

Genome-wide association studies in developing countries raise important new ethical issues

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Typically conducted in richer, developed countries but now increasingly done in the developing world, genome wide association (GWA) studies raise a host of ethical issues that must be addressed, argues a Policy Forum article published this week in *PLoS Medicine*.

Among the most pressing ethical issues is the release of data, says Michael Parker of the University of Oxford and his colleagues, who highlight the importance of developing policies and procedures for data release appropriate to GWA studies in developing countries. To highlight the practical ethical issues, they describe the development of a GWA data-release policy for the Malaria Genomic Epidemiology Network (MalariaGEN), a partnership of malaria researchers in over 20 countries supported by the Grand Challenges in Global Health initiative.

Several ethical concerns are apparent in data release of GWA studies, say the authors: privacy, whether anonymity can be guaranteed, security, the implications of collecting and storing vast amounts of data and about its uncertain future use, the implications of data release for populations, and for family members of participants, the need to strike a proper balance between research and protection, the development of appropriate governance mechanisms, the implications for trust, consent, and autonomy, commercialization, and the ethical importance of the sustainability of databases and of emerging scientific capacity in developing countries.

To address these concerns, MalariaGEN developed a "managed" approach to oversee open access, define acceptable uses of data, and guide the timing of data release.

"It is our view that an ethical data-release policy must, in addition to providing adequate protections for research participants and their communities, be combined with adequate protections for the research aspirations of developing country scientists and with capacity-building activities to ensure that those aspirations have the potential to be realized," say the authors.

More information: Parker M, Bull SJ, de Vries J, Agbenyega T, Doumbo OK, et al. (2009) Ethical Data Release in Genome-Wide Association Studies in [Developing Countries](#). PLoS Med 6(11): e1000143. [doi:10.1371/journal.pmed.1000143](https://doi.org/10.1371/journal.pmed.1000143)

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