# Ethical issues arising in research into health and climate change



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# Balancing act: ethical considerations in data-intensive health research and environmental sustainability in Kenya and Senegal

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## Brief description of context

This case study explores the ethical considerations associated with addressing the environmental impacts of data-intensive health research methodologies in Kenya and Senegal. It sought to understand how health research stakeholders (researchers, institutions, and funding bodies) using these methodologies perceive the integration of environmental considerations into their research practices, and to consider the ethical implications of these views. There is a rising significance of data-intensive research in addressing health challenges in Africa, alongside growing concerns about its adverse environmental impacts. Using exploratory interviews, we examined the perceptions of Kenyan and Senegalese researchers regarding environmental sustainability in research. Our findings reveal that the framing of environmental sustainability in research often differs between Western and African contexts. While Western approaches tend to emphasize individual responsibility, researchers in Kenya and Senegal often view environmental considerations through a different lens influenced by local priorities and constraints.

#### Discussion of ethical issues

Data-intensive health research methods have significant environmental impacts through their digital infrastructures and technologies. Samuel and Lucassen (2022; 2023) highlight concerns with energy consumption, complex algorithms, and environmental hazards from digital technology. These environmental impacts raise important questions of justice and fairness, particularly in how responsibilities for addressing these impacts should be distributed across global research communities.

In considering questions of responsibility, Caney (2010, 2017) argues that advantaged parties have special responsibilities to address climate change, not only due to historical contributions but also their greater capacity to act. His hybrid model of responsibility, combining "polluter pays" with "ability to pay" principles, suggests that researchers and institutions in high-income countries might have greater responsibilities to address research-related environmental impacts. This aligns with Young's (2006) "social connection model of responsibility," which posits that those with the most capacity to effect change have the greatest responsibility to address structural injustices.

When considering the fairness of environmental responsibilities in diverse global contexts, it is crucial to recognize that climate change impacts vary significantly by region. Researchers in regions facing more severe climate impacts might have different priorities and constraints, underscoring the importance of contextually appropriate frameworks that account for both global responsibilities and local realities.

While there's growing awareness of environmental responsibility in UK health research (Samuel, 2023; 2024), implementation faces challenges due to economic pressures and lack of institutional support. Equally, Western framings of individual responsibility may not align with LMIC researchers' perspectives and

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constraints (Hedt-Gauthier et al., 2019). To ensure fairness, it's essential to understand LMIC researchers' unique challenges and perspectives in developing collaborative frameworks.

## Key findings

- Participants' varied views on addressing environmental harms in African contexts: Some participants conveyed that environmental responsibility discourse holds more significance in Western contexts. This perspective is often rooted in the belief that Western nations have higher energy consumption and different research priorities, and was sometimes expressed using the notion of "victimhood." Statements like "Those who develop most of these algorithms are often very large organizations, most of which are not in Africa. So, in reality, we are just consumers" highlight this sentiment.
- 2. Participants acknowledged the intricate relationship linking diseases, human health, and the environment. There was a shared understanding that robust disease treatments play a pivotal role in empowering communities to tackle overarching environmental challenges. Quoted statements such as "Sick people or a sick nation does not care about the environment" underscore that a population grappling with health issues tends to prioritize immediate health over broader environmental concerns. This perspective emphasizes the imperative to conduct research aimed at developing effective disease treatments, aligning health initiatives with broader environmental goals.
- 3. Incentivizing the need to address environmental harms. Participants recognized incentives as crucial catalysts for incentivizing addressing environmental harms. They described how tax credits and funding could encourage researchers and institutions to prioritize environmental issues. However, it was noted that there is a tendency for institutions handling researchers' data to pass responsibility to the cloud providers, particularly major tech companies, who are seen as the primary custodians of environmental sustainability due to their role in storing research data.

#### **Conclusions and recommendations**

This case study reveals that Western framings of environmental sustainability in health research, which often emphasize individual and institutional responsibility, do not always align with the perspectives of researchers in Kenya and Senegal. The participants frequently viewed environmental responsibilities as primarily belonging to Western countries and tech companies, reflecting a moral framework in which immediate health outcomes take priority over environmental concerns. This misalignment reflects broader questions of fairness in how research priorities and resources are distributed between Western and African contexts (Kirigia et al., 2016; Hedt-Gauthier et al., 2019).

These recommendations aim to promote fair and contextually appropriate approaches to balancing health research needs with environmental sustainability concerns in LMICs, recognizing the unique perspectives and priorities of African researchers:

- 1. **Further research into ethical frameworks:** There is a need for more research into ethical frameworks that can fairly balance the immediate health needs of populations in LMICs with long-term environmental sustainability concerns. This should be led by scholars and stakeholders from LMICs to ensure frameworks reflect local perspectives on justice and fairness.
- 2. **Explore collective responsibility models:** Given the global nature of both health research and environmental impacts, models of collective responsibility that go beyond individual researchers or institutions require exploration. This could involve examining how "common but differentiated responsibilities" from international environmental law could apply to health research.
- 3. **Investigate contextually appropriate incentive structures:** Further research is needed to understand what kinds of incentives would be effective and fair in encouraging environmentally sustainable research practices in LMIC contexts, without compromising primary health research objectives.
- 4. Enhance researchers' capacity for ethical analysis: This study revealed limitations to researchers' understanding of environmental impacts of data-intensive research practices. Training programs should focus on environmental ethics in health research and support for implementing sustainable practices in resource-limited settings.

5. Analyze tech companies' responsibilities: Given the significant role of global tech companies in research infrastructure, further ethical analysis of their responsibilities in mitigating environmental impacts is required. This analysis should incorporate LMIC perspectives and consider how these companies can fairly support sustainable research practices in resource-limited settings.

#### References

- 1. Kirigia, J. M., Nabyonga-Orem, J., & Dovlo, D. Y. T. (2016). Space and place for WHO health development dialogues in the African Region. BMC Health Services Research, 16(4), 221.
- Hedt-Gauthier, B. L., Jeufack, H. M., Neufeld, N. H., Alem, A., Sauer, S., Odhiambo, J., ... & Volmink, J. (2019). Stuck in the middle: a systematic review of authorship in collaborative health research in Africa, 2014–2016. *BMJ global health*, *4*(5), e001853.
- 3. Owusu-Nimo, F., & Boshoff, N. (2017). Research collaboration in Ghana: patterns, motives and roles. Scientometrics, 110(3), 1099-1121.
- Chersich, M. F., Blaauw, D., Dumbaugh, M., Penn-Kekana, L., Thwala, S., Bijlmakers, L., ... & Rees, H. (2016). Mapping the types and characteristics of research collaborations in Africa: A systematic review. The Lancet Global Health, 4(10), e710-e719.
- 5. Nyasulu, J. C., & Pandya, H. (2020). The Africa we want: Contextualizing the sustainable development goals for Africa. South African Journal of Science, 116(3-4), 1-4.
- 6. Caney, S. (2010). Climate change and the duties of the advantaged. Critical Review of International Social and Political Philosophy, 13(1), 203-228.
- 7. Caney, S. (2010). Climate change and the duties of the advantaged. *Critical Review of International Social and Political Philosophy*, *13*(1), 203–228. <u>https://doi.org/10.1080/13698230903326331</u>
- 8. Caney, S. (2017). Climate change and the duties of the advantaged. In *Intergenerational Justice* (pp. 321-346). Routledge.
- 9. Ferretti, A., Ienca, M., Sheehan, M., Blasimme, A., Dove, E. S., Farsides, B., ... & Vayena, E. (2021). Ethics review of big data research: What should stay and what should be reformed?. *BMC medical ethics*, 22(1), 51.
- 10. Gooding, P., & Kariotis, T. (2021). Ethics and law in research on algorithmic and data-driven technology in mental health care: scoping review. *JMIR Mental Health*, *8*(6), e24668.
- 11. Haraway, D. J. (2016). Staying with the trouble: Making kin in the Chthulucene. In *Staying with the Trouble*. Duke University Press.
- 12. Ienca, M., Ferretti, A., Hurst, S., Puhan, M., Lovis, C., & Vayena, E. (2018). Considerations for ethics review of big data health research: A scoping review. *PloS one*, *13*(10), e0204937.
- 13. Martuzzi, M., Mitis, F., & Forastiere, F. (2010). Inequalities, inequities, environmental justice in waste management and health. European Journal of Public Health, 20(1), 21-26.
- 14. Nijman, S. (2019). UN report: Time to seize opportunity, tackle challenge of e-waste. United Nations Environment Programme.
- 15. Pellow, D. N. (2020). Electronic Waste and Environmental Justice.
- 16. Samuel, G. (2023). UK health researchers' considerations of the environmental impacts of their dataintensive practices and its relevance to health inequities. BMC Med Ethics 24, 90.
- 17. Samuel, G. (2024). Responsibility for the Environmental Impact of Data-Intensive Research: An Exploration of UK Health Researchers' perceptions. Science and Engineering Ethics. In press.
- 18. Samuel, G., & Lucassen, A. M. (2022). The environmental sustainability of data-driven health research: A scoping review. Digital Health, 8, 20552076221111297.
- 19. Samuel, G., & Lucassen, A. M. (2023). The environmental impact of data-driven precision medicine initiatives. Cambridge Prisms: Precision Medicine, 1, e1.
- Serrano-Santoyo, A., Kuri-Alonso, I., Durazo-Watanabe, E., & Rojas-Mendizabal, V. (2021). Ethical implications regarding the adoption of emerging digital technologies: An exploratory framework. Progress in Ethical Practices of Businesses: A Focus on Behavioral Interactions.
- Shaw, J., Ali, J., Atuire, C. A., Cheah, P. Y., Español, A. G., Gichoya, J. W., ... & Vayena, E. (2024). Research ethics and artificial intelligence for global health: perspectives from the global forum on bioethics in research. BMC Medical Ethics, 25(1), 46.
- 22. Thurston, W. E., Burgess, M. M., & Adair, C. E. (1999). Ethical issues in the use of computerized databases for epidemiological and other health research. *Chronic Diseases in Canada*, *20*(3), 127-131.

- 23. Wellcome Trust. (n.d.). Environmental sustainability concordat. Wellcome. https://wellcome.org/who-we-are/positions-and-statements/environmental-sustainability-concordat
- 24. World Health Organization. (2021). Children and digital dumpsites: e-waste exposure and child health. World Health Organization.
- 25. Young, I. M. (2006). Responsibility and global justice: A social connection model. Social philosophy and policy, 23(1), 102-130.