Ethical issues arising in research into health and climate change

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Pecha Kucha presentation

Examining the ethical implications of the burden of heat waverelated illnesses in indigenous communities in Puruliya, West Bengal, India

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Brief description of context

The study will be conducted in Puruliya district of West Bengal, India. Puruliya district is facing severe droughts due to rising temperatures and unpredictable rainfall. This vulnerability affects agriculture, health, and livelihoods, leading to a 65% decline in agricultural productivity. Groundwater loss and low harvests exacerbate the problem, affecting human development and increasing poverty.¹ The rural areas of Puruliya account for 87.26 per cent of the total population. These areas also have the second-highest concentration (10.52 per cent) of scheduled tribes (various indigenous communities recognised by the Government of India for special protection assistance) in West Bengal.

In 2018, Puruliya district's multi-dimensional poverty index (MPI) was 0.161, 1.4 times higher than India's overall. The Indigenous group experienced the highest income poverty levels, followed by Scheduled Castes (SCs), Other Backward Castes (OBCs), and general population.² These tribes primarily reside in forested areas. The significant forest cover, accounting for 29.69 per cent of the entire land area, highlights the region's intricate socio-economic dynamics and ecological significance.³ The district has a sub-tropical climate characterized by high evaporation rates and limited rainfall, leading to extreme heat with temperatures reaching about 50°C, while winters are very cold, with temperatures plummeting to 3.8°C. This climate intensifies temperature extremes and reduces precipitation, causing agricultural difficulties. Groundwater is limited, and shallow wells often experience water depletion. Government-supplied solar taps provide limited relief, forcing many to rely on contaminated river water for daily tasks.¹

Our study in four blocks of Puruliya namely, Bandwan, Manbazar-I, Manbazar-II and Puncha aimed to understand the impact of heat waves on Indigenous communities and their coping mechanisms. Our self-financed study revealed that the Indigenous populations experienced increased incidences of exhaustion, dehydration, headaches, fever and dizziness due to increased temperatures in the last two years. The ethical challenges that we faced in this study are discussed in the following sections. These issues may be customized and scaled at national level to the Indigenous communities in India.

Discussion of ethical issues

It is clear that climate change and health cannot be studied in isolation. They are both complex phenomena involving biotic and abiotic components of the environment.

Justice and fairness in the research agenda: A nuanced and just research agenda is imperative to meaningfully address the health impacts of climate change, especially for those most vulnerable, like the Indigenous communities in Puruliya, West Bengal. The disproportionate impact of climate phenomena on these communities, which contribute minimally to global warming yet face the brunt of its consequences, underscores the need for a research focus that is both ethical and equitable.

However, data availability and accessibility especially pertaining to Indigenous health in LMICs is lacking which limits the development a just research agenda.

In the study of heat waves in Puruliya, justice demands that Indigenous voices are central in shaping research questions and strategies, not just as passive participants but as co-creators of knowledge. The research should address their specific needs, customs, and environmental realities. However, the research question and strategies did not originate from them but from the researchers. Addressing these ethical issues involves overcoming challenges such as communication barriers, ensuring equitable stakeholder inclusion, and addressing specific vulnerabilities like the reliance of Indigenous communities on traditional coping mechanisms that may no longer be sufficient for the rapidly changing climate.

To address these challenges, strategies such as community-based monitoring systems led by Indigenous women and the establishment of local climate-health knowledge hubs can facilitate ongoing, participatory research that empowers Indigenous communities while ensuring the research agenda remains equitable.

Equitable stakeholder inclusion is critical. For Indigenous communities in Puruliya, this means their active involvement in all research phases—from planning to dissemination. We faced several challenges but made concerted efforts to move beyond symbolic participation and to empower them to genuinely influence research directions and outcomes. We prioritized their involvement by engaging them in discussions about their needs, concerns, and the cultural significance of their environment. Manbhum Ananda Ashram Nityanada Trust (MANT), won the 2023 Grassroots Science Advice Promotion Awards from International Network for Governmental Science Advice (INGSA-Asia). With this support, the centre organised a <u>workshop</u> for elevating tribal perspectives on climate change, addressing challenges related to livestock, agriculture, and health, fostering stakeholder dialogue, and synthesising these discussions into a <u>comprehensive report</u>.

To ensure ethical stakeholder inclusion, MANT engaged tribal women in discussions about climate change, livestock, agriculture, and health. Community media were used to empower tribal women and bridge the gap between research agendas and their beliefs. Local facilitators familiar with the community's language and culture were employed to communicate effectively and respectfully.

Another ethical challenge was ensuring the benefits of the research were equitably shared, we aimed to establish long-term partnerships that would not only benefit the current study but also contribute to sustainable, culturally sensitive interventions for the future.

Addressing specific vulnerabilities: One of the significant barriers we encountered was the lack of access to basic resources, including clean water, healthcare, and infrastructure to withstand extreme heat waves.

Ethical research involves not only identifying vulnerabilities, but also working with the community to co-create solutions. Addressing historical exclusion of Indigenous voices, integrating traditional knowledge, adapting methods, and ensuring culturally sensitive interventions are crucial for fostering ownership and relevance. An example is the government-supported housing scheme where homes in tribal areas were built using concrete, ignoring the community's traditional, environmentally sustainable house-making practices, creating a disconnect between modern interventions and their ecological knowledge. This disregard for their practices further highlighted the need for culturally sensitive and sustainable approaches in our research.

The success of this endeavour involves reducing climate-induced vulnerabilities by implementing interventions that are not only scientifically sound, but also based on community needs and beliefs, strengthening local resilience through sustainable solutions, and respecting Indigenous knowledge in research efforts.

Communication barrier: One of the primary challenges we faced in our research with the Indigenous communities in Puruliya was overcoming communication barriers, which had a significant impact on both the ethical conduct and the success of our work.

Our association with this community is over 6 decades old, which helps us to understand some nuances and we utilized culturally sensitive communication strategies, including community media, traditional wall painting, and storytelling, led by local leaders, with tribal women acting as intermediaries to bridge scientific information with community understanding. Hence, in December of 2023, MANT hosted a <u>National Symposium</u> on tribal health where clinician, scientists, researchers, academicians and Indigenous populations from Puruliya shared their concerns.

Research governance: The intersection of climate change and health in districts like Puruliya, West Bengal, brings complex ethical challenges to research that existing frameworks may not fully address. The unique vulnerabilities and dynamic contexts of these districts necessitate specific adaptations in research ethics oversight to ensure thorough and respectful engagement with affected communities and the environment.

A localized ethical review process involved community representatives, specifically the traditional tribal leadership ('council of 5 brothers'), to evaluate research risks and benefits, ensuring Indigenous voices were included. Community input from tribal assemblies ('*Kulhidurup*') informed data collection methods that respected local customs while maintaining scientific rigor.

To ensure long-term benefits for the community, protocols were established for communicating findings and co-creating intervention strategies. This participatory governance model aimed to prevent extractive research practices and foster resilience against climate change-related health impacts. Success in this governance framework meant ensuring that the research was ethical, community-centric, and adaptable while maintaining scientific integrity and accountability.

Conclusions and recommendations

This study highlighted the severe impact of climate change on vulnerable populations, especially marginalized Indigenous groups. It emphasizes the need for community engagement and the integration of Indigenous knowledge with scientific research to develop sustainable solutions to climate-induced health issues, while ensuring ethical considerations like stakeholder inclusion and transparency.

- Establish a local climate-health knowledge hub: Develop a permanent local centre in Puruliya that serves as a hub for climate and health knowledge, keeping in mind Indigenous language and culture. This hub should facilitate the integration of local and scientific knowledge systems, provide training and resources for local data collection, and distribute health advisories. It would function as a critical link between researchers, local communities, and policymakers, ensuring that research findings and strategies are directly applicable to and beneficial for the local population.
- 2. Community-based monitoring systems: Encourage the adoption of community-based environmental and health monitoring systems. These systems would use local resources and technologies, such as mobile apps, community-based weather stations, and local sensors, to track climate variables and health outcomes in real-time. This approach empowers communities by making them active participants in monitoring and responding to health risks posed by climate change and ensuring timely interventions and adaptations based on accurate, localized data.
- 3. A **social return on investment** evaluation is recommended in order to emphasize the advantages of projects to policymakers, thereby obtaining long-term funding for heat and climate change related efforts.

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