

Review of: "Responsible Governance of Genomics Data and Biospecimens in the Context of Broad Consent: Experiences of a Pioneering Access Committee in Africa"

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Greetings, authors.

Thank you for sharing this informative case study on the potential benefits of genomic research on the African continent and the real challenges of ensuring responsible governance of community resources.

Please find below a point on the framing of benefits in the context of H3Africa aimed at enriching the discussion.

In the description of conditional approval of applications, you refer to section 6 of the DAR application form, which requires applicants to “justify the benefits to Africa and particularly how the proposed use of data and specimens could improve the health of the African population” (p. 8, 2nd to the last paragraph, under *Decisions on the requests*). There has been much written in ethics scholarship noting how complicated framing research benefits can be for individual participants in low-resource settings (e.g., at what point does compensation become coercive?). Given the collective impact of data use on vulnerable groups (last paragraph of p. 10), it would be useful to comment on what “benefits to Africa” means from a group perspective. Groups can be demographically or legally defined, but given the nature of genomic research, it is especially relevant from an ethics perspective to consider benefits (and risks) in terms of groups made up of genetically related persons. In the African context, this would involve discussing, at least, pre-colonial socio-political collectives currently existing within postcolonial African states. A possible framing for the discussion is the concept of “peoples” as used in international human rights law (e.g., African Charter on Human and Peoples’ Rights, United Nations Declaration on the Rights of Indigenous Peoples, United Nations Charter), in which the analysis of rights and interests extends to such collectives. There is also a growing literature on the governance of Indigenous Peoples’ data that shows how a concern for collective priorities and concerns can shape discussions about the ethical use of data (e.g., Maori Data Sovereignty and Privacy, https://www.waikato.ac.nz/assets/Uploads/Research/Research-institutes-centres-and-groups/Institutes/Te-Ngira-Institute-for-Population-Research/MDSov-and-Privacy_20March2023_v2.pdf). It would be informative to hear whether/how the DBAC is able to incorporate the considerations of sub-national communities in its decision-making (including about benefits).

Whether or not “peoples” is useful as a concept, this comment urges you to acknowledge or speak to the gap in discussions about research benefits that presume individual citizenship in modern nation-states. More specifically, the individualist model frames research benefits at a national (or continental, i.e., “health of the African population”) scale



without considering factors (e.g., colonialism, minority status, marginalization) that can affect the ability of sub-national socio-political collectives to benefit meaningfully from genetic research that uses resources from their communities. Does the DBAC operate under more specific guidelines for determining what counts as benefit and in relation to whom? Speaking to the gap will help address the observation that large-scale, externally funded projects like H3Africa are hard-pressed to offer benefits in a meaningful and localized way to the Africans who participate in such ventures.

Thank you for the enlightening piece and the opportunity to contribute to the conversation you have started.