

Biospecimen, Biobanking and Data Governance in Africa



Policy Brief

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Key Messages

- ✓ Biobanks are specialised facilities or repositories that store and manage a large collection of biospecimens, such as blood, tissue, cells, DNA, and RNA.
- ✓ They play a crucial role in health research and public health initiatives, enabling tailored and context-specific health services for the African continent.
- ✓ Concerns over informed consent and privacy in the collection and use of biospecimens should be addressed to support the use of biobanks in improving health outcomes.
- ✓ Harmonised governance and regulatory frameworks across the continent can ensure the protection of African citizens in biospecimen collection, transfer and use.

Context

Biospecimens are biological samples derived from living organisms such as humans, animals, or plants, which hold significant potential for scientific and medical research. They include blood, tissue, DNA, and proteins. They are collected, processed, and analysed to better understand health, disease, genetics, and physiology. They also facilitate critical research that enhances understanding of diseases, supports personalised medicine, and contributes to drug development and clinical diagnostics.

Biobanks, which amass large collections of biological samples along with associated data, are vital for biomedical research, clinical trials, and epidemiological studies. They not only provide invaluable resources for local researchers to conduct studies on health disparities and disease prevalence, but also enable African scientists to lead initiatives that align with the health



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needs of the local communities. Increased research in the use of biospecimens and biobanks can enhance healthcare delivery in Africa.

Methodology

The data and other information used to compile this brief were drawn from a review of existing sources, including scholarly and conference papers, books and reports, newspapers and reputable online literature. The brief also used information gathered during meetings with experts on emerging technologies convened by the African Institute for Development Policy (AFIDEP) and the African Union Development Agency (AUDA-NEPAD) in August, September and October 2024. The meetings included the emerging health technologies expert meeting, biannual statutory meeting for the African Union High Level Panel on Emerging Technologies (APET) and a Regional Dialogue on Leveraging Emerging Technologies to Improve Healthcare Delivery Systems in Africa.

Findings

In Africa, biobanks are important for several reasons. They support precision medicine by facilitating tailored healthcare solutions based on genetic and environmental factors. They also contribute to local capacity building, empowering African scientists and enhancing the overall public health landscape. Biobanks can significantly improve healthcare equity across the continent by helping to address health disparities and fostering ethical frameworks.

Some examples of biobanks established in Africa include the following:

- The Human, Heredity and Health in Africa (H3Africa) research initiative studies the genetic and environmental factors contributing to health and disease in African populations. The H3Africa Biobank Network includes multiple biobanks located in various African countries that collect and store biospecimens for genetic and genomic research.

- The South African National Cancer Biobank collects and stores biospecimens from cancer patients in South Africa, to support cancer research, biomarker discovery, and personalised medicine.

- The East African Consortium for Clinical Research Biobank collects biospecimens from patients participating in clinical research studies across the East African region and supports multidisciplinary research on infectious diseases, non-communicable diseases, and other health priorities in the region.

- The Nigerian Institute of Medical Research Biobank supports research on infectious diseases, genetic disorders, maternal and child health, and other health challenges facing Nigeria and West Africa in general.

- The Moroccan Human Biobank collects and stores biospecimens from Moroccan individuals for biomedical research and clinical applications.

- The African Genome Variation Project (AGVP) Biobank collects and store biospecimens, including blood samples and DNA, from diverse populations across Africa, with detailed demographic, clinical, and phenotypic data, allowing researchers to study the genetic and environmental factors influencing health and disease in African populations.

However, the operation of biobanks in Africa faces various challenges and controversies, particularly regarding informed consent, data privacy, and the potential for exploitation of local communities. Ethical governance structures are vital to ensure that biospecimens are collected and used transparently and responsibly, respecting the rights of participants and protecting sensitive information. Furthermore, a lack of harmonised regulations can lead to inconsistencies across nations, complicating compliance and collaboration.

To navigate these challenges effectively, there is a pressing need for comprehensive ethical and legal frameworks that outline the rights and protections of all stakeholders

involved in biobanking efforts. Governance structures surrounding biobanks must prioritise ethical standards, informed consent, and data privacy. Additionally, biobank initiatives should foster collaboration and capacity building to strengthen the healthcare infrastructure in Africa, and promote equitable access to research benefits, and ultimately improve health outcomes for diverse populations.

The future of biobanking in Africa hinges on advancing research that leverages biospecimens to address pressing health issues. Key focus areas include disease surveillance for infectious and chronic diseases, genomics

for personalised medicine, and research into maternal and child health, cancer, and mental health disorders. African nations can ensure that biobanks fulfil their scientific objectives by investing in monitoring systems, capacity building, and community engagement, and that they also align with the cultural values and needs of local populations. A proactive, inclusive approach to biobanking has the potential to significantly enhance health outcomes and elevate the medical research landscape in Africa, contributing to global health knowledge and equity.

Policy Recommendations

Polymakers in Africa should consider and act of the following recommendations to advance establishment of biobanks and governance of biospecimens in the region:

1.

Establish clear regional and national legal frameworks that govern the collection, storage, and use of biospecimens, including laws, regulations, and policies that define the rights and responsibilities of researchers, biobanks, participants, and other stakeholders.

2.

Develop and implement institutional policies that govern the operations of biobanks, including procedures for sample collection, processing, storage, and sharing; data management and access; quality assurance and control; governance and oversight; and stakeholder engagement.

3.

Establish transparent governance structures that define roles, responsibilities, and decision-making processes within biobanks, including ethics committees, scientific advisory boards, data access committees, and community engagement forums.

4.

Develop and implement comprehensive ethical guidelines that outline the principles, standards, and procedures for the ethical conduct of biobanking activities.

5.

Implement robust data security and privacy measures to protect the confidentiality, integrity, and security of biospecimen data, including encryption, access controls, data anonymization, and data sharing agreements.

6.

Provide training and capacity-building programmes for researchers, biobank staff, ethics committee members, and other stakeholders involved in biobanking activities to enhance their knowledge, skills, and competencies in ethical, legal, and operational aspects of biobanking.

7.

Engage with diverse stakeholders, including researchers, participants, community representatives, policymakers, and regulatory authorities, to ensure that biobanking activities are aligned with the needs, priorities, and expectations of the populations they serve.

Conclusion

Advancing biospecimen, biobank, and data governance in Africa requires a holistic and proactive approach that prioritises ethical conduct, community engagement, data integrity, and capacity-building in research collaborations. By promoting ethical, responsible, and inclusive utilisation of biospecimens and biobanks, researchers, policymakers, and stakeholders can contribute to the advancement of science, healthcare, and societal well-being in Africa and beyond.

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