

Health data, ethics, and governance: pathways to the common good in global health in contexts of power asymmetries, accelerated digitalization, and health vulnerabilities

Datos de salud, ética y gobernanza: caminos hacia el bien común en la salud global en contextos de asimetrías de poder, digitalización acelerada y vulnerabilidades en salud

Dados de saúde, ética e governança: caminhos para o bem comum na saúde global em contextos de assimetrias de poder, digitalização acelerada e vulnerabilidades em saúde

DOI: 10.5281/zenodo.20386148

Received: Mai 22, 2026

Approved: Mai 24, 2026

Mateus Henrique Dias Guimarães

Master's degree in Nursing in Primary Health Care.

Member of the International Epidemiological Association (IEA), 2025-2031.

Trainee Member of the International Society of Hypertension (ISH), 2025-2026.

ORCID: <https://orcid.org/0009-0008-0206-0011>

Rozineide Iraci Pereira da Silva

PhD and Doctorate with dual degree from the Federal University of Alagoas (UFAL), State of Alagoas, Brazil.

Professor and graduate advisor for *stricto sensu* programs.

ORCID: <https://orcid.org/0009-0000-6863-7874>

ABSTRACT

Introduction: The exponential growth of *health data*, including *electronic health records* and information collected outside traditional healthcare settings, presents unprecedented opportunities and ethical challenges for *global health*. Accelerated digitalization and the influence of technology corporations increase vulnerabilities and inequalities, demanding a reassessment of *health governance* frameworks, particularly in contexts marked by power asymmetries.

Objective: This study aims to analyze the ethical and governance challenges arising from the expansion of health data ecosystems in global health and to propose pathways oriented toward the *common good*, ensuring that data-driven initiatives reduce vulnerabilities and promote equity. **Methodology:** A qualitative literature review was conducted, covering studies, reports, and policy documents published between 2015 and 2025. Selection criteria included relevance, currency, and reliability, focusing on types of data, actors involved, trends in data collection and circulation, and the role of health data in surveillance and crisis response. **Results and Discussion:** Findings reveal that power asymmetries shape the production, control, and use of *health data*, highlighting practices of *data colonialism* that limit local autonomy and reinforce global inequalities. The increasing use of digital technologies and artificial intelligence offers opportunities for epidemiological surveillance and innovation but raises ethical risks related to privacy, commercial exploitation, and digital exclusion. Governance models oriented toward the *common good* require transparency, social participation, protection of vulnerable populations, and international cooperation to ensure equitable distribution of the benefits of health data. **Conclusion:** Implementing participatory and ethical *health data governance* frameworks is essential to strengthen local sovereignty, reduce inequalities, and establish a foundation for *health data justice*. Such approaches ensure that health data advance collective well-being and contribute to a more equitable global health landscape.

Keywords: Electronic Health Records. Global Health. Ethics. Health Governance. Technical Cooperation.

RESUMEN

Introducción: El crecimiento exponencial de los datos de salud, incluidos los registros electrónicos de salud y la información recopilada fuera de los entornos tradicionales de atención sanitaria, presenta oportunidades sin precedentes y desafíos éticos para la salud global. La digitalización acelerada y la influencia de las corporaciones tecnológicas aumentan las vulnerabilidades y las desigualdades, lo que exige una reevaluación de los marcos de gobernanza en salud, especialmente en contextos marcados por asimetrías de poder. **Objetivo:** Analizar los desafíos éticos y de gobernanza derivados de la expansión de los ecosistemas de datos de salud en la salud global y proponer vías orientadas al bien común, garantizando que las iniciativas basadas en datos reduzcan las vulnerabilidades y promuevan la equidad. **Metodología:** Se realizó una revisión cualitativa de la literatura, que abarcó estudios, informes y documentos de políticas publicados entre 2015 y 2025. Los criterios de selección incluyeron relevancia, actualidad y confiabilidad, con énfasis en los tipos de datos, los actores involucrados, las tendencias en la recopilación y circulación de datos, y el papel de los datos de salud en la vigilancia y la respuesta a crisis. **Resultados y Discusión:** Los hallazgos revelan que las asimetrías de poder configuran la producción, el control y el uso de los datos de salud, poniendo de manifiesto prácticas de colonialismo de datos que limitan la autonomía local y refuerzan las desigualdades globales. El uso creciente de tecnologías digitales y de inteligencia artificial ofrece oportunidades para la vigilancia epidemiológica y la innovación, pero plantea riesgos éticos relacionados con la privacidad, la explotación comercial y la exclusión digital. Los modelos de gobernanza orientados al bien común requieren transparencia, participación social, protección de las poblaciones vulnerables y cooperación internacional para garantizar una distribución equitativa de los beneficios de los datos de salud. **Conclusión:** La implementación de marcos participativos y éticos de gobernanza de datos de salud es esencial para fortalecer la soberanía local, reducir las desigualdades y sentar las bases para la justicia de los datos en salud. Estos enfoques garantizan que los datos de salud promuevan el bienestar colectivo y contribuyan a un panorama de salud global más equitativo.

Palabras clave: Registros Electrónicos de Salud. Salud Global. Ética. Gobernanza en Salud. Cooperación Técnica.

RESUMO

Introdução: O crescimento exponencial dos dados em saúde, incluindo prontuários eletrônicos e informações coletadas fora dos ambientes tradicionais de atenção à saúde, apresenta oportunidades inéditas e desafios éticos para a saúde global. A digitalização acelerada e a influência de corporações tecnológicas ampliam vulnerabilidades e desigualdades, exigindo a reavaliação dos marcos de governança em saúde, especialmente em contextos marcados por assimetrias de poder. **Objetivo:** Analisar os desafios éticos e de governança decorrentes da expansão dos ecosistemas de dados em saúde na saúde global e propor caminhos orientados ao bem comum, assegurando que iniciativas baseadas em dados reduzam vulnerabilidades e promovam a equidade. **Metodologia:** Foi realizada uma revisão qualitativa da literatura, abrangendo estudos, relatórios e documentos de políticas publicados entre 2015 e 2025. Os critérios de seleção incluíram relevância, atualidade e confiabilidade, com foco nos tipos de dados, nos atores envolvidos, nas tendências de coleta e circulação de dados e no papel dos dados em saúde na vigilância e na resposta a crises. **Resultados e Discussão:** Os achados revelam que as assimetrias de poder moldam a produção, o controle e o uso dos dados em saúde, evidenciando práticas de colonialismo de dados que limitam a autonomia local e reforçam desigualdades globais. O uso crescente de tecnologias digitais e de inteligência artificial oferece oportunidades para a vigilância epidemiológica e a inovação, mas levanta riscos éticos relacionados à privacidade, à exploração comercial e à exclusão digital. Modelos de governança orientados ao bem comum requerem transparência, participação social, proteção de populações vulneráveis e cooperação internacional para garantir a distribuição equitativa dos benefícios dos dados em saúde. **Conclusão:** A implementação de marcos participativos e éticos de governança de dados em saúde é essencial para fortalecer a soberania local, reduzir desigualdades e estabelecer as bases para a justiça dos dados em saúde. Tais abordagens asseguram que os dados em saúde promovam o bem-estar coletivo e contribuam para um cenário de saúde global mais equitativo.

Palavras-chave: Prontuários Eletrônicos de Saúde. Saúde Global. Ética. Governança em Saúde. Cooperação Técnica.

1 INTRODUCTION

The exponential growth in the collection and utilization of health-related data, encompassing everything from electronic health records to data gathered outside traditional healthcare contexts, presents both unprecedented opportunities and significant ethical challenges for global health (Holly et al., 2023; Shaw & Sekalala, 2023).

This surge is fueled by accelerated digitalization and the pervasive influence of technology corporations, raising critical questions about health equity and social justice (Shaw & Sekalala, 2023).

This necessitates a re-evaluation of existing governance frameworks to ensure that the benefits of data-driven healthcare are equitably distributed, particularly in contexts marked by significant power asymmetries and heightened health vulnerabilities (Shaw & Sekalala, 2023).

The proliferation of digital health technologies, especially amplified by events like the COVID-19 pandemic, has further intensified the demand for diverse health data, including patient information, staff metrics, disease surveillance, and treatment outcomes, thereby underscoring the urgent need for robust ethical and governance frameworks (Fast, 2023; Silva et al., 2025).

This expansion highlights the imperative for strengthened health data governance, driven by a growing consensus among stakeholders on maximizing public value while safeguarding individual rights and fostering trust in data sharing (Holly et al., 2023). This re-evaluation must explicitly address the implications of commercial exploitation of personal health data within a global political economy that often entrenches historical inequalities (Couldry & Mejias, 2020).

Power asymmetries between countries, institutions, and private actors shape how health data are produced, accessed, and used. These imbalances often take the form of *health data colonialism*, whereby actors with greater technical and financial capacity extract data from resource-constrained settings and repurpose them for commercial profit or strategic insight, frequently without delivering proportional benefits to the communities from which the data originate (Couldry & Mejias, 2020; Shaw & Sekalala, 2023).

Such extractive practices reflect a broader logic of techno-solutionism, in which technological interventions are privileged over efforts to address the structural, social, and institutional determinants of health. Rather than mitigating inequities, this approach risks reinforcing existing global health disparities (Shaw & Sekalala, 2023).

This paper seeks to analyze the ethical and governance challenges arising from the rapid expansion of health data ecosystems in global health, particularly in regions characterized by pronounced power imbalances and susceptibility to health crises. It aims to propose pathways toward a common good

framework that explicitly addresses these complexities, ensuring that data-driven health initiatives genuinely serve to reduce vulnerabilities and promote health equity. Specifically, this analysis will delve into the risks associated with unrestricted collection and transfer of personal health data, examining the broader implications of the burgeoning health data sector on global social power dynamics (Couldry & Mejias, 2020).

2 LITERATURE REVIEW

This literature review examines the multiple and often contested conceptualizations of the *common good* within data-intensive healthcare, with particular attention to how the intensified extraction and circulation of health data frequently justified through promissory narratives of innovation, efficiency, and improved outcomes reconfigures healthcare goals and priorities.

Such promissory framings tend to privilege data-driven and technologically mediated solutions, potentially marginalizing non-digital, community-based, or structural interventions that may be more appropriate for addressing complex and context-specific health challenges (Grön, 2021).

Sharon argues that any contemporary understanding of the common good in health data governance must be situated within the broader political economy of digital capitalism and acknowledge the plurality of competing goods at stake. From this perspective, developing normative frameworks requires careful balancing: advancing collective well-being while simultaneously safeguarding other essential common goods, such as equity, autonomy, solidarity, and democratic accountability, which risk being undermined by unchecked datafication and market-driven logics (Grön, 2021).

Consequently, neglecting to integrate diverse stakeholder perspectives, including those from ethicists, regulators, and research participants, in the development of ethical frameworks for digital health risks perpetuating existing social inequalities and even fostering discrimination (Neff, 2019).

Moreover, the increasing complexity of digital health ecosystems introduces significant interoperability challenges across diverse infrastructures and datasets, thereby diminishing users' control over the trajectory of their health data within seamless models of data-driven healthcare (Gonzalez-Polledo, 2018).

In the contemporary landscape of global health, health data play a central and multifaceted role, encompassing everything from individual clinical records and population-level data to digital information generated by mobile devices, online platforms, big data, and artificial intelligence applications.

This pervasive integration highlights the growing urgency to understand global perspectives on personal information sharing, especially as digital health technologies advance rapidly and increase the demand for health data for secondary uses such as personalized treatments and research (Alam et al., 2024).

These data are produced, collected, and utilized by a broad network of actors, including national governments, international organizations such as the WHO, research institutions, the private sector, technology companies, and global digital platforms, which expands both the opportunities for innovation and the challenges of governance.

This complex interplay often leads to a privatization of health data infrastructures and research, raising concerns about transparency in data governance and the potential for informational asymmetry favoring corporate interests over public and civic needs (Batifoulrier & Diaz-Bone, 2022).

There is a growing trend toward digitalization, transnational integration of databases, and the use of advanced analytics to support health decision-making, driven by the expansion of digital technologies and the global circulation of information. This rapid digital transformation within healthcare, termed 'health 4.0', necessitates a re-evaluation of existing governance structures to address emerging ethical dilemmas related to data ownership, access, and equitable benefit distribution (Brall et al., 2019).

In this context, data are essential for epidemiological surveillance, early risk identification, monitoring of social and environmental determinants, as well as for the prevention of and rapid response to health crises, as demonstrated during recent pandemics, while simultaneously raising ethical, political, and legal debates around sovereignty, privacy, and global inequalities.

The increasing reliance on digital health technologies for personalized medicine, often involving networked resources and the aggregation of diverse data types, intensifies concerns regarding data protection, privacy, and the potential for misuse, including discriminatory practices and surveillance (Bak et al., 2023).

This necessitates a comprehensive re-evaluation of ethical frameworks to safeguard individual rights while leveraging the potential of digital health for public good, especially considering the commercial pressures for expanding AI in the health sector (Couldry & Mejias, 2020). Such frameworks must critically assess the implications of digital surveillance practices, which can deter individuals from seeking or sharing sensitive health information due to concerns about anonymity (Strange & Tucker, 2023).

3 METHODOLOGY

This study adopted a qualitative literature review approach, focusing on studies, reports, and documents on health data in global health published over the last ten years. Academic sources, reports from

international organizations, public policy documents, and publications from the private sector were selected using keywords such as “health data,” “global health,” “big data,” “digital health,” and “artificial intelligence in health.” The analysis focused on identifying types of data, actors involved, trends in data collection and circulation, as well as the role of these data in surveillance and crisis response. Selection and interpretation of the materials followed criteria of relevance, currency, and reliability, allowing the synthesis of patterns, challenges, and gaps in the existing literature.

The following databases were consulted for the selection of materials: PubMed, Scopus, Web of Science, Embase, Google Scholar, and databases from international organizations such as the WHO (World Health Organization), World Bank, and PAHO (Pan American Health Organization). The search included academic articles, official reports, policy documents, and private sector publications published between 2015 and 2025, using terms related to health data, global health, big data, digital health, and artificial intelligence.

The inclusion criteria were: (i) studies, reports, or documents published between 2015 and 2025; (ii) materials addressing health data in the context of global health; (iii) publications in English, Spanish, or Portuguese; (iv) studies discussing types of data, actors involved, trends in collection, use or circulation, or the role of data in health surveillance and crisis response.

The exclusion criteria were: (i) materials outside the established period; (ii) studies focused exclusively on national contexts without relevance to global health; (iii) opinion articles, non-systematic reviews, or news reports; (iv) publications without full-text access.

The evaluation of the selected studies was conducted in two main stages. First, all titles and abstracts retrieved from the databases were assessed for relevance to the topic, according to the predefined inclusion and exclusion criteria. Next, the full texts of the selected materials were evaluated for methodological quality, clarity of information, and reliability of the sources, prioritizing documents from international organizations, peer-reviewed articles, and official reports.

The extracted information was organized into a summary table, enabling the identification of patterns, trends, gaps, and points of convergence in the literature on health data in global health.

4 RESULTS AND DISCUSSION

Power asymmetries in global health are particularly evident in the production, control, and appropriation of health data, reflecting and reinforcing structural inequalities between countries of the Global North and South (Ferretti et al., 2023).

Health data, often presented as neutral or universal, are produced within systems that historically favor the collection, storage, and analysis capacities of economically and technologically more powerful actors (Ferretti et al., 2023).

This imbalance materializes in practices known as data colonialism or informational extractivism, in which data collected in low- and middle-income countries are predominantly used, processed, and monetized by companies, academic institutions, and organizations based in the Global North, often without equitable return to the countries and communities that originated them (Ferretti et al., 2023).

These dynamics have profound implications for sovereignty and autonomy, limiting the capacity of states and local populations to decide on the collection, use, and governance of their own health information (Ferretti et al., 2023).

Moreover, they perpetuate health injustices by directing resources, policies, and interventions based on external perspectives and interests, while local needs remain underrepresented or invisible. Recognizing these asymmetries is crucial for rethinking data governance models, emphasizing principles of justice, equity, and responsible information sharing, in order to promote truly inclusive and sustainable global health (Ferretti et al., 2023).

This approach requires a paradigm shift towards models that empower local communities and nations in the Global South to assert control over their health data, ensuring that the benefits derived from such data are equitably distributed and contribute directly to local health improvements (Ferretti et al., 2023).

The ethics of health data has emerged as a central concern in global health, highlighting the tension between viewing data as a common good and its increasing commodification. While health data have the potential to generate significant collective benefits including advances in epidemiological surveillance, policy planning, and scientific innovation their treatment as a commodity raises ethical dilemmas related to ownership, access, and commercial exploitation (Shaw & Sekalala, 2023).

The literature emphasizes the importance of grounding data collection, use, and sharing practices in classical bioethical principles such as justice, equity, beneficence, non-maleficence, and autonomy, ensuring that the benefits derived from data are distributed fairly and potential harms are minimized (Shaw & Sekalala, 2023).

However, persistent issues of data colonialism, where actors from resource-rich settings leverage digital technologies to acquire data from lower-resource contexts, often lead to the commercial exploitation of health data with limited reciprocal benefit (Shaw & Sekalala, 2023).

Issues of informed consent, privacy, and data protection are particularly critical in digital contexts and in analyses involving big data and artificial intelligence, where secondary use of information can occur without individuals' explicit knowledge or approval. Moreover, the application of algorithms and AI in health introduces additional ethical risks, including discriminatory biases, opaque decision-making, and the reinforcement of structural inequalities (Reis et al., 2021).

The protection of vulnerable populations is therefore imperative, requiring legal, policy, and technological safeguards to ensure that data do not reproduce injustices or exacerbate social exclusion. Ultimately, the ethics of health data demands a careful balance between innovation, public utility, and respect for human rights, ensuring that data advance collective health while safeguarding individual dignity and autonomy (Reis et al., 2021).

This necessitates robust governance frameworks that address not only technical aspects of data security but also the societal implications of data practices, especially concerning equitable access and benefit-sharing (Reis et al., 2021).

Data Governance for the Common Good

Health data governance encompasses a set of principles, regulations, and practices that guide the collection, use, sharing, and protection of information, aiming to maximize social benefits while minimizing ethical and societal risks. Governance operates at multiple levels, from local management within healthcare facilities and municipalities, to national frameworks establishing policies and regulatory standards, and global initiatives involving international organizations, treaties, and transnational cooperation (Reis et al., 2021).

Effective data governance frameworks are essential for ensuring that health data serve the common good, particularly in an era of rapid digitalization and increasing data interconnectedness, necessitating transparent mechanisms for community oversight and accountability (Reis et al., 2021).

Regulatory and institutional frameworks, such as the European Union General Data Protection Regulation (GDPR), the Brazilian General Data Protection Law (LGPD), and WHO guidelines, establish principles of transparency, accountability, and social participation, ensuring that decisions about data are not dominated by powerful actors alone but incorporate public and community perspectives (Silva & Souza, 2022).

Governance models oriented toward the common good emphasize equity, protection of vulnerable populations, responsible information sharing, and international cooperation, fostering a health data ecosystem that prioritizes social utility over isolated commercial interests (Silva & Souza, 2022).

This includes evaluating the benefits of health data beyond improved access to services, extending to enhanced quality, efficiency, effectiveness, and sustainability of healthcare systems, as well as fostering innovation and advancements in medical sciences (Silva & Souza, 2022).

Accelerated Digitalization and Health Vulnerabilities

The rapid digitalization of health, marked by the expansion of digital platforms, telemedicine, and big data systems, has transformed how information is collected, analyzed, and utilized. Simultaneously, it has generated new vulnerabilities, including technological dependency, data breaches, and potential biases in artificial intelligence algorithms (Storey & Soshnikov, 2023).

These vulnerabilities are particularly pronounced in contexts with existing power asymmetries, where accelerated digitalization can exacerbate disparities in access to technology, digital literacy, and data governance capacity (Storey & Soshnikov, 2023).

This technological shift has ambivalent effects on health inequalities: while it can expand access to services and improve epidemiological surveillance, it can also reproduce social exclusions, particularly among populations with limited connectivity and digital literacy (Storey & Soshnikov, 2023).

In health emergencies, such as the COVID-19 pandemic, intensive data use created opportunities for rapid response, real-time monitoring, and resource allocation, while also exposing ethical risks and challenges to institutional legitimacy, including misinformation and erosion of public trust (“Transitioning to Good Health and Well-Being,” 2022).

The push for digitalization, often framed as a solution to healthcare access disparities, has inadvertently highlighted unequal access to its benefits, placing increased demands on patients to manage their own health data and raising concerns about digital inequality and cognitive skills (“Transitioning to Good Health and Well-Being,” 2022).

Case Studies or Empirical Examples

Empirical experiences provide crucial insights into the challenges and potential of health data governance. In the Global South, ethical data-sharing initiatives have sought to strengthen local autonomy, enhance public policy, and reduce structural inequalities (Erdoğan et al., 2024; Robinson et al., 2020).

During COVID-19, data use for contact tracing, hospital bed monitoring, and epidemiological modeling demonstrated both the value of digitalization and the risks associated with privacy and concentration of informational power (Erdoğan et al., 2024; Robinson et al., 2020).

These cases underscore the imperative for nuanced approaches to digital health interventions, ensuring that technological advancements do not inadvertently deepen existing disparities or compromise fundamental rights (Erdoğan et al., 2024; Robinson et al., 2020).

Other initiatives highlight international cooperation, such as open health data platforms or collaborative programs between governments and research institutions, aiming to balance scientific innovation with social justice (Erdoğan et al., 2024; Robinson et al., 2020).

Lessons learned include the need for transparency, clear regulation, technological capacity-building, and mechanisms for community participation, demonstrating that while data can generate significant global benefits, improper use can perpetuate inequalities and constrain the sovereignty of vulnerable populations (Shaw & Sekalala, 2023).

This underscores the importance of a "health data justice" approach, which seeks to build new norms for health data governance centered on achieving health equity and mitigating the harms of existing colonial systems of inequality (Shaw & Sekalala, 2023).

Pathways and Recommendations

Advancing toward ethical and equitable health data governance requires adopting guiding principles that promote transparency, accountability, social participation, justice, and respect for individual autonomy. These principles should inform both public policies and institutional practices, ensuring that data are used for the common good rather than concentrated commercial or political interests (Holly et al., 2023).

Among the strategies to reduce power asymmetries are the promotion of equitable data sharing between Global North and South countries, the development of local technological and analytical capacity, and mechanisms for co-authorship and recognition of the communities that generate the data. Strengthening local sovereignty and capacity involves investments in data infrastructure, human resource development, data protection policies, and participatory governance, enabling states and communities to make informed decisions about their own health information (Holly et al., 2023).

Guidelines for public policy and international cooperation should include the establishment of clear regulatory frameworks, ethical data-sharing protocols, international standards for security and interoperability, and multi-stakeholder dialogue forums involving governments, researchers, the private sector, and civil Society (Holly et al., 2023).

Finally, the role of health professionals and civil society is central to implementing these recommendations, as they are key actors in responsible data collection, ethical monitoring of digital practices, and fostering a culture of trust and social responsibility in health (Holly et al., 2023).

Furthermore, it underscores the critical need for participatory approaches that engage diverse stakeholders, including patients and communities, in the co-creation of governance frameworks to ensure relevance and legitimacy (Pellegrini & Lovati, 2025; Silva & Souza, 2022).

The analysis of the interplay between ethics, power, and health data governance demonstrates that decisions regarding the collection, use, and sharing of information are not merely technical but deeply political and normative, shaped by global power relations and structural inequalities (Pellegrini & Lovati, 2025; Silva & Souza, 2022).

The implications for global health and health systems are significant: ethical and inclusive governance practices can strengthen epidemiological surveillance, evidence-based decision-making, and the protection of vulnerable populations, while unequal or extractive approaches may exacerbate injustices and limit local Sovereignty (Pellegrini & Lovati, 2025; Silva & Souza, 2022).

This study has certain limitations, including reliance on available literature, the predominance of case studies and experiences from the Global North, and the lack of primary data from some Global South regions, which may restrict the generalizability of the findings (Pellegrini & Lovati, 2025; Silva & Souza, 2022).

Nevertheless, the research provides important theoretical and practical contributions by integrating debates on ethics, data colonialism, and governance, offering guidance for public policies, governance models oriented toward the common good, and strategies to reduce power asymmetries in health data management (Pellegrini & Lovati, 2025; Silva & Souza, 2022).

Furthermore, it underscores the critical need for participatory approaches that engage diverse stakeholders, including patients and communities, in the co-creation of governance frameworks to ensure relevance and legitimacy (Pellegrini & Lovati, 2025; Silva & Souza, 2022).

This study contributes to public health by highlighting how the increasing use of health data, accelerated by digitalization and advanced technologies, presents both opportunities and ethical and social risks, particularly in contexts of global inequality.

By analyzing practices of data colonialism and power asymmetries between countries and institutions, it proposes governance models oriented toward the common good, promoting equity, protection of vulnerable populations, transparency, community participation, and local sovereignty over health information (Marcucci et al., 2023).

Furthermore, it provides guidance for evidence-based public policies, strengthening epidemiological surveillance, health system planning, and crisis response, while also encouraging responsible innovation and ethical use of artificial intelligence and big data. In this way, the study offers

theoretical and practical foundations for building “health data justice,” ensuring that the benefits of data collection and use are distributed fairly, contributing to the reduction of inequalities, the protection of individual rights, and the advancement of global public health (Leslie et al., 2022).

This perspective emphasizes that a health data justice framework is essential for developing new norms in health data governance that prioritize health justice as their core objective (Shaw & Sekalala, 2023).

Such an approach acknowledges that existing frameworks often fall short in addressing the unique challenges faced by low- and middle-income countries, necessitating a concerted effort to foster equitable data sharing and capacity building (Marcucci et al., 2023).

Furthermore, it underscores the need for robust regulatory frameworks that safeguard data privacy and promote data sovereignty, especially given the rapid proliferation of digital health technologies (Leslie et al., 2022; Shaw & Sekalala, 2023).

CONCLUSION

This concluding section synthesizes the critical insights from the preceding analysis, underscoring the urgent need for an ethical, equitable, and justice-oriented approach to health data governance in a rapidly digitalizing world marked by pervasive power asymmetries and heightened health vulnerabilities.

It emphasizes that techno-solutionism, despite its promises, often neglects the complex social, institutional, and structural determinants of health, highlighting the necessity of a more holistic framework for data use that foregrounds justice and equity.

Achieving this requires moving beyond interventions focused solely on user experience to embrace deeper infrastructural and systemic changes that align health data systems with principles of data justice and solidarity.

Central to this approach is fostering community engagement as a collective endeavor oriented toward the public good, cultivating solidarity through shared interests, mutual responsibilities, and inclusive participation.

The analysis further argues that framing data sharing primarily as an individual responsibility is insufficient in data-intensive healthcare systems; it must be complemented by institutional and societal commitments to justice, reciprocity, and recognition, ensuring that health data serve collective well-being rather than solely individual or commercial interests.

Future research on health data ethics and governance should prioritize the development and empirical evaluation of participatory, equity-oriented frameworks that integrate local communities, health professionals, and policymakers in decision-making processes.

Such studies could examine how context-specific data governance models mitigate power asymmetries between the Global North and South, ensuring that the collection, use, and sharing of health data advance the common good while protecting individual rights.

Additionally, research should assess the impact of digitalization and AI-driven health technologies on vulnerable populations, investigating strategies to prevent bias, discrimination, and data exploitation, while promoting transparency, accountability, and sustainable public health outcomes.

REFERENCES

- Alam, P., Bolio, A., Lin, L., & Larson, H. J. (2024). Stakeholders' perceptions of personal health data sharing: A scoping review [Review of Stakeholders' perceptions of personal health data sharing: A scoping review]. *PLOS Digital Health*, 3(11). Public Library of Science. <https://doi.org/10.1371/journal.pdig.0000652>
- ARAÚJO, Flávio Eduardo Silva et al. A SAÚDE COLETIVA COMO ESPAÇO DE DIÁLOGO: INTERCÂMBIO DE SABERES ENTRE PROFISSIONAIS DA SAÚDE E EDUCAÇÃO. *Revista Multidisciplinar do Nordeste Mineiro*, v. 21, n. 02, p. 1-19, 2025. DOI: <https://doi.org/10.61164/w0axck40>.
- Bak, M., Ploem, M. C., Tan, H. L., Blom, M. T., & Willems, D. L. (2023). Towards trust-based governance of health data research. *Medicine Health Care and Philosophy*, 26(2), 185. <https://doi.org/10.1007/s11019-022-10134-8>
- Batifoulier, P., & Diaz-Bone, R. (2022). Perspectives on the economics and sociology of health. Contributions from the institutionalist approach of economics of convention -an introduction. HAL (Le Centre Pour La Communication Scientifique Directe). <https://hal.science/hal-03584852>
- Brall, C., Schröder-Bäck, P., & Maeckelberghe, E. (2019). Ethical aspects of digital health from a justice point of view. *European Journal of Public Health*, 29, 18. <https://doi.org/10.1093/eurpub/ckz167>
- Conclusion: Data Paradoxes. (2023). In *The MIT Press eBooks* (p. 213). The MIT Press. <https://doi.org/10.7551/mitpress/14926.003.0010>
- CORREA, Joana Paula Carvalho et al. Indicadores de Qualidade no Sistema Único de Saúde: abordagens para Avaliação da Eficiência e Eficácia dos serviços prestados. *INTERFERENCE: A JOURNAL OF AUDIO CULTURE*, v. 11, n. 2, p. 2130-2140, 2025. DOI: <http://doi.org/10.36557/2009-3578.2025v11n2p2130-2140>.
- CORRÊA, Joana Paula Carvalho et al. TRANSFORMAÇÃO DIGITAL NO SISTEMA ÚNICO DE SAÚDE: DESAFIOS, ESTRATÉGIAS E IMPLICAÇÕES PARA A GESTÃO PÚBLICA EM SAÚDE

COLETIVA. **Revista DCS**, v. 22, n. 85, p. e4065-e4065, 2025. DOI: <https://doi.org/10.54899/dcs.v22i85.4065>.

Couldry, N., & Mejias, U. A. (2020). Health data and global power inequalities: challenging the world data order. *Receis*, 14(4). <https://doi.org/10.29397/receis.v14i4.2243>

DE BRITO, Lara Tuanna et al. SAÚDE COLETIVA-INOVAÇÕES TECNOLÓGICAS E OS DESAFIOS DA SAÚDE GLOBAL NO SÉCULO XXI. **ARACÊ**, v. 6, n. 4, p. 17338-17348, 2024. DOI: <https://doi.org/10.56238/arev6n4-367>.

DE GÓES, Amanda Tavares; HEDLER, Helga Cristina; MORESI, Eduardo Amadeu Dutra. Blockchain no setor público: um estudo bibliométrico. **Boletim de Conjuntura (BOCA)**, v. 24, n. 71, p. 121-147, 2025. DOI: DOI: [10.56238/](https://doi.org/10.56238/). Disponível em: <https://revistaboletimconjuntura.com.br/boca/article/view/7987>.

DE SOUZA, Bárbara Peixoto Nascimento Ferreira; DE ANDRADE FERREIRA, Sheila; MONTE, Mário Ferreira. Governança Pública e Inteligência Artificial na Saúde: Um Estudo Sobre Privacidade e Direitos Fundamentais. **Pensar-Revista de Ciências Jurídicas**, v. 30, p. 1-14, 2025. DOI: <https://doi.org/10.5020/2317-2150.2025.14917>.

DOS REIS, Thaís Silva et al. INTELIGÊNCIA ARTIFICIAL NA SAÚDE DO TRABALHADOR: DESAFIOS, PERSPECTIVAS E GOVERNANÇA TECNOLÓGICA. **Editora Impacto Científico**, p. 141-154, 2025. DOI: <https://doi.org/10.56238/edimpacto2025.091-015>.

DUARTE, Franciely Fernandes *et al.* INOVAÇÃO SOCIAL E SAÚDE COLETIVA: ESTRATÉGIAS COLABORATIVAS PARA O BEM-ESTAR POPULACIONAL. **Revista Ibero-Americana de Humanidades, Ciências e Educação**, [S. l.], v. 11, n. 7, p. 3013–3021, 2025. DOI: <https://doi.org/10.51891/rease.v11i7.20451>.

Erdoğan, A., Turcan, G., Doğan, O., & Coşkun, E. (2024). Prioritizing Digital Health: Key Municipal Services Identified Through Fuzzy Methods. *DergiPark* (Istanbul University). <https://dergipark.org.tr/pub/aita/issue/87553/1465981>

Fast, L. (2023). Governing Data: Relationships, Trust & Ethics in Leveraging Data & Technology in Service of Humanitarian Health Delivery. *Daedalus*, 152(2), 125. https://doi.org/10.1162/daed_a_01996

Ferretti, A., Vayena, E., & Blasimme, A. (2023). Unlock digital health promotion in LMICs to benefit the youth [Review of Unlock digital health promotion in LMICs to benefit the youth]. *PLOS Digital Health*, 2(8). Public Library of Science. <https://doi.org/10.1371/journal.pdig.0000315>

Gonzalez-Polledo, E. (2018). Can digital health save democracy? Meeting the cosmopolitical challenge of digital worlds. *Journal of Social and Political Psychology*, 6(2), 631. <https://doi.org/10.5964/jspp.v6i2.939>

GUIMARÃES, Mateus Henrique Dias *et al.* Gestão Participativa na Saúde Coletiva: Caminhos para a Efetivação de Políticas Públicas Locais. **Brazilian Journal of Implantology and Health Sciences**, v. 7, n. 2, p. 1495-1503, 2025. DOI: <https://doi.org/10.36557/2674-8169.2025v7n2p1495-1503>

GUIMARÃES, Mateus Henrique Dias *et al.* INDICADORES DE SAÚDE COLETIVA: FERRAMENTAS PARA AVALIAÇÃO DA QUALIDADE E EFETIVIDADE DAS POLÍTICAS PÚBLICAS. **ARACÊ**, v. 7, n. 7, p. 36607-36616, 2025. DOI: <https://doi.org/10.56238/arev7n7-083>.

GUIMARÃES, Mateus Henrique Dias *et al.* PROMOÇÃO DA SAÚDE E PREVENÇÃO DE DOENÇAS NO CONTEXTO DA SAÚDE COLETIVA: ESTRATÉGIAS INTEGRADAS PARA A SUSTENTABILIDADE DOS SISTEMAS DE SAÚDE. **Revista CPAQV - Centro de Pesquisas Avançadas em Qualidade de Vida**, [S. l.], v. 17, n. 2, p. 7, 2025. DOI: <https://doi.org/10.36692/V17N2-59R>.

Holly, L., Thom, S., Elzemety, M., Murage, B., Mathieson, K., & Petralanda, M. I. I. (2023). Strengthening health data governance: new equity and rights-based principles. *International Journal of Health Governance*, 28(3), 225. <https://doi.org/10.1108/ijhg-11-2022-0104>

Huber, L. (2025). *Computing Care: Governing U.S. Healthcare Through Markets and Data*. Deep Blue (University of Michigan). <https://doi.org/10.7302/26977>

Leslie, D., Katell, M., Aitken, M., Singh, J., Briggs, M., Powell, R., Rincón, C., Chengeta, T., Birhane, A., Perini, A., Jayadeva, S., & Mazumder, A. (2022). *Advancing Data Justice Research and Practice: An Integrated Literature Review*. arXiv (Cornell University). <https://doi.org/10.48550/arxiv.2204.03090>

LOPEZ, Andres Santiago Quizhpi *et al.* ATENÇÃO PRIMÁRIA À SAÚDE E ASSISTÊNCIA ÀS DOENÇAS CRÔNICAS DA POPULAÇÃO NEGRA. **LUMEN ET VIRTUS**, v. 16, n. 46, p. 2540-2552, 2025. DOI: <https://doi.org/10.56238/levv16n46-065>

MACEDO, Y. M. .; FERLINI , N. P.; BAMBIRRA , A. P. F. TECNOLOGIA E INOVAÇÃO NA SAÚDE: PENSAMENTOS CONTEMPORÂNEOS OU UTOPIA?. **Boletim de Conjuntura (BOCA)**, Boa Vista, v. 9, n. 26, p. 161–168, 2022. DOI: 10.5281/zenodo.7854103 . Disponível em: <https://revista.ioles.com.br/boca/index.php/revista/article/view/1195> .

Marcucci, S., Alarcón, N. G., Verhulst, S., & Wüllhorst, E. (2023). Informing the Global Data Future: Benchmarking Data Governance Frameworks. *Data & Policy*, 5. <https://doi.org/10.1017/dap.2023.24>

Neff, G. (2019). *The Political Economy of Digital Health*. In Oxford University Press eBooks (p. 281). Oxford University Press. <https://doi.org/10.1093/oso/9780198843498.003.0017>

Pellegrini, G., & Lovati, C. (2025). Stakeholders' engagement for improved health outcomes: a research brief to design a tool for better communication and participation. *Frontiers in Public Health*, 13. <https://doi.org/10.3389/fpubh.2025.1536753>

Reis, A., Malpani, R., Vayena, E., Majumder, P. P., Swaminathan, S., Pujari, S., Reeder, J., Bernardo, M., Shorbachi, N. A., Ema, A., Ghoulia, A., Gibson, J. K., Goodman, K. W., Hoven, J. van den, Jayaram, M., Jjingo, D., Leong, T.-Y., London, A. J., Marwala, T., ... Zeng, Y. (2021). ETHICS AND GOVERNANCE OF ARTIFICIAL INTELLIGENCE FOR HEALTH : WHO GUIDANCE. In Research Portal Denmark (p. 150). Technical University of Denmark. <https://local.forskningsportal.dk/local/dki-cgi/ws/cris-link?src=ku&id=ku-e505319d-a404-4d93-bfa7-577735b36fdd&ti=ETHICS%20AND%20GOVERNANCE%20OF%20ARTIFICIAL%20INTELLIGENCE%20FOR%20HEALTH%20%3A%20WHO%20GUIDANCE>

RIBEIRO, Rafael Dias; GOMES, Valter; GOMES, Daniela. Saúde digital e políticas públicas: evolução e desafios para o Brasil. **ARACÊ**, v. 6, n. 3, p. 7428-7442, 2024. DOI: <https://doi.org/10.56238/arev6n3-184>.

Robinson, L., Ragnedda, M., & Schulz, J. (2020). Digital inequalities: contextualizing problems and solutions. *Journal of Information Communication and Ethics in Society*, 18(3), 323. <https://doi.org/10.1108/jices-05-2020-0064>

RORIZ, Fernanda Aguiar Silvestre *et al.* A SAÚDE COLETIVA NO COTIDIANO DA ATENÇÃO BÁSICA: PRÁTICAS, SABERES E DESAFIOS. **ARACÊ**, v. 7, n. 6, p. 31036-31046, 2025. DOI: <https://doi.org/10.56238/arev7n6-114>.

Shaw, J., & Sekalala, S. (2023). Health data justice: building new norms for health data governance [Review of Health data justice: building new norms for health data governance]. *Npj Digital Medicine*, 6(1), 30. *Nature Portfolio*. <https://doi.org/10.1038/s41746-023-00780-4>

Silva, A. B., & Souza, V. de L. E. (2022). Data governance as a human right. *HAL (Le Centre Pour La Communication Scientifique Directe)*. <https://doi.org/10.13140/rg.2.2.30833.56161>

Silva, A. M., Ventura, M., Coeli, C. M., & Zeeb, H. (2025). SUSData, proporcionalidade e equidade em saúde: dados trabalhando pelo direito à saúde digital no Sistema Único de Saúde. *Revista de Direito Sanitário*, 25(1). <https://doi.org/10.11606/issn.2316-9044.rdisan.2025.231541>

Storey, M. A., & Soshnikov, S. (2023). Guest editorial: Digital health and governance: implications and challenges. *International Journal of Health Governance*, 28(3), 213. <https://doi.org/10.1108/ijhg-09-2023-158>

Strange, M., & Tucker, J. (2023). Global governance and the normalization of artificial intelligence as 'good' for human health. *AI & Society*. <https://doi.org/10.1007/s00146-023-01774-2>