approaches to disease control and service delivery, collective health critiques these models for neglecting the broader structural determinants of health. Rooted in Latin American social medicine, collective health emphasises the social determination of the health-disease-care process, situating health outcomes within the dynamics of class, labour, territory, gender, and power. It encompasses interdisciplinary perspectives, integrating contributions from the social sciences, critical epidemiology, and health policy analysis, and positions itself as a project for the democratic transformation of health systems and society. Key figures in this tradition include Jairnilson Paim, Naomar de Almeida-Filho, and Cecília Donnangelo, among others.

[7] World Health Organization, Global Strategy on Digital Health 2020–2025 (Geneva: World Health Organization, 2019); Organisation for Economic Co-operation and Development, Health in the 21st Century: Putting Data to Work for Stronger Health Systems (Paris: OECD Publishing, 2019); Klaus Schwab, The Fourth Industrial Revolution (Geneva: World Economic Forum, 2016).

From an economic perspective, these tools are expected to reduce operational costs—especially those related to the workforce and the management of supplies—while increasing productivity through automation and algorithmic decision-making. Datafication technologies are also valued for their predictive capacities, which are considered strategic for anticipating demand, setting prices, and optimising resource allocation, thereby reinforcing a logic of profitability and system rationalisation.

In the social sphere, these solutions promise to expand access to care through earlier diagnoses, better-targeted interventions, and expansion of services via telemedicine and remote monitoring—particularly in hard-to-reach areas—theoretically contributing to the reduction of health inequalities.

This optimism has been widely shared by multilateral organisations. The World Health Organization (WHO), for example, has consistently promoted digital health as a key enabler of the United Nations' Sustainable Development Goals (SDGs), emphasising the need for standardisation, interoperability, data sharing, and integration between national policies and international networks.[8] The Organisation for Economic Co-operation and Development (OECD), in turn, as an intergovernmental body focused on macroeconomic stability and modernisation of public administration, has promoted digital reforms centred on efficiency and innovation, frequently guided by market principles.

Private Sector Partnerships and Peripheral Dependencies

Both WHO[9] and the OECD[10] have advocated for broad coordination between different sectors—public and private—to enable the implementation of digital health on a global scale. The WHO, for instance, encourages governments to collaborate with a range of non-state actors, including financial institutions, health insurers, technology companies, and digital solution developers. While framed within a logic of multisectoral cooperation, this guidance reflects and deepens the insertion of neoliberal principles into the health field, repositioning the state as a facilitator of private interests—often linked to transnational corporations. In peripheral countries, this model tends to intensify dependency relations, as such "partnerships" frequently involve the procurement of proprietary services and platforms developed in the Global North—such as Google, Amazon, Microsoft, and Palantir—to structure systems, store data, and deliver digital solutions. In doing so, they reproduce historical patterns of technological, economic, and social asymmetry, especially as these technologies promote an individualised perspective on health.

---

[8] World Health Assembly, Resolutions WHA58.28–WHA71.7 (Geneva: World Health Organization, 2005–2018).

[9] World Health Assembly, Resolution WHA71.7: Digital Health (Geneva: World Health Organization, 2018), https://apps.who.int/gb/ebwha/pdf_files/WHA71/A71_R7-en.pdf

[10] Organisation for Economic Co-operation and Development, Recommendation of the Council on Health Data Governance (Paris: Organisation for Economic Co-operation and Development, 2019), https://legalinstruments.oecd.org/en/instruments/OECD-LEGAL-0463

Financialisation and the Commodification of Health Data

These practices reveal a global trend of financialisation11 and commodification within digital health, where health data become high-value economic assets—including clinical records, biometric and physiological information, behavioural patterns, location history, and even social and emotional indicators captured through digital technologies. These assets are traded in opaque markets and are subject to both direct and indirect monetisation practices. 12Such dynamics deepen inequalities and dependency between nations, as they transfer knowledge, value, and technological sovereignty to hegemonic centres of digital production, particularly in the United States.

It is within this context that the global digital health ecosystem is being constructed—a structure that concentrates technological advances and the knowledge arising from these processes in a few hubs, essentially in core countries. Peripheral nations, such as those in the Global South, are turned into sites of experimentation and extraction of data, knowledge, and profit.

The Political and Social Risks of Digital Health Expansion

The implications of the current stage of development and expansion of digital health are therefore manifold. At the individual level, issues emerge around privacy, surveillance, algorithmic discrimination, medicalisation, and self-monitoring. At the collective level, challenges arise in relation to regulation, data sovereignty, digital exclusion, and the right to health as a public good promoted by the state. These include the lack of clear and enforceable regulatory frameworks for public-private partnerships; dependence on foreign cloud services and proprietary platforms for data storage and processing; and persistent gaps in connectivity and digital literacy, especially in rural and marginalised areas. In this scenario, it becomes urgent to develop critical and contextualised approaches to the evolution of digital health, taking into account its political, economic, social, and epistemic dimensions.

---

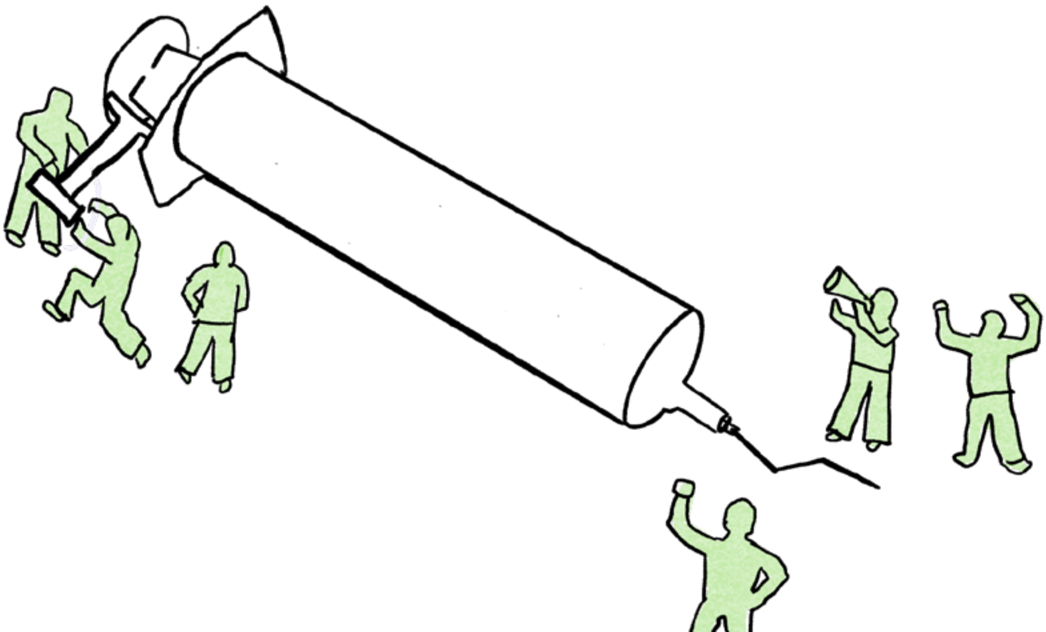
11 C. Rikap (2021) examines how leading tech firms like Apple and Amazon deploy financial assets and intangible rents as central mechanisms of corporate financialisation. In Chapter 7, she shows how Apple transforms data and intellectual property into monopolistic rentiership, inflating its intangible asset base to bolster financial valuations. Chapter 8 explores how Amazon integrates cloud- and AI-based knowledge assets into its balance sheet—not only as operational tools, but also as financial instruments that enhance market capitalisation and reinforce intellectual monopoly power. Through these case studies, Rikap argues that intangible-driven intellectual rent extraction becomes a powerful form of assetised financialisation, distinct from traditional debt-based corporate finance.

12 Tamar Sharon, “Self-Tracking for Health and the Quantified Self,” Health Sociology Review 25, no. 1 (2016); Barbara Prainsack, The Value of Health Data: Who Benefits from Electronic Patient Data? (Cambridge: Cambridge University Press, 2019).

Towards a Critical Analytical Framework

To this end, it is essential to understand how the digital health ecosystem has been structured. From this perspective, this report presents an analytical flowchart developed from official publications of international guidelines and strategies, documents produced by civil society organisations, academic references, field experiences, and interviews with public officials involved in the implementation of digital technologies in public healthcare. The model aims to represent the multiple layers of the digital health ecosystem—from infrastructure, through institutional and data governance, to care practices and global impacts— highlighting key points of tension, contestation, and possibility.

The report then analyses two case studies. The first examines the Keep Our NHS Public movement in the United Kingdom, which has, albeit modestly, been developing resistance to the entry of private companies and opaque algorithms into the National Health Service (NHS). The second focuses on an initiative led by the organisation Direitos na Rede in Brazil, which challenges the direction of digital health within the Unified Health System (SUS), denouncing the risks of privatisation and proposing citizen-led regulatory alternatives as well as the development of publicly owned national digital infrastructures.



Objectives

The overall objective of this work is to contribute to the strengthening of critical approaches to digital health, particularly from the perspective of social justice, technological sovereignty, and the defence of the right to health as a public and free good, guaranteed by the state. To this end, the report presents:

- A critical analysis of international digital health guidelines and their impacts on peripheral countries;
- The presentation of an analytical model (flowchart) of the digital health ecosystem;
- A comparison of two national experiences, focusing on social resistance and political tensions in the face of digitalisation;
- A reflection on the challenges and opportunities for a fairer governance of digital health.

Methodology

A qualitative approach was adopted for this report, focusing on the identification of actors, experiences, and perceptions regarding the development of digital health, with particular attention to one core country (the United Kingdom) and one peripheral country (Brazil). The main data collection method was based on the technique known as snowball sampling[13], widely used in research involving hard-to-reach populations or when the subject matter includes sensitive issues and low transparency. Snowball sampling begins with key informants (seeds), identified through documents, research networks, and participation in strategic events.

These informants then refer to other individuals or sources, creating a chain of references that allows the mapping of groups, opinions, experiences, and publications. This methodology is especially relevant in the case of digital health, where many processes related to the contracting of companies, use of data, and formulation of public policies occur opaquely and are heavily influenced by private interests.

---

[13] H. Russell Bernard, Research Methods in Anthropology: Qualitative and Quantitative Approaches (Lanham, MD: AltaMira Press, 2005); Patrick Biernacki and Dan Waldorf, “Snowball Sampling: Problems and Techniques of Chain Referral Sampling,” Sociological Methods & Research 10, no. 2 (November 1981): 141–163.

Furthermore, this approach is recommended when dealing with sensitive topics, where interviewees—such as public or private managers—may prefer not to be directly associated with certain issues due to potential reprisals. For this reason, the data was recorded anonymously, without the direct use of identified interviews, relying instead on document analysis, network observation, reports, and public outputs from the scenarios examined.

The methodology was crucial for tracing how sociotechnical relations are structured between governments, platforms, companies, health professionals, social movements, and citizens. Thus, the data analysis considered both discourse and institutional practices, forms of collective organisation, and experiences of resistance.

Flowchart of the Digital Health Ecosystem

Before presenting the flowchart, it is important to clarify the normative perspective that informs this analysis. In this report, we adopt the notion of an ethical digital health ecosystem to describe systems grounded in the public interest and oriented by principles of equity, technological sovereignty, transparency, democratic participation, and protection of rights. This framing serves as a critical lens to assess prevailing digital health practices and to identify pathways for transformation that resist commodification, surveillance, and technological dependency. The flowchart that follows was developed in light of these normative principles, mapping not only what currently exists but also what should be collectively built.

The flowchart presented below was developed drawing on international guidelines, civil society contributions, and insights from experts and activists in Brazil and the United Kingdom.[14]

Towards Ethical Digital Health Systems: Introducing the Framework

Building on the political and technical analyses presented throughout this report, one of its key contributions is the formulation of a conceptual and operational framework for what we define as ‘ethical digital health systems’. This term refers to digital health infrastructures, practices, and governance models that are explicitly grounded in the defence of health as a public and universal right, and that aim to resist the dominant logic of commodification, surveillance, and technological dependency.

---

[14] Based on detailed analyses of resolutions and strategies issued by the World Health Organization (WHO) and recommendations of the Organisation for Economic Co-operation and Development (OECD), as well as documents produced by international civil society organisations, such as the People’s Health Movement (PHM). Additional inputs were gathered through interviews and exchanges with health and digital security specialists from Brazil and the United Kingdom—in the latter case, particularly independent researchers and activists engaged in defending the NHS (National Health Service). In Brazil, the process was enriched by dialogue with activists and researchers working on data justice, digital rights, and technological sovereignty within the Unified Health System (SUS).

In contrast to prevailing models shaped by market imperatives and opaque public-private partnerships, an ethical digital health system must be rooted in principles of equity,[15] technological sovereignty, transparency, democratic participation, and territorial relevance.

In this context, the flowchart serves not only as a descriptive model of existing processes and structures, but also as a normative and analytical tool that identifies the foundational elements necessary for building digital health systems aligned with ethical, social, and democratic values. It articulates a vision for digital transformation in healthcare that prioritises public interest over commercial gains and recognises the centrality of community-based knowledge, participatory governance, and systemic accountability. The macro- and micro-categories outlined in the flowchart thus represent not only dimensions of analysis, but also strategic pillars for the construction and evaluation of ethical digital health ecosystems. As such, it provides both a diagnostic lens for assessing current practices and a normative guide for reorienting them towards justice, equity, and public interest.

The flowchart was developed according to a conceptual organisational logic that structures the digital health ecosystem into four interdependent dimensions: Foundations and National Structure; Data Governance and Management in Health; Digital Health Operation and Practice; and Impacts, Evaluation and Health Justice. Each of these macro-categories is further broken down into specific micro-categories, detailing essential aspects for a critical and strategic understanding of the current digital health landscape, both nationally and globally.

1. **Foundations and National Structure** – Encompasses foundational elements such as connectivity, technological infrastructure, energy sustainability, institutional governance, legal and regulatory frameworks, digital human rights guarantees, and financing models. This dimension represents the material and normative basis upon which digital health systems are built.

2. **Data Governance and Management in Health** – Covers data architecture and levels of interoperability, mechanisms for the protection and ethical use of sensitive data, regulation of systems based on artificial intelligence and predictive algorithms, as well as the effects of these technologies on clinical, administrative, and epidemiological decision-making.

3. **Digital Health Operation and Practice** – Refers to the way technologies are integrated into everyday healthcare practices, including the training and upskilling of professionals to work in digitised environments, the reorganisation of care models, and the adoption of practices such as automation, telemedicine, mobile devices, and digital platforms.

---

[15] Equity is understood here according to the definition established by the UN Committee on Economic, Social and Cultural Rights in General Comment No. 14 (2000), which frames equity through the AAAQ criteria: availability, accessibility, acceptability, and quality.

4. **Impact, Evaluation and Global Justice** – Proposes a broader view of the social, political, and geopolitical impacts of health digitalisation, considering both quality and efficiency assessment processes, and the risks associated with digital exclusion, technological dependency, and the loss of sovereignty over infrastructures, data, and algorithms.

Each of these dimensions, connected through the micro-categories, enables a comprehensive and systematic analysis of the many facets that shape the development of digital health in the 21st century. The flowchart, therefore, goes beyond a mere exercise in categorisation: it serves as a strategic tool to guide evaluations, inform public policy, and support practical action by various actors committed to the defence of health as a right.

Its relevance lies precisely in its ability to offer a conceptual and analytical map that can be used by civil society organisations, digital rights collectives, researchers, health councils, and public managers committed to a critical, participatory, and democratic approach to digital health.

It is important to note, however, that the flowchart represents a synthesis of what could be systematised from the analysis of official documents, academic publications, and interviews,[16] revealing how digital health is meant to be implemented globally according to different institutional and social agendas. This means that many of the macro- and micro-categories presented here are already being applied in certain contexts; others, however, remain neglected or are implemented in a partial, fragmented, or interest-driven way—particularly by market forces. This asymmetry between design and practice will be explored further in the case studies that follow, which illustrate how the principles and structures of globalised digital health are realised—or fail to be realised—in different and unequal realities.

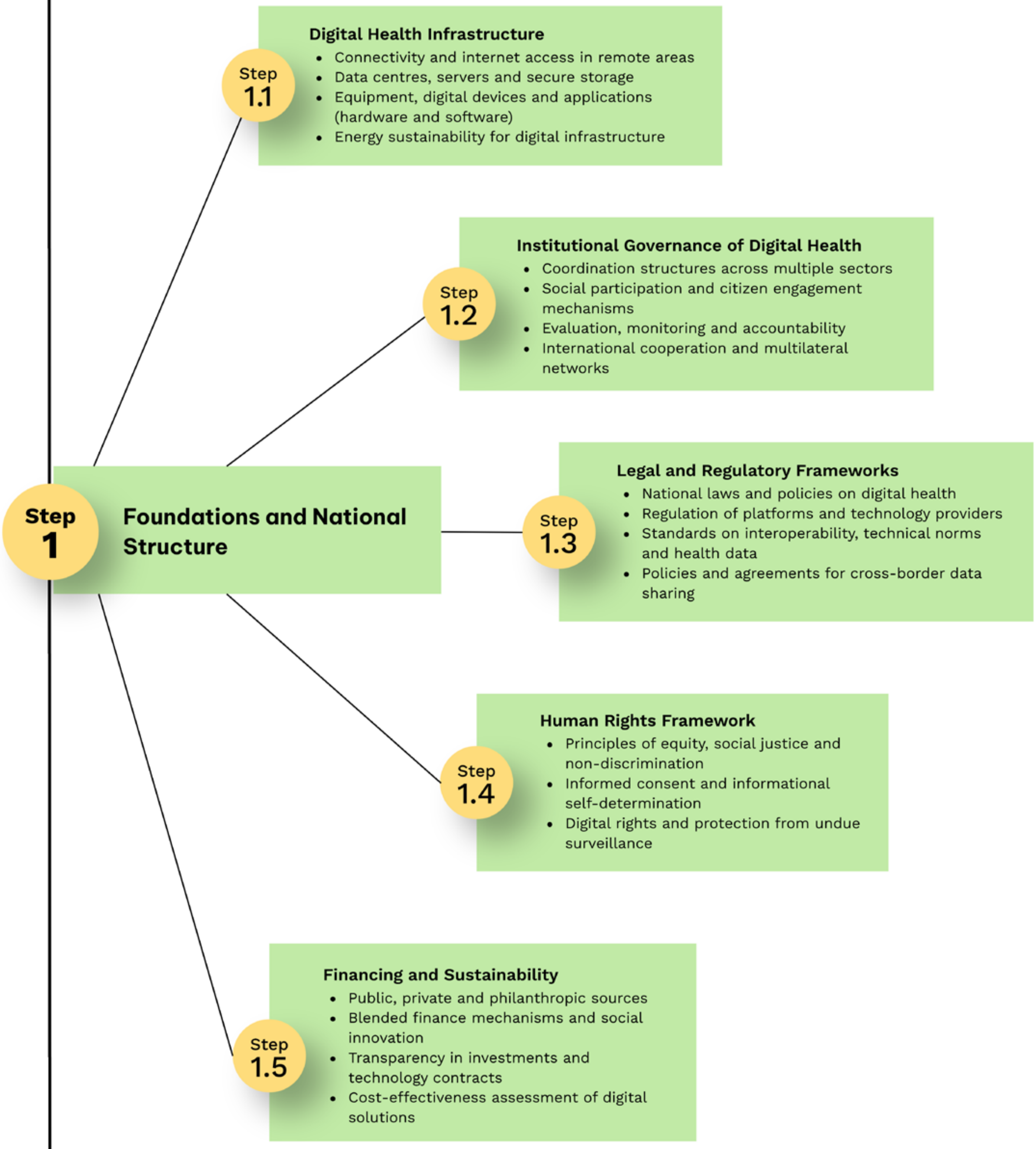
The following case studies—focusing on the United Kingdom and Brazil— explore how the elements identified in the flowchart are materialised, challenged, or absent in real-world settings. They provide grounded insights into the tensions between global digital health agendas and national implementation processes.

---

[16] World Health Assembly, Resolution WHA58.28: eHealth (Geneva: World Health Organization, 2005), https://apps.who.int/iris/handle/10665/20378; World Health Assembly, Resolution WHA71.7: Digital Health (Geneva: World Health Organization, 2018), https://apps.who.int/gb/ebwha/pdf_files/WHA71/A71_R7-en.pdf; Organisation for Economic Co-operation and Development, Recommendation of the Council on Health Data Governance (Paris: Organisation for Economic Co-operation and Development, 2019), https://legalinstruments.oecd.org/en/instruments/OECD-LEGAL-0463; People's Health Movement, A People's Health Movement Perspective on Digital Health (2020); interviews conducted with researchers and civil society organisations in Brazil and the United Kingdom (anonymised).

Digital Health Development Ecosystem

(Organised by Macro-Categories and Subcategories)



Step 1

Foundations and National Structure

Step 1.1

Digital Health Infrastructure

- Connectivity and internet access in remote areas
- Data centres, servers and secure storage
- Equipment, digital devices and applications (hardware and software)
- Energy sustainability for digital infrastructure

Step 1.2

Institutional Governance of Digital Health

- Coordination structures across multiple sectors
- Social participation and citizen engagement mechanisms
- Evaluation, monitoring and accountability
- International cooperation and multilateral networks

Step 1.3

Legal and Regulatory Frameworks

- National laws and policies on digital health
- Regulation of platforms and technology providers
- Standards on interoperability, technical norms and health data
- Policies and agreements for cross-border data sharing

Step 1.4

Human Rights Framework

- Principles of equity, social justice and non-discrimination
- Informed consent and informational self-determination
- Digital rights and protection from undue surveillance

Step 1.5

Financing and Sustainability

- Public, private and philanthropic sources
- Blended finance mechanisms and social innovation
- Transparency in investments and technology contracts
- Cost-effectiveness assessment of digital solutions

Step 2

Data Governance and Management in Health

Step 2.1

Data Architecture and Interoperability

- Integrated and open systems (open standards)
- Unified and continuous electronic health records

Step 2.2

Privacy, Security and Personal Data Protection

- Encryption, access control and technical security measures
- Audit mechanisms and accountability for data use
- Algorithmic governance and responsibility for automation
- Implementation of data protection laws (e.g. LGPD/Brazil or GDPR/Europe)

Step 2.3

Decision Support and Health Surveillance Systems

- Predictive and triage tools based on AI
- Epidemiological surveillance and emergency response systems
- Data- and evidence-based clinical decision-making models

Step 3

Digital Health Operation and Practice

Step 3.1

Workforce and Training in Digital Health

- Training professionals in digital skills
- Inclusion of community workers and agents in the digital ecosystem
- Incentives and recognition of digital health work

Step 3.2

Digital Care Models and Telemedicine

- Patient-centred care supported by digital tools
- Solutions for primary, specialised and emergency care
- Hybrid models (in-person + remote) and mobile health services

Step 3.3

Digital Transformation and Clinical Innovation

- Smart clinical operations (smart hospitals, AI, automation)
- Innovations in workflows, scheduling and logistics
- Smart and interoperable systems for clinical data management

Step 4

Impacts, Evaluation and Global Justice

Step 4.1

Indicators of Quality and Effectiveness in Digital Health

- Digital health outcomes (mortality, adherence, screening, etc.)
- Efficiency and problem-solving capacity of digital services
- User and health professional satisfaction

Step 4.2

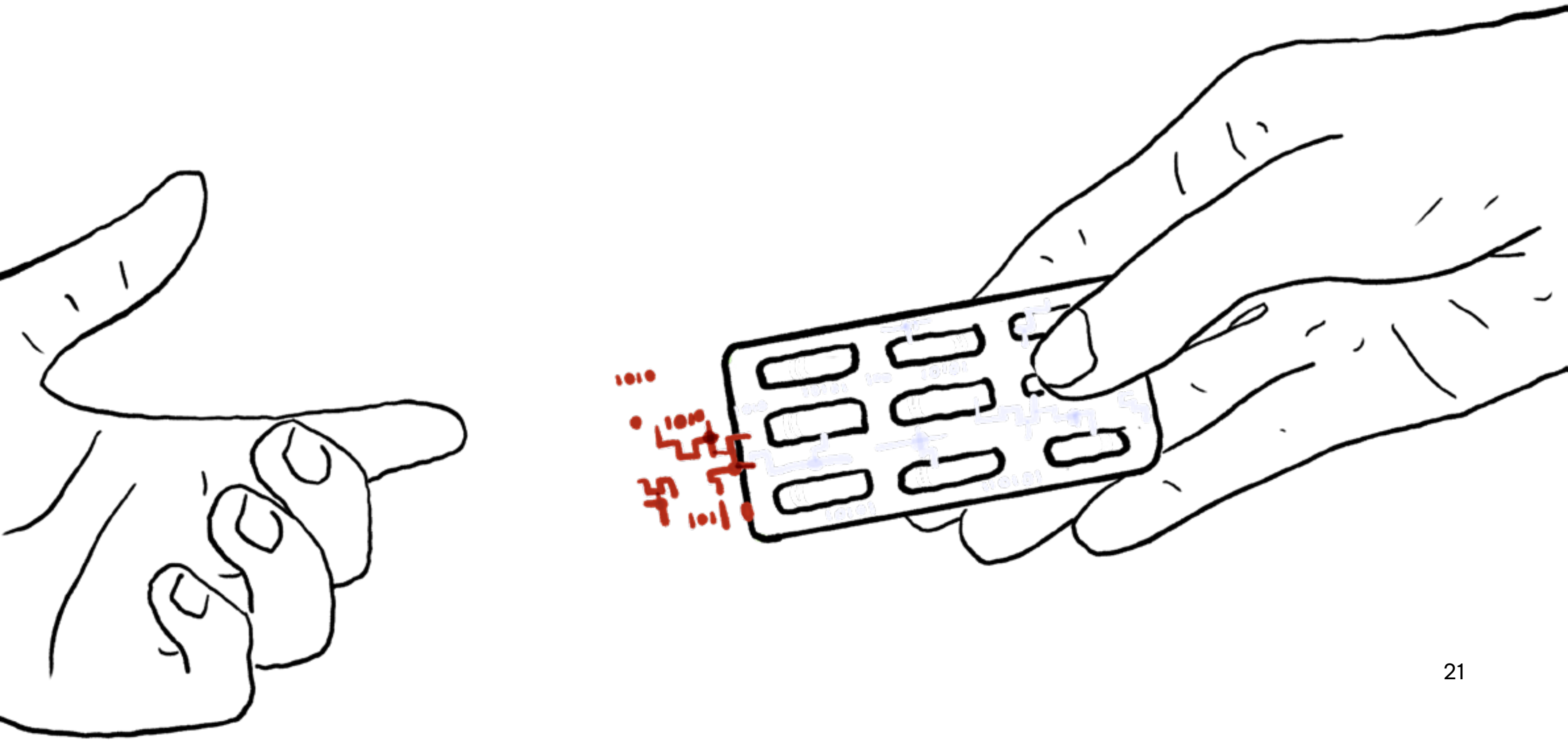
Universal Coverage and Inequity Reduction

- Integration of technologies for vulnerable populations and Indigenous, quilombola and rural communities
- Tackling regional, ethnic, racial and gender inequalities

Step 4.3

Sustainability, Digital Justice and Technological Sovereignty

- Reducing technological dependence and promoting local production
- Development of open, ethical and reusable solutions
- Risk analysis of digital infrastructures (social, environmental, geopolitical)



Understanding the NHS and SUS: Histories, Structures, and Digitalisation Trajectories

To contextualise the case studies that follow, it is essential to offer a comprehensive overview of the two public health systems that serve as the empirical focus of this report: the United Kingdom's National Health Service (NHS) and Brazil's Unified Health System (Sistema Único de Saúde – SUS). While rooted in distinct political, historical, and socio-economic conditions, both systems embody critical projects of universal health coverage and offer contrasting insights into the challenges and implications of digitalisation in public health.

The NHS, established in 1948, emerged as a foundational institution of the British welfare state. It was designed to provide comprehensive healthcare, free at the point of use, based on principles of universality, equity, and public funding through general taxation. Today, the NHS serves a population of over 67 million people and employs more than 1.2 million staff, making it one of the largest employers in Europe. It operates across four devolved systems—England, Scotland, Wales, and Northern Ireland—each with distinct administrative structures.[17] Over the past four decades, the NHS has experienced ongoing transformations marked by austerity policies, increased outsourcing, and private sector participation. These trends have significantly influenced its digital trajectory. Notably, the development of the Federated Data Platform (2023), contracted to the US-based company Palantir, has sparked widespread concern among healthcare professionals, privacy advocates, and civil society groups regarding the commodification of patient data and the erosion of digital sovereignty.[18]

---

[17] NHS England, About the NHS (London: NHS England, 2023); Office for National Statistics, UK Population Estimates (London: Office for National Statistics, 2022); The King's Fund, The NHS Workforce (London: The King's Fund, 2023); NHS Confederation, The Structure of the NHS in the UK (London: NHS Confederation, 2022).

[18] Keep Our NHS Public, Health Data Working Group, https://keepournhspublic.com/health-data-working-group/

The SUS was created in 1988 as a direct outcome of Brazil's democratisation process and social mobilisation during the country's sanitary reform movement. Enshrined in the Federal Constitution, the SUS is one of the largest public health systems in the world, serving over 190 million people. It is founded on principles of universality, integrality, equity, decentralisation, and community participation. Its structure integrates services across federal, state, and municipal levels, encompassing a wide array of health functions—from epidemiological surveillance to high-complexity care. A distinguishing feature of the SUS is its formal architecture of social participation, institutionalised through Health Councils and Health Conferences, which enable the involvement of civil society, health workers, and users in policy-making and oversight. In terms of digitalisation, initiatives such as the Meu SUS Digital platform have aimed to centralise access to health data, vaccination records, and patient histories. While potentially useful, these developments have raised serious concerns regarding data security, lack of transparency in partnerships with private tech firms, and the risk of reinforcing existing territorial and social inequalities through digital exclusion.[19]

Both systems reflect broader global dynamics in which public health is increasingly shaped by data infrastructures, algorithmic governance, and commercial interests. The NHS and SUS differ in their governance models and institutional legacies, yet both are being reconfigured through digital health agendas driven by efficiency narratives, fiscal constraints, and private sector engagement. Their digitalisation pathways are not merely technical processes; they are deeply political and contested, involving negotiations over ownership of data, public accountability, citizen participation, and the very meaning of health as a public good.

Understanding these distinct yet interconnected trajectories is critical for assessing how digital health technologies are being implemented in practice, what actors are shaping these transformations, and how social movements and policy communities are resisting or reimagining digitalisation in the name of justice, sovereignty, and collective care.

---

[19] Brazil, Constituição da República Federativa do Brasil (Brasília: Senado Federal, 1988); Ministério da Saúde, Sistema Único de Saúde (SUS) (Brasília: Ministério da Saúde, 2023); Jairnilson Paim et al., "The Brazilian Health System: History, Advances, and Challenges," The Lancet 377, no. 9779 (2011): 1778–1797; Ministério da Saúde, Meu SUS Digital (Brasília: Ministério da Saúde, 2022).

Case Study 1: Keep Our NHS Public (KONP): Resisting the Neoliberal Digitalisation of Healthcare in the United Kingdom

The Keep Our NHS Public (KONP) movement is a British coalition made up of healthcare professionals, academics, activists, and citizens committed to defending the National Health Service (NHS) as a public, free, and universal system. Since its founding, KONP has positioned itself against the processes of privatisation and marketisation of healthcare, denouncing policies that prioritise corporate interests over collective wellbeing. KONP is primarily funded through individual donations, contributions from trade unions, and proceeds from public events. It operates as a grassroots coalition with a decentralised governance structure based on local chapters.

Although KONP's core work is centred on political advocacy and public mobilisation, the movement has also made strategic use of the existing legal frameworks in the UK. For instance, it has leveraged provisions of the Data Protection Act 2018 and the UK General Data Protection Regulation (UK GDPR) to question the legality of data-sharing agreements between NHS Digital and private companies. KONP has also raised concerns about the lack of public consultation, transparency, and safeguards in accordance with these legal norms—particularly regarding patient consent and the commercial use of anonymised data.

Engagement with Digital Health: Critiques, Proposals, and Strategies

In recent years, KONP has expanded its scope to include digital health in its campaigning and advocacy work, recognising the risks associated with the uncritical adoption of digital technologies. In 2022, the movement established the Health Data Working Group, tasked with analysing the development and expansion of digital health within the NHS and confronting the privatisation and commodification of patients' health data, and addressing the growing influence of private companies in the development of the NHS's digital infrastructures.

In addition to its monitoring and advocacy efforts, the Health Data Working Group has also conducted case studies on specific NHS data initiatives, including Palantir's contracts, the OpenSAFELY platform, and the NHS App.20 These case studies expose how digital infrastructures are increasingly shaped by opaque partnerships with private companies, often without sufficient public oversight or informed consent. They highlight the risks of embedding corporate logic into core systems of public health governance.[21]

---

20 OpenSAFELY is a secure analytics platform created during the COVID-19 pandemic to allow access to NHS electronic health records for research purposes, hosted within the health service's secure servers. The NHS App is a mobile application launched by NHS England that allows patients to access health information, book appointments, order prescriptions, and view medical records.

21 Keep Our NHS Public, How Our Data Is Used: Case Studies by the Health Data Working Group (2023), https://keepournhspublic.com/how-our-data-is-used

This group[22] has identified several key concerns, including:

- Intrusive access to patients' personal data—including medical records and information from wearable devices—by private technology companies and data analytics firms, often without adequate transparency or informed consent;
- The use of data to develop algorithms that influence clinical decisions, potentially undermining medical judgement and patient safety;
- The NHS's growing dependence on tech companies for cloud storage and digital data processing platforms, with financial, environmental, and digital sovereignty implications.

In response to these concerns, KONP has coordinated its efforts through interconnected areas of action aimed at promoting:[23]

1. Critical knowledge production and public policy advocacy:

The group has developed analyses and public documents proposing alternatives to the current model of digitalisation. While these measures remain primarily at the advocacy stage, they have contributed to shaping public debates and informing discussions within civil society coalitions and oversight bodies. Key measures include:

- Public investment in national digital infrastructure for health data storage and management;
- Independent audits of NHS partnerships with tech companies, evaluating associated risks and impacts;
- A ban on the secondary use of pseudonymised data by government departments and private companies;
- The establishment of an independent regulator for data and artificial intelligence, with a focus on citizens' rights protection;
- The cessation of algorithmic decision-making in clinical resource allocation.

Although these proposals have not yet been formally incorporated into legislation or national policy frameworks, they play a crucial role in expanding public awareness, challenging dominant narratives, and articulating rights-based alternatives to the current digital health model.

---

[22] Keep Our NHS Public, How Our Data Is Used: Case Studies by the Health Data Working Group (2023). https://keepournhspublic.com/how-our-data-is-used/

[23] Keep Our NHS Public, How Our Data Is Used: Case Studies by the Health Data Working Group (2023), https://keepournhspublic.com/how-our-data-is-used/ and Keep Our NHS Public, "Data and Digital Technology," https://keepournhspublic.com/category/news/data-and-digital-technology/

2. Mobilisation and political advocacy:

KONP has launched public campaigns[24] to raise awareness about the risks of health data commodification. It has also lobbied Members of Parliament for greater transparency and stricter regulation of digital technologies in the health sector. These efforts include:

- Active participation in public hearings and parliamentary consultations;
- Producing accessible materials[25] to inform the general public about the use, protection, and privacy of health data;
- Collaboration with local health councils and health workers' unions.

3. International engagement and denunciations of digital colonialism:

The movement has engaged in international dialogues to expose the UK's subservience to US-based corporations and interests in the healthcare sector. These dialogues include informal exchanges with networks such as the People's Health Movement, which works to connect struggles against the commodification of health across regions, including Latin America and Europe. Through these spaces, KONP has shared its concerns about the growing role of foreign tech companies in shaping national health systems.

One of the most alarming examples is the government's contract with Palantir—a company known for its links to US intelligence agencies—to operate the NHS's new federated data platform.[26] This partnership raises serious concerns about national sovereignty and the security of patient data. KONP interprets this dependence on foreign digital infrastructures as a contemporary form of digital colonialism and a subordination of the country to US economic interests in public healthcare.

4. Defence of democracy and citizen participation:

KONP has drawn attention to the democratic deficit in the processes surrounding the digitalisation of healthcare. Many decisions have been taken without broad public consultation, undermining the legitimacy of adopted policies. The movement demands:

- The inclusion of health professionals, users, and social movements in digital governance bodies;
- Transparent and participatory processes in the formulation of digital health policies;
- Full disclosure of contracts signed between the NHS and private tech companies.

---

[24] Keep Our NHS Public, "Campaigns," https://keepournhspublic.com/campaigns

[25] Keep Our NHS Public, "Campaigns," https://keepournhspublic.com/campaigns; Keep Our NHS Public, "Health Data Working Group, https://keepournhspublic.com/health-data-working-group

[26] "Palantir Secures £330m NHS Contract," The Guardian, November 21, 2023, https://www.theguardian.com/society/2023/nov/21/patient-privacy-fears-us-spy-tech-firm-palantir-wins-nhs-contract

By promoting a critical approach, KONP exposes how digital health is being appropriated by market forces - particularly global ones—in ways that diverge from the principles that historically underpinned the NHS. Its proposals and actions point towards a digital transformation rooted in social justice, technological sovereignty, and democratic participation.

Critical Analysis: Disconnects Between Practice and the Ideal Digital Health Ecosystem

The critiques and proposals of KONP highlight how, even in countries at the centre of global policymaking such as the UK, the digitalisation of healthcare has been pursued in ways that conflict with the principles of social justice, technological sovereignty, and democratic participation that should guide an ethical digital health ecosystem. Using the analytical framework set out in this study, it is possible to systematise the main gaps identified by the movement across the different dimensions that structure this ecosystem:[27]

Macro Categories	**Elements Present in KONP's Critical Analyses**
Foundations and National Structure	Criticism of the lack of transparency in partnerships between the NHS and large private companies, and of the growing commercialisation of the public health system. KONP denounces the replacement of a universal public system by a fragmented, outsourced model driven by corporate interests. Additional concerns include insufficient investment in public digital infrastructure; the reliance on imported technologies developed by large corporations (seen as threats to digital sovereignty and continuity of care); the absence of participatory processes in decisions about digitalisation, including the exclusion of healthcare workers and the public from consultation; disregard for informed consent; and strong opposition to public-private partnership models involving companies such as Palantir, Google, and Amazon, which are seen as vehicles for corporate capture of the NHS's digital agenda and the privatisation of strategic public functions.
Data Governance and Management in Health	Denunciation of the mass, non-consensual collection of patient data, with questions about who controls, accesses, and profits from this information. The movement questions the opaque governance of health data and the transfer of datasets to companies such as Palantir.
Digital Health Operation and Practice	Alert about the precarisation of healthcare work, exacerbated by the use of technologies that automate parts of care, increase administrative burdens, and reduce human contact. KONP also denounces tools that reinforce inequalities—such as mobile apps that are poorly accessible to vulnerable populations and systems that replace in-person care without ensuring quality.
Impact, Evaluation and Global Justice	Criticism of the lack of robust mechanisms for oversight and accountability, and the difficulty civil society faces in accessing clear information about digital contracts, impacts, and outcomes.

---

[27] Based on materials published by Keep Our NHS Public, How Our Data Is Used: Case Studies by the Health Data Working Group (2023), https://keepournhspublic.com/how-our-data-is-used/; Keep Our NHS Public, “Data and Digital Technology,” https://keepournhspublic.com/category/news/data-and-digital-technology/.

This systematisation highlights how KONP's actions go beyond the specific critique of individual technologies, articulating a comprehensive view of the risks posed by the neoliberal digitalisation of healthcare. By challenging the current ecosystem, the movement contributes to the construction of a counter-hegemonic digital health agenda, grounded in social justice, transparency, participation, and sovereignty.

More recently, KONP has mobilised against the Labour Party's proposed Data Use and Access Bill,[28] warning that it could open the door to further commodification of NHS patient data. The group criticises the bill for its lack of safeguards regarding data ownership, commercial exploitation, and the role of private actors in shaping public digital infrastructure. KONP's position emphasises the need for legally binding guarantees of public control, transparency, and democratic accountability at all stages of data governance.

While KONP has played a vital role in denouncing the risks of corporate capture and promoting public awareness of digital health issues, the tangible institutional impact of its advocacy has been limited so far. Its efforts have helped sustain public pressure and keep the debate open, but have not yet translated into significant policy reversals. From a critical perspective, KONP's strategies could be expanded through deeper engagement with policy design processes and by articulating alternative proposals for democratic and socially just digital infrastructures. Strengthening connections with international movements and incorporating debates on global data governance could further broaden the scope and impact of its work.

Case Study 2: A Collective Agenda for an Ethical Digital Health Ecosystem in Brazil

In Brazil, the advancement of digital health has taken place amidst profound social asymmetries, territorial inequalities, and persistent challenges related to the governance and underfunding of the Unified Health System (SUS). Digitalisation in this context is far from a neutral process—it often reflects and deepens existing structural inequalities. For instance, the lack of internet access in remote regions, low digital literacy among users and professionals, and growing dependence on private technology providers increase the risk of exclusion, data misuse, and the weakening of public health infrastructures. These concerns were heightened by the growing use of digital platforms and health data systems during the COVID-19 pandemic, which exposed vulnerabilities in data governance, consent mechanisms, and accountability frameworks.

---

[28] Keep Our NHS Public, Labour Data Use and Access Bill and Use of NHS Data (2023), https://keepournhspublic.com/labour-data-use-and-access-bill-and-use-of-nhs-data/

In response to these risks, a mobilisation emerged in 2023, articulated by the Coalizão Direitos na Rede,[29] a network of civil society organisations working on digital rights in Brazil. The coalition created a dedicated working group composed of activists, researchers, and public health professionals committed to defending the principles of SUS. This group began to monitor digital health policies, promote public debates, and formulate recommendations to ensure that digital health tools respect privacy, equity, and democratic control. One of its first initiatives was to engage with the Ministry of Health to demand greater transparency in partnerships with technology companies and to call for the creation of participatory mechanisms in digital health governance.

This initiative led to the collective development of 'An Agenda for Digital Health in Brazil',30 published in 2024. The proposal not only denounces the structural issues of the digital health process in the country but also articulates concrete guidelines and recommendations for building public policies guided by social justice, the protection of rights, and the strengthening of SUS. The agenda advocates, among other points:

- The development of a national digital health policy driven by the public interest and aligned with the protection of sensitive data. This includes the adoption of robust data governance frameworks, transparency in public-private partnerships, community participation in decision-making, and the prioritisation of open-source technologies and public infrastructure. The policy proposals also emphasise the need for clear consent mechanisms, interoperability standards that do not promote vendor lock-in, and the establishment of independent oversight bodies to ensure accountability and safeguard the rights of patients and health professionals;

- Ensuring transparency in contracts and partnerships with technology companies, through public disclosure of terms, risk assessments, and the establishment of accountability mechanisms that prevent undue corporate influence over public health policies;

- Encouraging the adoption of open and auditable technologies, especially those based on free and open-source software, to ensure transparency, interoperability, and public control over digital health systems. However, the policy also acknowledges the need for safeguards, including rigorous security audits, ethical review protocols, and institutional capacity to evaluate and maintain such technologies. It is essential that openness does not compromise data protection or system resilience, and that public institutions are adequately equipped to manage and govern these tools responsibly;

- Promoting the inclusion of healthcare workers and SUS users in decision-making processes related to digital health, by institutionalising participatory forums, listening channels, and co-creation methodologies that reflect the diversity of the Brazilian population;

---

29 Coalizão Direitos na Rede, "Who We Are," https://direitosnarede.org.br/quem-somos

30 Coalizão Direitos na Rede, "Uma Agenda para a Saúde Digital [An Agenda for Digital Health]," April 17, 2024, https://direitosnarede.org.br/2024/04/17/uma-agenda-para-a-saude-digital

- Addressing territorial inequalities in connectivity and digital access by expanding public investment in digital infrastructure, particularly in rural, Indigenous, and underserved urban areas, and by supporting community-based initiatives that strengthen digital inclusion as a condition for equitable healthcare delivery;

- Creation of regulatory frameworks that ensure technological sovereignty and democratic governance of health data. This includes prioritising the use of public digital infrastructure and nationally hosted data systems, reducing dependence on transnational technology corporations, and fostering local innovation through public investment in research and development. The agenda also advocates for mandatory transparency in algorithms used in public health systems, public control over data storage and processing, and the establishment of participatory mechanisms—such as multi-stakeholder councils—to oversee digital health governance. By strengthening national capacities and aligning technological choices with constitutional principles of universality, equity and decentralisation in healthcare, these measures aim to build a digital health system that is both sovereign and democratically accountable.

Next, we propose a systematisation of the Coalition Network's Agenda in dialogue with the categories that structure an ethical digital health ecosystem, as presented in this work:

Macro Categories	**Elements Present in the Agenda for Digital Health in Brazil**[31]
Foundations and National Structure	Advocates for a national digital health policy centred on the SUS, with public funding, social control, and institutional strengthening—in contrast to privatised and fragmented models. It also proposes the development of open-source and interoperable public infrastructure, along with investment in connectivity in underserved regions to address digital exclusion. In addition, it emphasises the role of participatory policymaking through Health Councils, Health Conferences, and open public consultations, aiming to align digital health strategies with equity, ethics, and justice. It further anchors digital health in the principles of social justice, transparency, informed consent, and the right to health. Finally, it calls for public-interest criteria in technology procurement, including transparency in contracts, mandatory tenders, bans on the secondary use of data, consultation with health councils, and data localisation requirements.

---

[31] Based on the proposals and statements from Coalizão Direitos na Rede, "Propostas para uma Saúde Digital Pública e Democrática," August 18, 2022, https://direitosnarede.org.br/2022/08/18/propostas-para-uma-saude-digital-publica-e-democratica/; Coalizão Direitos na Rede, "Cartilha: Saúde Digital em Debate," June 2, 2021, https://direitosnarede.org.br/2021/06/02/cartilha-saude-digital-em-debate/.

Macro Categories	**Elements Present in the Agenda for Digital Health in Brazil**[31]
Data Governance and Management in Health	Calls for democratic and transparent governance of health data, including enforcement of the General Data Protection Law (LGPD), institutional oversight by the Federal Court of Accounts (TCU), and civil society monitoring of public-private data arrangements.
Digital Health Operation and Practice	Proposes a critical approach to the adoption of digital tools, including impact assessments, accessibility, and responsiveness to the needs of users and territories—informed by consultations with health workers, local councils, and digital rights groups. It also highlights the importance of valuing SUS professionals through training, active listening, and inclusion in decisions about technology adoption.
Impact, Evaluation and Global Justice	Demands independent and continuous evaluation of digital health policies, with participation of civil society and public health institutions. Recommends transparency reports, open data portals, and rotating civil society seats on oversight bodies.

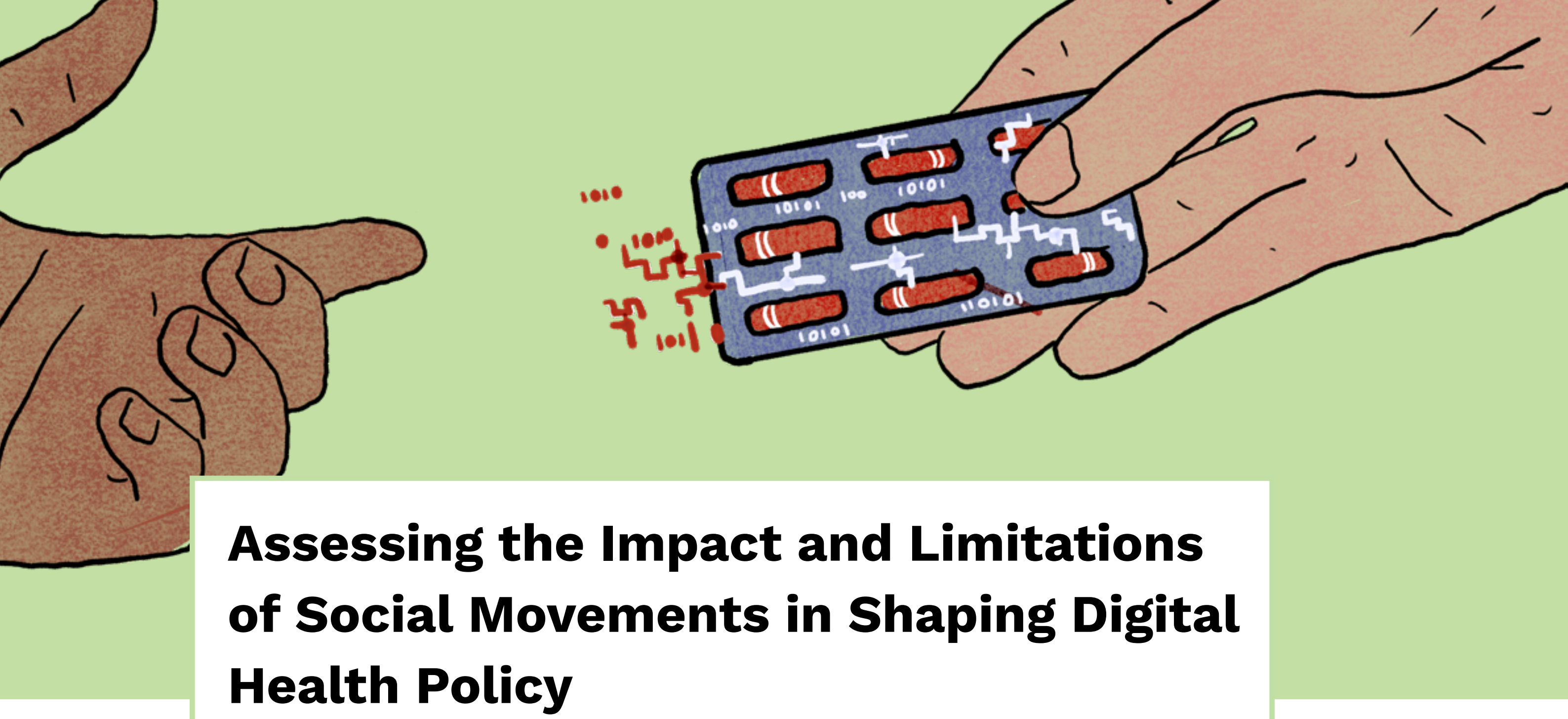
This articulation highlights how the Brazilian case represents an affirmative proposal for the transformation of the digital health ecosystem. Unlike the British case study, where civil society responses have largely emerged reactively—for example, in response to controversies such as the NHS data deal with Palantir or the centralisation of health records without adequate consent - the Rede Coalizão initiative puts forward a proactive and structuring agenda from the outset. Rather than merely resisting harmful policies, it aims to build a digital health model aligned with the constitutional principles of the SUS, such as universality, equity, decentralisation, and participatory governance.

One key distinction lies in the emphasis on 'technological justice'—a principle that frames digital health not merely as a set of technical solutions, but as a political and social project grounded in equity, democratic accountability, and the right to health. This approach rejects opaque, corporate-led systems that prioritise profit over public interest, and instead insists that technological choices must be transparent, participatory, and aligned with broader commitments to social justice. For instance, while the UK Government has faced criticism for its reliance on closed, proprietary systems with little public debate, the Brazilian coalition advocates for open-source tools, public infrastructure, and democratic oversight, positioning technological justice as a vital condition for safeguarding universal and equitable healthcare.

Although the agenda is recent, it has already contributed to raising public awareness and influencing debates within the Ministry of Health. Members of the coalition have been invited to consultations on digital health strategies, and their critiques have helped spark broader discussions about transparency in partnerships (such as those involving Amazon Web Services, which the Federal Government of Brazil hired in 2021 for cloud computing services, including hosting the National Health Data Network) and the need for stronger data protection mechanisms.[32] The impact is still unfolding, but the coalition's role as an independent and collective actor has positioned it as a relevant force in shaping Brazil's digital health future.

---

32 Ministry of Health of Brazil, Press Release on the Contracting of Amazon Web Services for Cloud Computing Services (Brasília: Ministry of Health of Brazil, 2021); Federal Court of Accounts of Brazil, Report on the Contracting of AWS for Cloud Services in the Scope of Digital Health (Brasília: Federal Court of Accounts of Brazil, 2021); Coalizão Direitos na Rede, Contributions to the Digital Health Strategy for Brazil 2020–2028 (2021).



Assessing the Impact and Limitations of Social Movements in Shaping Digital Health Policy

Social movements play a crucial role in shaping the digital health landscape—both by resisting the encroachment of private interests and by formulating alternatives grounded in public values. While this report has presented two case studies as examples of critical engagement with health digitalisation, it is also essential to assess the actual influence these initiatives have had on national policy agendas, and to reflect critically on their strategies and limitations.

Keep Our NHS Public (KONP): Impact and Strategic Gaps

KONP has made significant contributions to raising public awareness about the privatisation and datafication of the NHS. Through its Health Data Working Group, parliamentary advocacy, publications, and direct action, the movement has surfaced key risks in partnerships between the NHS and private tech firms—particularly regarding data governance, algorithmic influence on care, and the lack of democratic oversight. It has warned of the potential commercial exploitation of sensitive patient data, the dangers of opaque algorithms undermining clinical judgement, and the democratic deficit created by limited public accountability. While this advocacy has spurred greater parliamentary and media scrutiny, concrete policy change remains limited, with ongoing debates around regulation but few enforceable protections to date. Despite its important role in challenging the commodification of health data, KONP's influence on official digital health policy has been modest. Government contracts with companies such as Palantir have proceeded largely uninterrupted, and NHS digitalisation has continued on a market-oriented path, underscoring a structural disconnect between grassroots resistance and institutional responsiveness.

From a critical standpoint, KONP could consider broadening its approach in at least three areas:

1. **Transnational analysis:** While the group critiques US corporate influence, it could more explicitly situate the UK's digitalisation within global patterns of digital colonialism and technological dependency, aligning with movements in the Global South. Specifically, KONP could engage with feminist and indigenous-led movements in regions such as Latin America, Africa, and South Asia that actively challenge hegemonic datafication programmes. These groups organise resistance against technological developments that perpetuate poverty, exclusion, and cultural erasure, and promote algorithmic and digital literacy as part of a broader effort to decolonise data and technology. By collaborating with these movements, KONP would strengthen global efforts to oppose the commercialisation of health data and foreign technological impositions, fostering more equitable and locally accountable digital health governance.

2. **Proactive proposals:** Much of KONP's discourse is defensive or reactive. Developing and amplifying concrete, public-led models of digital infrastructure and algorithmic governance could increase its influence. For example, organisations such as the Ada Lovelace Institute in the UK have pioneered participatory and inclusive approaches to data stewardship, promoting public engagement and ethical oversight in digital policy. Similarly, groups like Data for Black Lives in the US focus on community-driven data justice initiatives, addressing algorithmic bias and advocating for marginalised voices in data governance. Additionally, Tactical Tech works globally to empower civil society with tools and knowledge for transparent and accountable technology use. KONP could learn from and potentially collaborate with these organisations to move beyond a defensive stance and champion positive, publicly accountable digital health infrastructures.

3. **Alliance-building:** Strengthening alliances with digital rights organisations, labour unions in tech and care sectors, including auxiliary and support workers-and a broad spectrum of patient groups, with particular attention to underrepresented communities, could help expand KONP's legitimacy and social base beyond the NHS user and worker community. Focusing on underrepresented patient groups ensures that voices often marginalised or overlooked in healthcare debates, such as ethnic minorities, disabled people, and low-income populations-are included, making the movement more inclusive and socially representative.

In short, while KONP's advocacy is necessary and courageous, its long-term effectiveness may depend on a more systemic articulation of alternatives, and on forging stronger, intersectional coalitions to counter the technocratic reorganisation of healthcare.

Saúde Digital - Coalizão Direitos na Rede: Strategic Contributions and Emerging Limits

The initiative led by Coalizão Direitos na Rede in Brazil demonstrates a contrasting and more proactive approach. Rather than focusing solely on resistance, the coalition developed a comprehensive 'Agenda for Digital Health' that articulates clear normative principles, policy guidelines, and demands for public digital infrastructures. It also explicitly links digitalisation to broader structural issues such as territorial inequality, platform dependency, and data sovereignty.

Despite the movement's efforts to broaden public discourse and involve multiple stakeholders in digital health debates, significant structural and political challenges remain. Although the digital health movement has fostered significant public debate on the advancement of this sector in Brazil, mobilising civil society and various social movements linked to digital health policies, its impact on concrete government decisions has so far been modest. Movement members actively participate in events, meetings, assemblies, and public consultations organised by both the federal government and its agencies, as well as by civil society. However, their proposals and ideas have yet to be meaningfully reflected in the policies and developments related to digital health in the country. For example, the Secretariat for Information and Digital Health (SEIDIGI), responsible for the digital transformation of the Unified Health System (SUS), continues to shape the national digital health agenda through opaque procurement processes and fragmented implementations of digital infrastructures, predominantly managed by large international corporations.

A few critical considerations may further strengthen its intervention:

1. **Engagement with health professionals at the frontline:** Although the agenda includes the perspective of workers, stronger links with unions and local health councils could broaden its reach and legitimacy;
2. **Territorial grounding:** The coalition could support more decentralised, community-based pilots of ethical digital health systems to test and demonstrate the feasibility of its proposals;
3. **Institutional pressure:** Establishing stronger dialogue with oversight institutions, such as public prosecutors, audit courts, and data protection authorities, could enhance the enforcement potential of its agenda.

Despite these limitations, the Brazilian experience represents a powerful example of how civil society can move from critique to proposal, and from fragmentation to coordination, in the struggle for technological justice in health.

Strategic Reflection

Both KONP and Coalizão Direitos na Rede illustrate key pathways for confronting the digital restructuring of public health systems. Their combined efforts point to the necessity of coupling discursive resistance with programmatic alternatives, and of building transversal alliances that link the struggles for health, data justice, and democratic governance. Assessing their impact and limitations not only strengthens the analytical depth of this report, but also highlights the terrain on which future strategies must operate: one that is global, politicised, and deeply contested.

Key Findings and Implications for Economic, Social, and Cultural Rights

Why Ethical Digital Health Systems Matter

Digital health is not merely a technical or managerial shift. It represents a profound transformation in the way healthcare is organised, accessed, and experienced. As such, it has significant implications for the protection and realisation of economic, social, and cultural rights (ESCR), particularly the right to health, the right to privacy, the right to information, and the right to participation. Without ethical and democratic governance, digital health risks reinforcing structural inequalities, enabling opaque data extraction practices, and displacing the public ethos of care with market-driven logics.

This report puts forth a framework for 'ethical digital health systems' precisely because the stakes are high. At its core, this proposal contends that technological infrastructures and practices must be publicly governed, socially accountable, and grounded in the principles of universality, equity, and justice. In their absence, digital systems may not only fail to deliver on their promises but may also actively cause harm.

Material Harms Emerging from the Case Studies

The case studies of the United Kingdom and Brazil illustrate how the digitalisation of healthcare, when led by private interests or implemented without democratic safeguards, has already produced tangible harms for individuals and communities—particularly marginalised groups. In the United Kingdom, the National Health Service (NHS) has increasingly outsourced digital infrastructure and data governance to private corporations such as Palantir, raising profound concerns over digital sovereignty, data commodification, and the erosion of public accountability. Patient health data has been shared without adequate transparency or consent mechanisms, while algorithmic tools have been deployed to influence clinical decision-making-potentially overriding professional judgement.

These processes not only threaten the right to privacy but also diminish the capacity of users and professionals to meaningfully engage in decisions affecting their care, undermining core principles of accountability and participation in public health systems.

Similarly, in Brazil, the digitalisation of the Unified Health System (SUS) has occurred in a context marked by stark territorial inequalities—both between regions (such as North and South) and within states—and chronic underfunding. Initiatives such as Meu SUS Digital, while ostensibly aimed at improving access, have often lacked adequate participatory processes or public scrutiny. The risks of digital exclusion are particularly severe in rural areas and among low-income populations, where poor connectivity and low digital literacy act as significant barriers to care access. Furthermore, the reliance on private, often opaque, platforms to store and process sensitive health data raises questions about long-term technological dependency and the constitutional duty of the state to protect the right to health.

An additional and often overlooked dimension of harm relates to the environmental externalities of digital health infrastructures. Large-scale cloud computing, data centres, and AI-driven systems entail significant energy consumption, water use, and material extraction, with ecological costs that are rarely accounted for in health policy planning or procurement decisions. These environmental burdens are frequently displaced onto marginalised territories and communities—both within and across countries—reinforcing patterns of environmental injustice. When digital health strategies ignore their ecological footprint, they risk undermining the very social determinants of health they claim to improve, particularly in contexts already affected by climate vulnerability and infrastructural inequality.

Rights at Stake

From an ESCR perspective, digital health policies must also be assessed through the principle of freedom from harm. This principle emphasises that states and public authorities have a positive obligation to prevent foreseeable harms arising from data-driven health systems, rather than merely responding after damage has occurred. An ESCR-compliant approach to digitalisation therefore requires mandatory ex ante human rights and equity impact assessments, continuous post-deployment monitoring of digital tools, accessible grievance and redress mechanisms, and enforceable obligations for private vendors involved in public health infrastructures. Without these safeguards, harm risks being normalised as an acceptable by-product of technological innovation.

Across both contexts, the findings highlight critical violations or erosions of ESCR, including:

- **Right to health:** Fragmented and privatised digital systems weaken the universality and comprehensiveness of public care, often shifting responsibility onto individuals;

- **Right to participation:** Public decision-making on digital health infrastructure is frequently opaque and exclusionary, with minimal involvement from health users, professionals, or social movements. This points to the need for recognising ‘a public right to participation’ in digital health governance—similar to the Aarhus Convention in environmental matters—that extends from shaping policy to ensuring citizens’ claims to proactive disclosure by governments of private partnerships and data use cases. Such a right would also reframe consent beyond the individual level, grounding it in wider processes of collective deliberation;

- **Right to privacy and data protection:** The mass collection and transfer of health data—often to private actors—occurs without proper consent, oversight, or safeguards. This also raises concerns about digital sovereignty, as public data is frequently handled by transnational corporations beyond meaningful public control;

- **Right to non-discrimination:** Algorithmic systems, when designed without transparency and accountability, risk reproducing biases related to class, race, gender, and geography.

- **Right to science and to the benefits of scientific progress:** When digital health innovation is locked into proprietary and closed ecosystems, the social value generated by public investment and collective data is effectively privatised. This restricts access to knowledge, limits transparency and auditability, and undermines the fair distribution of technological benefits. Open, interoperable, and publicly governed digital infrastructures are therefore essential to ensure that scientific and technological progress in health serves the public interest rather than reinforcing market concentration and inequality;

- **Collective rights and technological sovereignty:** The increasing reliance on transnational data infrastructures and foreign digital platforms, without robust public stewardship, weakens technological sovereignty and undermines domestic accountability. Such arrangements constrain the capacity of states and communities to define public-interest terms for health data governance, including decisions about storage, access, reuse, and regulation. From an ESCR perspective, safeguarding collective rights requires public control over critical digital infrastructures and democratic oversight of cross-border data arrangements.

These violations are not incidental-they are structurally embedded in a model of digitalisation that prioritises efficiency, scalability, and corporate partnerships over social justice and public sovereignty.

Challenging Techno-Solutionism

A deeper structural problem underpinning these harms is the rise of 'techno-solutionism'—the belief that complex public issues can be resolved through data and technology alone, without addressing underlying political, economic, or social inequalities. This ideology reduces public health to a matter of optimisation and prediction, while sidelining human relationships, collective knowledge, and socio-territorial realities.

As highlighted by scholars and organisations such as the Centre for Internet and Society (CIS), techno-solutionism in healthcare often obscures the extractive and opaque nature of data supply chains. In their report on artificial intelligence in Indian healthcare systems, CIS exposes how algorithmic systems lack auditability, operate without meaningful user oversight, and reinforce asymmetries of power between state, citizens, and private actors.[33] These critiques resonate strongly with the cases explored in this report and point to a broader global trend of digitisation as a vehicle for financialisation, surveillance, and dispossession.

A further structural concern relates to vendor lock-in in digital health infrastructures. When public health systems rely on proprietary architectures that lack open standards, data portability, and modular design, they become dependent on specific vendors, limiting public control, flexibility, and long-term sustainability. Ethical digital health systems thus depend on open (with adequate guardrails), technically interoperable infrastructures designed to ensure portability and modularity, enabling public authorities to adapt, replace, or audit technological components without jeopardising continuity of care or public accountability.

Reclaiming Rights Through Ethical Digital Health

If digital health is to contribute to the advancement of ESCR, it must be reclaimed as a public, participatory, and territorially grounded project. Ethical digital health systems must actively resist the logics of commodification and control, and instead centre care, dignity, and democratic governance. This involves:

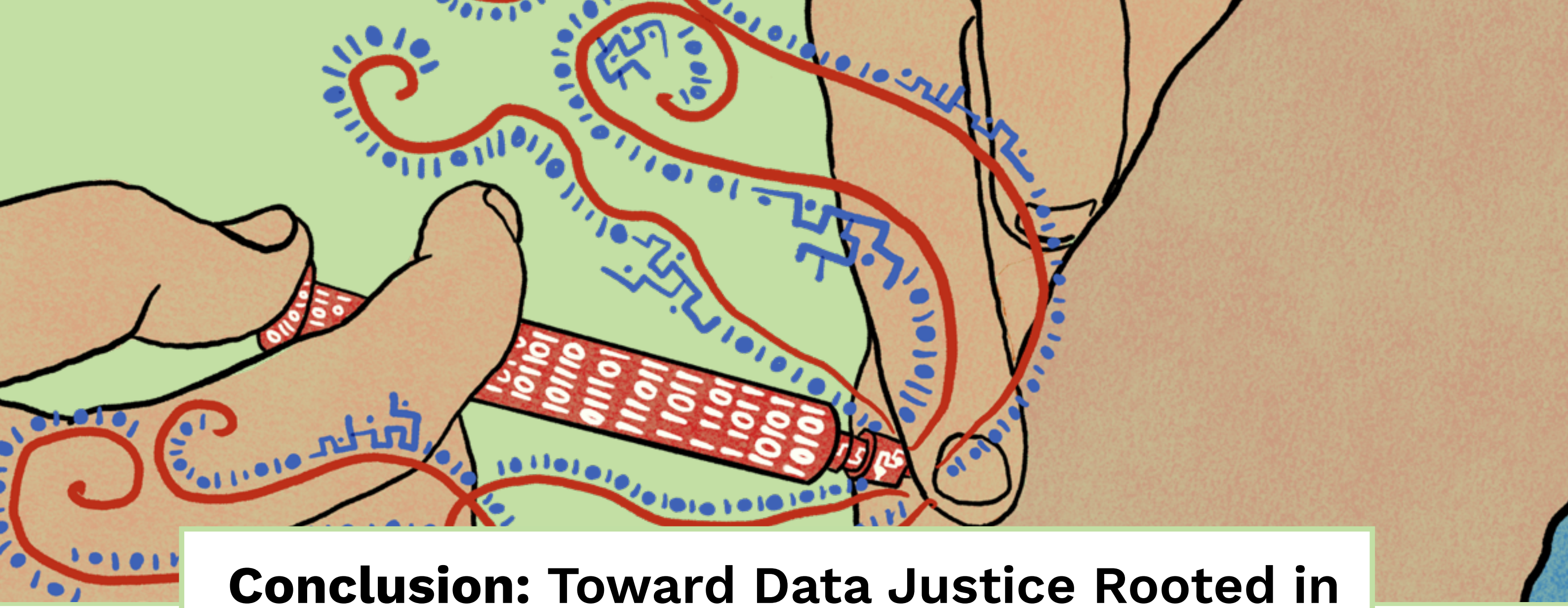
- Ensuring full transparency in digital health policies and contracts;
- Establishing robust, citizen-led data governance frameworks;
- Prioritising investment in public technological infrastructure and open-source systems;
- Embedding participatory mechanisms across all levels of decision-making;
- Recognising digital access and literacy as social determinants of health.

---

[33] Centre for Internet and Society, Artificial Intelligence in the Indian Healthcare System: A Critical Perspective (2023), https://cis-india.org/internet-governance/ai-in-indian-healthcare-report

Ultimately, this report argues that ‘ethical digital health systems’ are not only technically possible—they are politically necessary. They are essential for upholding the collective right to health in an increasingly datafied world, and for resisting the deepening of social injustices under the guise of innovation.

The analysis of material harms and rights-based implications presented above reinforces the urgency of reorienting digital health processes through a framework grounded in ethics, equity, and public control. These findings are not isolated; rather, they reveal structural tensions that must be addressed if digital transformation is to strengthen, rather than undermine, public health systems. As we move into the final section, we draw together the conceptual, empirical, and political insights developed throughout this report to propose a collective and justice-oriented vision for digital health—one that is territorially rooted, democratically governed, and centred on care as a common good.



Conclusion: Toward Data Justice Rooted in Territories and Focused on Collective Care

The comparative findings from Brazil and the United Kingdom underscore these dynamics and provide the ground for the concluding reflections that follow.

The digital transformation of health systems has largely been steered by economic imperatives, technological promises, and managerial rationalities—often disconnected from the lived realities of users and workers in public healthcare. In response, this report has advanced a critical and situated approach to data justice in digital health: one that moves beyond harm mitigation and reorients socio-technical processes around equity, transparency, sovereignty, and social justice.

To that end, the ethical digital health ecosystem model proposed here offers a framework for mapping the multiple dimensions shaping health data infrastructures. By integrating aspects such as governance, infrastructure, workforce, citizen participation, and public-private relations, the model helps identify areas of tension, mechanisms of capture, and, crucially, opportunities for socio-technical reconfiguration in the public interest. For example, the Brazilian 'Agenda for Digital Health' articulates participatory principles for designing digital infrastructures and data governance strategies grounded in health equity. In the UK, initiatives like NHS's early experiments with citizen juries—forums in which randomly selected citizens deliberate on health data issues—and data trusts—legal frameworks that assign fiduciary responsibility for data stewardship—signal the potential for more democratic and accountable models of digital governance, even if still limited in scope and scale.

Fundamentally, achieving data justice in health requires recognising health as a collective right—not as an individualised responsibility as framed by personalised health models under neoliberal logics. These models shift the burden of risk and cost onto individuals, obscure the social determinants of health, and erode the notion of care as a shared societal responsibility.

Therefore, it is urgent to reaffirm that digitalisation in health must support the consolidation of public, universal, and free systems—not their fragmentation under market-driven paradigms. To be just, digital health must be rooted in territories, guided by collective care, respectful of diverse knowledge systems, and committed to technological development that upholds life, dignity, and social justice.

In the digital age, connectivity must be recognised as a structural precondition for the right to health. Without universal, reliable, and publicly supported internet access, digital health initiatives risk reproducing and deepening territorial and social inequalities, particularly in rural, Indigenous, and marginalised urban areas. Treating connectivity as a market commodity rather than as part of health policy undermines the universality of public health systems and transforms digitalisation into an additional barrier to care, rather than a tool for equity and inclusion.

Importantly, data justice in health should be understood as a political and ongoing process—a site of contestation over infrastructure, power, and meaning. Advancing this agenda demands the articulation of critique and proposal, technical analysis and ethical commitment, institutional advocacy and territorial mobilisation. Within this context, the ethical digital health ecosystem is not merely a conceptual model—it is a strategic tool and an invitation to co-design public policies grounded in care, equity, and democratic participation.

Key Challenges and Opportunities for Advancing Data Justice in Public Health

While this report has identified urgent risks related to the digitalisation of public health systems, it also seeks to contribute to a broader, forward-looking debate: how can digital health be reimagined to serve justice, equity, and care-rather than reinforcing extraction, exclusion, and surveillance?

Achieving data justice requires more than harm reduction. It calls for the equitable distribution of value, knowledge, and technological capacity. The following are some of the key challenges that must be addressed:

- Persistent power asymmetries between states, corporations, and civil society in health data governance;
- Opaque multistakeholder arrangements that bypass democratic control and accountability;
- Absence of redistributive mechanisms to ensure digital innovations serve historically marginalised populations;
- Technological dependency in the Global South, reinforcing neo-colonial dynamics and limiting local autonomy;
- Techno-solutionist narratives that obscure structural inequalities and displace community-based alternatives;

- Limited institutional capacity and digital literacy within public systems, particularly in parliaments, local governments, and health ministries;
- The ecological footprint of digital health technologies-especially AI and large-scale data systems-that contribute to environmental degradation and climate impacts, disproportionately affecting marginalised communities in both the Global South and North.

Moreover, key decisions on software procurement and infrastructure design are often made by interministerial bodies or auxiliary agencies-such as ministries of finance or planning-without a clear understanding of their implications for public health equity and democratic governance.

Despite these barriers, there are strategic opportunities that can guide transformative change in digital health, requiring interconnected actions that ground practice in the macro-categories of the ethical digital health ecosystem and in economic, social, and cultural rights (ESCR):

Public-interest digital infrastructures:

> Build and maintain open-source, interoperable, and democratically governed infrastructures under transparent frameworks that recognise health data as a common good and guarantee the right to connectivity as a precursor to digital inclusion.

Ethical digital health systems require open (with adequate guardrails), technically interoperable, and publicly governed architectures for data storage, integration, and analytics. Public authorities should prioritise sovereign hosting options and public cloud infrastructures where feasible, and design systems to avoid vendor lock-in through open standards, data portability, and modular architectures. Ensuring universal and reliable internet connectivity must be recognised as a basic requirement for the right to health, alongside sustained investment in local infrastructure and community networks to address digital and territorial inequalities.

Democratic health data governance:

> Develop governance models that prevent corporate capture and ensure democratic stewardship of data, independent oversight bodies, and enforceable public-interest clauses in procurement and data-sharing agreements.

Public stewardship models must embed fiduciary duties to the public, including mechanisms such as public data trusts and multi-stakeholder oversight bodies with statutory powers.

Governments should mandate proactive transparency by publishing contracts, Data Protection Impact Assessments (DPIAs), Human Rights and Equity Impact Assessments (HREIAs), algorithm registers, audit results, and performance metrics. Clear rules are also needed to regulate secondary use of health data, enforce purpose limitation, define time-bounded data retention, and ensure fair benefit-sharing.

Algorithmic accountability in care:

Before deployment, algorithmic systems used in healthcare should be subject to clinical validation, bias and safety testing, and explainability requirements, alongside mandatory human-in-the-loop protocols. Continuous post-deployment audits and public reporting of errors, disparate impacts, and remediation measures are essential. In contexts involving clinical allocation or triage, fully automated decision-making should be prohibited, and contestation rights for patients and health workers must be guaranteed.

Territorial justice and capacity building:

Digital health strategies must be grounded in territorial justice by addressing inequalities in connectivity, technological capacity, and digital literacy, so that digital health strengthens rather than deepens social and geographical disparities. This requires investment in public sector capacity, including digital literacy for health workers, technical training for public managers, and support for local developers and public digital laboratories. Place-based pilot projects co-designed with rural, Indigenous, and marginalised communities should be prioritised and scaled only after equity and usability benchmarks are met.

Public education and capacity building:

Promote digital rights, data literacy, and critical health technology education as pillars for democratic digital health systems.

Participation and collective consent:

Democratic digital health governance demands the institutionalisation of participatory mechanisms such as citizen juries, health councils, and algorithmic accountability forums to safeguard the rights to information, deliberation, and collective consent. Policy frameworks should move beyond narrow models of individual consent toward layered and collective participation for population-level data uses, ensuring meaningful representation of historically marginalised groups and frontline workers.

Accountability:

Strengthen monitoring and redress through transparent procurement processes, audit trails, grievance mechanisms, and public platforms for reporting digital harms.

Law, regulation, and enforceability:

Legal and regulatory frameworks must centre the right to health and freedom from harm in digital health policies. This includes mandatory ex ante human rights and equity impact assessments, enforceable procurement clauses on transparency, auditability, interoperability, and termination rights, as well as strengthened powers for independent regulators. Access to redress mechanisms, including public-interest litigation, should be ensured.

International cooperation and anti-dependency:

Foster transnational networks of resistance and co-creation—across the Global South and North—prioritising equitable knowledge-sharing, open technologies, and collective regulation of corporate power. Addressing technological dependency requires enhanced South–North cooperation on open technologies, shared audit tools, and rights-based standards. States should negotiate public-interest terms with cloud and platform providers, cooperate on cross-border enforcement, and support knowledge commons, open documentation, and reproducible public algorithms.

Plural epistemologies and feminist and Indigenous perspectives:

Digital health governance must recognise and resource plural knowledge systems. Feminist, Indigenous, and community-based approaches should be integrated into the design, evaluation, and governance of digital health technologies, recognising care work and community infrastructures as central to equitable and just health systems.

Critical stance against techno-solutionism:

Recognise that technological fixes alone cannot resolve deeply rooted injustices in global health systems, reaffirming the centrality of social justice and public sovereignty.

Taken together, these strategies outline how digital health can be reoriented away from market logics and towards democratic accountability, territorial justice, and the protection and advancement of fundamental rights.

References

Bernard, H. R. 2005. *Research Methods in Anthropology: Qualitative and Quantitative Approaches*. Lanham, MD: AltaMira Press.

Biernacki, P., and D. Waldorf. 1981. "Snowball Sampling: Problems and Techniques of Chain Referral Sampling." *Sociological Methods & Research* 10 (2): 141–163.

Brasil. 1988. *Constituição da República Federativa do Brasil*. Brasília: Senado Federal.

Centre for Internet and Society (CIS). 2023. *Artificial Intelligence in the Indian Healthcare System: A Critical Perspective*. Accessed January 2026. https://cis-india.org/internet-governance/ai-in-indian-healthcare-report.

Coalizão Direitos na Rede. 2024. *Uma Agenda para a Saúde Digital*. Accessed January 2026. https://direitosnarede.org.br/2024/04/17/uma-agenda-para-a-saude-digital/.

Coalizão Direitos na Rede. n.d. *Quem somos*. Accessed January 2026. https://direitosnarede.org.br/quem-somos/.

Gurumurthy, A., and N. Chami. 2022. *Beyond Data Bodies: New Directions for a Feminist Theory of Data Sovereignty*. Data Governance Network Working Paper No. 24. https://www.researchgate.net/publication/358552418_Beyond_data_bodies_New_directions_for_a_feminist_theory_of_data_sovereignty

Keep Our NHS Public. 2023. *How Our Data Is Used: Case Studies by the Health Data Working Group*. Accessed January 2026. https://keepournhspublic.com/how-our-data-is-used/.

Leslie, D. 2020. Understanding Artificial Intelligence Ethics and Safety: *A Guide for the Responsible Design and Implementation of AI Systems in the Public Sector*. London: The Alan Turing Institute.

Lupton, D. 2016. *The Quantified Self: A Sociology of Self-Tracking. Cambridge: Polity Press.*

Ministério da Saúde (Brazil). 2022. *Meu SUS Digital.* Brasília: Ministério da Saúde.

Ministério da Saúde (Brazil). 2023. *Sistema Único de Saúde (SUS).* Brasília: Ministério da Saúde.

Organisation for Economic Co-operation and Development (OECD). 2019. *Health in the 21st Century: Putting Data to Work for Stronger Health Systems. Paris*: OECD Publishing. Accessed January 2026. https://www.oecd.org/health/health-in-the-21st-century-e3b23f8e-en.htm.

Organisation for Economic Co-operation and Development (OECD). 2016. *Recommendation of the Council on Health Data Governance*. Accessed January 2026. https://legalinstruments.oecd.org/en/instruments/OECD-LEGAL-0463.

Paim, J., C. Travassos, C. Almeida, L. Bahia, and J. Macinko. 2011. “The Brazilian Health System: History, Advances, and Challenges.” *The Lancet 377 (9779)*: 1778–1797.

Prainsack, B. 2019. *The Value of Health Data: Who Benefits from Electronic Patient Data? Cambridge*: Cambridge University Press.

Rikap, C. 2021. *Capitalism, Power and Innovation: Intellectual Monopoly Capitalism Uncovered. London*: Routledge.

Scassa, T. 2020. “Administrative Law and the Governance of Automated Decision-Making: A Critical Look at *Canada’s Directive on Automated Decision-Making*.” Canadian Journal of Administrative Law & Practice 33 (2): 221–246.

Schwab, K. 2016. *The Fourth Industrial Revolution*. Geneva: World Economic Forum.

Sharon, T. 2016. “Self-Tracking for Health and the Quantified Self.” *Health Sociology Review* 25 (1).

Viljoen, S. 2021. “A Relational Theory of Data Governance.” *Yale Law Journal* 131 (2): 573–654.

World Economic Forum (WEF). 2016. *Shaping the Future of Health and Healthcare.* Geneva: World Economic Forum.

World Health Organization (WHO). 2005. “Resolution WHA58.28: eHealth.” Accessed January 2026. https://apps.who.int/gb/ebwha/pdf_files/WHA58/WHA58_28-en.pdf.

World Health Organization (WHO). 2013. “Resolution WHA66.24: eHealth Standardization and Interoperability.” Accessed January 2026. https://apps.who.int/gb/ebwha/pdf_files/WHA66/A66_R24-en.pdf.

World Health Organization (WHO). 2018. “Resolution WHA71.7: Digital Health.” Accessed January 2026. https://apps.who.int/gb/ebwha/pdf_files/WHA71/A71_R7-en.pdf.

World Health Organization (WHO). 2021. *Global Strategy on Digital Health 2020–2025. Geneva: WHO*. Accessed January 2026. https://www.who.int/publications/i/item/9789240020924.

Zuboff, S. 2019. *The Age of Surveillance Capitalism: The Fight for a Human Future at the New Frontier of Power.* New York: PublicAffairs.

IT for Change

https://itforchange.net/