

## GENETIC RESEARCH AMONG INDIGENOUS PEOPLES

In 2021, a study entitled “Genomic Characterization of the Filipino People” involving researchers from a European institution was published in a leading journal. This caused a furor in the scientific community (3)

As far back as 2015, the Chairperson of the National Commission on Indigenous Peoples (NCIP) issued a Memorandum Order [1] to provide an advisory to all NCIP Regional Directors that the study concerned failed to obtain ethical approval from the National Ethics Committee (NEC). Despite the lack of proper approvals, the researchers continued their study in indigenous communities.

In 2017, the Philippine Health Research Ethics Board (PHREB) issued Memorandum 2017-001 to research ethics committees, Filipino and foreign research institutions conducting research involving indigenous communities in the Philippines. This memorandum summarized policies and regulations regarding research involving Indigenous peoples, for “a shared understanding and consistent implementation” among all interested parties [2], to guide researchers, both foreign and local, on Philippines requirements for human research.

In view of the censure from the 2015 memorandum, the NCIP issued a statement condemning the conduct of research [4] on April 20, 2021. The NCIP reportedly complained to the journal and to the Office of Research Integrity of the foreign research institution, reiterating its’ five demands :

1. To stop using the data derived from the analysis of Philippine samples that had been unethically collected
2. Removal of all genetic data from all databases, including those already shared with other groups
3. Destruction of these samples to be overseen by a designated member of the NCIP delegation in Sweden
4. Issuance of a public apology to the Filipino people, specifically the indigenous communities involved,
5. To take down all related publications including those shared in social media ecosystem.

Apparently, the journal and the Office of Research Integrity decided in favor of the researchers, based on documents that were submitted by the researchers including an ethical endorsement from a Philippine government agency that had no mandate to issue ethical approvals for genomics research.

International interest increased which resulted in two opinion articles: “The Philippines Controversy and the Pitfalls of International Genomics Research” [5] and “Genomics’ Ethical Gray Areas Are Harming the Developing World” [6], in January and February 2022, respectively. These two articles highlighted that **“The international scientific community must be proactive in raising the standards of global research ethics,”** and that **“prestigious journals should ensure that researchers who collect human DNA samples make every effort to secure formal ethics approvals in the countries where the sample collection is performed.”**

## References

- [1] <https://ethics.healthresearch.ph/index.php/phoca-downloads/category/39-national-commission-on-indigenous-peoples-ncip#>
- [2] <https://ethics.healthresearch.ph/index.php/phoca-downloads/category/1-memorandum>
- [3] <https://www.pnas.org/content/118/13/e2026132118/tab-article-info>
- [4] <https://www.facebook.com/NCIPportal/posts/3357569147802777>
- [5] <https://science.thewire.in/the-sciences/uppsala-study-philippines-population-genetics-pitfalls-international-genomics-research/>
- [6] <https://undark.org/2022/02/24/genomics-ethical-gray-areas-are-harming-the-developing-world/#>

## QUESTIONS

1. Given the scenario above, how are the three bioethics principles relevant and in what ways were they violated? Grp 1 – Autonomy                      Grp 2 – Beneficence                      Grp3 - Justice
2. Comment on the scientific and ethical acceptability of the research based on the results reported in the research article.
3. What weaknesses in the system (local and international) are implied by the case? Which parties should address these weaknesses? Suggest corrective and preventive actions.