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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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Potential competing interests: I would like to mention that I know personally the first Author. I accepted to comment on this manuscript because I understood that Qeos seeks as many comments as possible on submitted manuscripts, so that to allow their possible enrichments. In this case, there would be no conflict of interest in reviewing the manuscript. If this is not true, I apologize for accepting to comment on this manuscript and ask you to discard the following review. No potential competing interests to declare.

General comments on the manuscript entitled:

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

By Ahmed Rebai, Akin Abayomi, Pamela Andanda, Daima Bukini, Robyn Kerr, Kobus Herbst, Jenniffer Mabuka, Rosalyn Wamuyu, Collet Dandara

-The manuscript deals with an extremely sensitive and important topic related to data protection.

On one hand, the data should be accessible for academic research in order to accelerate findings to better deal with health problems and human evolution understanding, and on the other hand, data should be protected against abuse, be it related to business or ethics, ensuring that research respects human and legal principles.

Before going into the use of data, the authors should first clearly define how they consider these two constraints in a general framework, not necessarily specific to Africa.

The limits between the two alternatives are too sharp and should be clearly presented before going into managerial/administrative aspects for allowing access to data.

-It should be noted that genome data protection is not specific to Africa but concerns many other minorities, including Australian and American indigenes, among others.

-Ancient DNA/ancient genomes are not mentioned in this manuscript.

-What about possible conflicts between this committee's rules and local national sovereignty in handling local data?

-It is not clear who the potential readers are to whom the manuscript is intended, probably limited to potential researchers interested in using these data? In this case, the organization's website is most appropriate to reach these researchers?

Otherwise, the authors should develop hints/ideas of general interests that might be helpful for wider groups of scientists interested in the data or in setting up similar organizations.

-In my opinion, seeking fair collaboration is more appropriate than controlling data access.

-It should be reminded that without free access to the many data repositories (as, for example, ncbi, ebi, ddbj, and institutional/projects genome databases,...), genomics will not be so worldwide developed.

-In conclusion, the manuscript needs a deep revision that takes care of at least all the above notes.

-I hope these comments will help the authors to revise their manuscript.

General notes when reading the manuscript:

-The manuscript is hard to read.

-The data under scrutiny are not clearly presented.

-The context in which access to data should be controlled is not presented.

-Given that access to data is fundamental for scientific development, why should access be controlled? This should be clearly explained and presented.

-Abstract: It is not stated why the “access governance framework established under the Human, Heredity, and Health in Africa (H3A) consortium…” is established?

-The context of data accessibility control should be clearly developed and justified.

Introduction :

Generating genomic data from African populations has a significantbenefit to the broader scientific community...

“Benefit” is an ambiguous term; “interest” would be more appropriate.

-“Whilst it is in the best interests of Africans and their health that genomic data be accessible to researchers and health care professionals across the global community, access needs to be both facilitated and controlled.” Why controlled?

-Access to genomics data can be regulated via three possible approaches:

-Unrestricted or public access

-Registered access

-Controlled access

For the sake of clarity, examples of the three approaches should be given with corresponding organisms.

Before going into access details, the authors should first introduce the kind of data that is collected, from where and why, as well as the objectives of controlling access to these data.

The authors should introduce first why genomic data access should be controlled.

-In my opinion, data access should be free and without control for academic research.

The only reason that should justify data access control is the possible abuse or for financial gain.

All other reasons should be rather discussed and coordinated so as to allow research advances.

-Note that not only in Africa is data access control set up, but also in Australia with indigenous people, the Inuit, and indigenous people in America.

For example, in two genomic studies presented in:

Nogrady, Bianca (2024). Australian Indigenous genomes are highly diverse and unlike those anywhere else.*Nature* **625**, 15-16 (2024)

https://doi.org/10.1038/d41586-023-04006-1

p. 3: CIOMS: Council for International Organizations of Medical Sciences

p. 3: DBAC? Data and Biospecimen Access Committee ? (indicated only p. 6, Fig. 1)

p. 7: The key issues that required significant discussion

Points 1, 2, and 3 OK, but were these points the final output/final agreement?

p. 7: Origins of the requests

Any comment about the requests?

p. 7: Is it necessary to mention the secretarial work?

p. 8: Rejection

Comment on the rejection reasons?

-Supra national status of the organization?

What about the national scientific/political decisions about the free availability of the data for academic research?

-“Whilst it is in the best interests of Africans and their health that genomic data be accessible to researchers and health care professionals across the global community, access needs to be both facilitated and controlled.”

The Authors recognize the importance of facilitating access to data, then indicate how to control it (or its use) by indicating different ways of accessing the data.

The Authors should discuss first the data that might be controlled and the reasons for this control. Is it solely about genomic data?

The Authors should give their opinion about data retention and its consequences on scientific research, particularly related to medical research and human health.

-It is important for the comprehension of the manuscript to detail these reasons and why to undertake control about the African data?

-Is it about samples for genomic studies?

Major comments:

-Add “doi” to ease access to references.

Minor comments:

-Line numbering to ease commenting.

-Although ~~T~~ there has been some,.... ,~~but~~ the impact of these,...

-The experience we describe in this paper is~~of an~~ about access governance framework established under the Human,

-..fostering the development of bioinformatics ...

Some suggested references:

See recent opinion:

Cameron John Sabet, Simar S. Bajaj, and Fatima Cody Stanford (2024). Community Review Boards offer a path to research equity. PNAS. 121 (19) e2320334121.

https://doi.org/10.1073/pnas.2320334121

Callaway, E. (2012). Hunter-gatherer genomes a trove of genetic diversity. *Nature.*

https://doi.org/10.1038/nature.2012.11076

Sequences from African groups offer genetic clues about disease, height and ancient human breeding.

Nordling, L. (2017). How the genomics revolution could finally help Africa.*Nature* **544**, 20–22.

https://doi.org/10.1038/544020a

New investments promise to get precision medicine and precision public health off the ground. But experts debate how much work needs to be done first.

Nordling L. (2018). African scientists call for more control of their continent’s genomic data.

https://doi.org/10.1038/d41586-018-04685-1

Voluntary guidelines aim to combat ‘helicopter’ science and ensure that studies benefit African citizens and scientists.

Researchers have begun sequencing the genomes of Africans in large numbers. The data offer insights into humanity’s past as well as predisposition to disease and potential reactions to drugs in African populations.