## Open research, biobanking and building public trust in genomics research at H3Africa

How a governance framework for genomics research and biobanking impacted policy and practice in Africa

Funded by the African Academy of Sciences, the National Institutes of Health, and Wellcome, and published on F1000's Open Research Africa Platform, H3Africa's <u>Framework for Best Practice for Genomics Research</u> and Biobanking In Africa provides ethical, equitable, and open guidance that has been adopted throughout the continent:



World Economic Forum (WEF) framework for genomic data policy

National health research ethics guidelines for Ethiopia, Uganda, & South Africa



30+ publications on genomics & biobanking research

## **Open research enables:**



Researchers and their peers to be able to rapidly **build on findings** 

Policies and practices

to utilize, and build on,

an evidence base

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Policymakers to have **fast access to data and research** 



The public to **see** research results that affect them



## Impact of publishing the Framework as open research

Speed and equity were decisive factors in publishing the Framework as open research. One of the Framework's authors, Dr Jantina de Vries (Associate Professor in Bioethics, the Department of Medicine, University of Cape Town) described Open Research Africa's "no lag" publication and the speed by which the text can be read and used by others as being "really important for us."

Another consideration in publishing openly was to make the Framework accessible to all, ensuring, in another author's words, Mr Aminu Yakubu (VP Research Planning and Ethics, 54gene), "that it was not published on a platform that in any way inhibits any African in any part of the world from accessing the document." Institutions or individuals were not blocked from accessing the Framework if they could not afford subscriptions and for Dr Jantina de Vries and the H3Africa team, this openness was a driver for change:

This model of **open research publishing** is obviously important if what you want to do is **affect change in the South or in Africa** and we want this document to be generally available to all ethics committee members in all institutions across the continent.

- Dr Jantina de Vries



## Creating the framework for genomics research and open research publishing: equity in action for African researchers and African people

A central tenet of **F1000**'s open research model is recognition of, and engagement with, all researchers and research contributions, from data notes to ethical frameworks. This two-way principle, whereby research is accessible, and researchers can build on all research outputs (whether their own or others,) is seen in the real-world application and impact of H3Africa's Framework, from WEF's genomic data policy to the smaller research projects targeting specific diseases. The subsequent drafting of the Framework kept in sight the need for continued engagement with research and policy communities across Africa while keeping focus on H3Africa's end goal of fostering genomics research – and the precision science and medicine it enables – to benefit African societies.

One thing that is **unique about this document** is that it was a document that was **developed by Africans for Africa**.

- Mr Aminu Yakubu









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