Ethical issues arising in research into health and climate change



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Balancing urgency and caution in the face of climate change: how to advance new research for malaria control?

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Brief description of context

Climate change requires global cooperation, yet it does not impact all countries and populations equally. It exacerbates existing inequalities, including in terms of health outcomes, vulnerability to diseases and access to healthcare.

Malaria, one of the greatest and most persisting public health burdens, is being impacted both directly and indirectly by climate change. Temperature and rainfall changes directly affect malaria's prevalence and seasonality. Indirect impacts on factors such as healthcare access, migration, and displacement are intensifying malaria's impact globally. The 2023 WHO Malaria Report, for example, reported that the catastrophic flooding in Pakistan in 2022 led to a fivefold increase in malaria cases in the country.

The overlap between the global map of countries most affected by climate change and those most affected by malaria highlights the importance of considering the nexus between these two issues. As noted by WHO, "climate change threatens the complex relationship between natural and human systems and undermines many of the social determinants of good health – such as livelihoods, nutrition, security and access to quality health services. It is both a singular threat to health and a 'threat multiplier'" (WHO, 2023¹).

Discussion of ethical issues

Malaria cases are back on the rise, and the risk of further increase in malaria prevalence looms: by the end of the 21st century, climate change will potentially increase the number of people at risk of malaria by 49% to 89% (Caminade et al, 2014²; Kulkarni et al., 2022³). In response, new tools such as genetic approaches to control the population of the main malaria vectors are being considered. There is urgency in getting these tools developed, tested, and into the hands of national malaria control programs to counter a growing convergence of threats, including mosquito resistance to insecticides. National governments, malaria program funders, and the people affected by this disease are demanding rapid action.

Yet, due to the novelty of these technologies and perceptions around genetic approaches, there has been an inverse pressure to adopt a slow, stepwise approach to R&D, combined with strong global oversight and guidance for this research. It is often suggested that decisions on whether to use these tools should not be made by endemic countries alone but should be the result of some

¹ WHO World Malaria Report 2023

² Caminade C, Kovats S, Rocklov J, Tompkins AM, Morse AP, Colón-González FJ, Stenlund H, Martens P, Lloyd SJ. Impact of climate change on global malaria distribution. Proc Natl Acad Sci U S A. 2014 Mar 4;111(9):3286-91. doi: 10.1073/pnas.1302089111

³ Kulkarni, M.A., Duguay, C. & Ost, K. Charting the evidence for climate change impacts on the global spread of malaria and dengue and adaptive responses: a scoping review of reviews. Global Health 18, 1 (2022). <u>https://doi.org/10.1186/s12992-021-00793-2</u>

global process to include other perspectives, including those outside of the countries affected by malaria. The risk-aversion towards innovative technologies appears to be relative to the disease exposure, and therefore the level of threat that they pose to a given individual or society. Researchers in this field have found that understanding and acceptance of genetic approaches to research are higher in regions where malaria is a primary health concern, compared to capital cities in endemic countries and non-endemic countries⁴. The tension about where this decision should be made can also be affected by paternalistic perceptions that endemic countries – which are developing countries – do not have the capacity to assess the technologies and affiliated risks and, therefore, cannot make informed decisions. Seeking a timely and effective response to the threat of climate change underscores the tension between the desire for globally coordinated action and the urgency of rapid domestic response and raises ethical questions similar to those highlighted in vaccine trials during pandemics (Alqahtani et al. 2021⁵), which critically evaluates the balance between trial rigor and expedited results.

As research progresses with field evaluations proposed in the near future, the tension between national and global priorities raises significant ethical questions: Should research be fast-tracked to deliver new tools more quickly, given that delays can cost thousands of lives each month? However, this urgency needs to be balanced against possible risks of an accelerated or simplified pathway. Those who are set to benefit the most from such technologies would also likely be the ones to be the most affected should risks be under-evaluated and not mitigated. How to balance the urgency to act to save lives, and the careful evaluation of potential risks when considering new technologies that have not been evaluated in the field before? Should decision-making rather take place primarily or solely at the national level, taking into account specific populations' needs and priorities? Or should the precautionary approach set at the international level, primarily by a majority of actors not affected by malaria, be the accepted path in the name of the global good, but possibly at the cost of many lives? These questions are further complicated by discussions around the global health architecture, which is intended to benefit all nations but has been criticized for predominantly reflecting the interests and viewpoints of a few countries.

This dilemma is well illustrated by genetic tools for malaria control, where the need and urgency felt by several countries is creating pressure for accelerated pathways to development, while the perspectives and priorities of other (including influential) actors are pushing in the direction of a limited and slow R&D process, with ever-increasing requirements to be met. This dilemma will not be unique to these health interventions as the pressure of adaptation and mitigation increase the need for timely action. But technological scepticism, global standards, and global power dynamics create a different set of expectations for what constitutes "good" research and appropriate responses to the threat of climate change.

How can research and use of these new technologies be fostered and the tension between a topdown approach to governance and domestic priorities be reconciled?

Conclusions and recommendations

Climate change is adversely impacting public health, with malaria a prime of example of a disease whose burden will be dramatically increased by climate change if rapid measures are not taken. Some of the tools and technologies that countries are seeking to use are the subject of global debates and efforts to build global governance processes which aim to guide, and to some extent supersede national level decision making. These global processes are mostly anchored by risk minimization priorities and highly precautionary approaches to new technologies. This results in an ethical tension between the need for rapid action to save lives today and prevent future loss of life, and the ambition to build and maintain global norms for technology development that aim to

⁴ Pare Toe, L., Dicko, B., Linga, R. *et al.* Operationalizing stakeholder engagement for gene drive research in malaria elimination in Africa—translating guidance into practice. *Malar J* **21**, 225 (2022). https://doi.org/10.1186/s12936-022-04241-3

⁵ Alqahtani AM, Almazrou SH, Alalweet RM, Almalki ZS, Alqahtani BF, AlGhamdi S. Impact of COVID-19 on Public Knowledge and Attitudes Toward Participating in Clinical Trials in Saudi Arabia: A Cross-Sectional Study. Int J Gen Med. 2021 Jul 13;14:3405-3413. doi: 10.2147/IJGM.S318753. PMID: 34285565; PMCID: PMC8286145.

provide for a greater global good, but tend to prolong research pathways to reach ever lower levels of uncertainty. The tension is sometimes described as transgenerational, where approving the technology would be for the benefit of people living today in endemic countries, while the potential negative impacts could affect future generations. However, this thinking is inaccurate as future generations would also inherit the possible elimination of this disease, and current generations could potentially be affected by negative impacts. More than this, the tension revolves around the issue of equity and how global norms are set in context where most vulnerable populations do not have a voice and yet are often the most affected by such decision.

The next 20 years are critical for malaria elimination. Without new interventions in the next decade, the impact of climate change could result in catastrophic increases in malaria cases in certain countries. This urgency needs to inform global discussion and the development of governance framework for new tools, such as genetic technologies. It calls for a re-evaluation of how global norms and governance structures are designed, to support and facilitate technology development and use. It should also recognize the primacy of the interest of those directly affected and focus on supporting their specific needs and priorities. Research on deliberative processes⁶, community engagement and agreement building to support decision-making on complex issues have demonstrated that it is possible to give a voice to affected people⁷. The challenge is to ensure that decision makers recognise and integrate those processes into their considerations.

⁶Moore, A., & O'Doherty, K. (2014). Deliberative voting: Clarifying consent in a consensus process. *Journal of Political Philosophy*, 22(3). https://doi.org/10.1111/jopp.12028

Fischer, Frank, *Reframing Public Policy: Discursive Politics and Deliberative Practices* (Oxford, 2003; online edn, Oxford Academic, 1 Nov. 2003), <u>https://doi.org/10.1093/019924264X.001.0001</u>, accessed 24 Sept. 2024.

⁷ Pare Toe, L., Nourou, B., Ky, A. D., Kekele, S., Wilfrid, M., Bayala, K., Drabo, M., Thizy, D., & Diabate, A. (2021). Small-scale release of non - gene drive mosquitoes in Burkina Faso: from engagement implementation to assessment, a learning journey IN REVIEW. *Malaria Journal*.