

# Ethical issues arising in research into health and climate change

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## Co-production of climate-sensitive infectious diseases ethics rules with women grassroots organizations in Paraguay

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### **Brief description of context**

Climate change suggests revising ethical principles and rules in health research. One circumstance that makes this revision necessary is that the temporal and geographical distribution of health risks and health research benefits will vary under different future climate scenarios. Currently, research on climate-sensitive infectious diseases primarily benefits the global south. However, in alternative climate scenarios, countries in the global north already feel the effects of tropicalisation on disease burden will also reap the rewards of such research. (Brem et al., 2024; Laverdeur et al., 2024).

This case aims to co-create ethical guidelines for climate-health research using a transdisciplinary reflective equilibrium methodology (Rekers et al., forthcoming) in collaboration with academic and non-academic participants, including members of grassroots women's organizations from Paraguay. Transdisciplinary approaches allow us to recognize that the ethical perspectives developed in academia often do not align with those of individuals experiencing climate change's impacts. Their views on justice may even challenge established ethical norms. However, by considering the specific needs and viewpoints of affected populations through the lens of epistemic justice, we can formulate impartial ethical guidelines that meet their demands without significantly compromising fundamental ethical principles.

This process involves: 1) engaging in ethical discussions with stakeholders, which 2) leads to normative outcomes rather than purely statistical ones. 3) Both the discussions and their outcomes have a social impact. During these conversations, 4) non-academic participants provide input at two stages: a. identifying relevant ethical dilemmas and b. refining the principles and judgments.

The focus on members of grassroots women's organizations is important for several reasons. First, women are at greater risk of climate-related health issues due to their vulnerability and the specific risks associated with their gendered roles (Cissé, G. R., et al., 2022). Second, both formal and informal participation in adaptation planning is often limited by gender inequality (Schipper, E. L. F., et al., 2022) and epistemic injustice (Byskov, M. F., & Hyams, K., 2022). Third, grassroots women's organizations have a long history of advocating for both environmental and reproductive rights, positioning them as key social players, particularly in shaping regional policies and research agendas that are ethically grounded (Báez et al., 2016; Bergallo et al., 2019), including discussions surrounding abortion rights.

In selecting non-academic participants, we considered the intersection between gender and other groups facing greater climate-health risks, such as Indigenous peoples (Cissé, G. R., et al., 2022), and those that are underrepresented in adaptation research, such as the LGBTQI community and people with disabilities (New et al., 2022). Since South American countries often have centralized policies concentrating research and development benefits in capital cities, we adopted a federal approach, prioritizing participants from more disadvantaged and underrepresented geographic areas.

Regarding the geographical location of the case, Paraguay is currently experiencing one of the highest Chikungunya incidence rates in the region, with 20 cases per 100,000 inhabitants (OPS, 2023, p. 5). This situation underscores the urgent need for research linking climate and health. Despite the high priority given to health in National Adaptation Plans (WHO, 2021), Paraguay's plan lacks the necessary funding, involvement of health-related institutions, and measurable indicators to effectively guide policy decisions (Paz-Soldán et al., 2023). Paraguay has no such plan unlike Brazil, Chile, Suriname, and Argentina, which have developed sector-specific Health National Adaptation Plans (Rekers et al., 2024). Additionally, its National Adaptation Plan, established when Chikungunya was just emerging (NAP Paraguay, 2015, p. 9), lacks resources and measurable metrics for addressing the health sector. These gaps highlight Paraguay's vulnerability to climate-sensitive infectious diseases, making it an important pilot case for targeted climate-health research.

The co-production ethical rules occur by engaging academic and non-academic stakeholders at key stages of the research process. First, stakeholders, such as local communities, health practitioners, and policymakers, collaboratively identify the ethical dilemmas concerning climate-sensitive infectious diseases. Then, through structured dialogues, they work together to refine and revise the ethical principles and judgments, ensuring that diverse perspectives are incorporated. This inclusive approach enriches the ethical frameworks and increases their applicability and legitimacy in real-world settings. The outcome of this ethical deliberation is normative rather than statistical; the aim is not to establish the moral beliefs of the stakeholders but rather to co-produce ethical guides with them. Although this method can be applied to a wide range of practical issues, in this case study, we will focus on the case of climate-sensitive infectious disease ethics due to the particular challenges it generates. Controlling infectious diseases requires demanding cooperation due to their communicable nature and the porous borders for people and goods. Moreover, available adaptation paths depend on epidemic evolution and will be under different mitigation scenarios in the future.

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### **Discussion of ethical issues**

One of the central ethical issues in climate-sensitive infectious disease research relates to **justice and fairness** in both the distribution of risks and benefits, as well as in the research process itself. Vector-borne diseases like the chikunguña and dengue virus disproportionately impact low-income countries and communities with limited adaptive capacity, where endemicity is already high and control mechanisms are weak (Castellanos et al., 2022). These areas often bear the brunt of climate-induced changes in disease transmission, yet they frequently lack access to the research agenda-setting that could mitigate these impacts.

In this context, ethical research should prioritize distributive justice—ensuring that vulnerable populations benefit fairly from research outcomes—and procedural justice, meaning that those most affected by climate change are included in the decision-making processes that shape the research. Involving local communities in the coproduction of ethical rules ensures that their needs and contexts guide the research rather than imposing solutions that may not be feasible or effective locally.

The current research agenda in climate health tends to overlook the disproportionate burden placed on low-resource regions, as the case of the COVID-19 pandemic has shown (Rekers & Luna, 2023). Ensuring justice and fairness in this context requires a fair distribution of resources for adaptation, mitigation and inclusive participation in the research process.

While there is growing research on climate-sensitive infectious diseases in low- and middle-income countries, only a small fraction of the literature explicitly analyzes the intersection of ethics, health,

climate change, and infectious disease (Markle et al., 2023). In Spanish, literature exists, but comprehensive reviews on the subject are lacking.

**Epistemic justice** is another key consideration in climate research, particularly regarding the exclusion and marginalization of indigenous, local, and grassroots communities. These communities hold valuable knowledge and adaptation strategies often overlooked in conventional scientific approaches. Incorporating their insights through co-producing ethical knowledge not only improves the relevance of research but also empowers these communities to actively shape the solutions to the challenges they face.

Integrating epistemic justice into the research agenda helps bridge the gap in the literature, where marginalized communities' voices and knowledge systems are frequently excluded. Co-producing ethical knowledge in collaboration with these communities ensures more contextually relevant and sustainable solutions, contributing to more effective climate adaptation policies and enhancing the adaptive capacities of vulnerable populations.

Furthermore, including indigenous, local, and grassroots organizations in ethical knowledge production offers additional benefits. These organizations bring unique experiences in managing crises and advocacy, which enriches the process. Co-production reduces the risk of maladaptation and the spread of misinformation, as highlighted during the COVID-19 pandemic (Furlan, 2021). It also strengthens ethical guidelines, potentially counteracting non-democratic trends in climate policy (Mittiga, 2022). Ultimately, co-producing normative knowledge fosters transformational change by altering the fundamental attributes of social-ecological systems (Castellanos et al., 2022), underscoring the importance of this collaborative approach.

## **Conclusions**

The co-production of ethical rules in climate-sensitive infectious disease research with women's grassroots organizations in Paraguay demonstrates the value of a transdisciplinary approach. By combining academic insights with the lived experiences and knowledge of local communities, this method ensures more contextually relevant and just ethical standards. It promotes epistemic justice by empowering marginalized groups to actively participate in shaping research and decision-making processes.

Involving stakeholders through co-production of knowledge builds capacities, fosters social dialogue, and ensures that ethical dilemmas are addressed collaboratively, leading to more effective and equitable climate adaptation strategies. This approach not only enhances research relevance but also strengthens the adaptive capacities of these communities.

## **Recommendations**

Two key recommendations are proposed to enhance research ethics in this field. The first is to adopt a transdisciplinary reflective equilibrium methodology by collaborating with diverse stakeholders to co-produce and review ethical rules. This approach ensures that ethical deliberations lead to meaningful social impacts and incorporates non-academic actors into the co-production process through methodological adjustments. The second recommendation is to actively engage women's organizations in climate-health research by identifying and involving regional stakeholders with demonstrated expertise. This inclusion integrates these groups into the co-production of ethical standards, promoting resilience, preventing maladaptation, and fostering transformative change.

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