

Data Sharing in Nigerian Genomics: Addressing Legal Fragmentation and Ethical Dilemmas

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Abstract

This study examined the legal and ethical challenges associated with genomic data sharing in Nigeria with focused on issues of consent, privacy, data ownership and international collaboration. Using doctrinal method, the study reviewed scholarly literature, national policies, institutional practices and international instruments to identify gaps in genomic data sharing. The study assessed the adequacy of existing frameworks including constitutional privacy protections under Section 37, the National Information Technology Development Agency (NITDA) guidelines, the Freedom of Information Act, the National Biosafety Management Agency (NBMA) Act and ethical directives of the National Health Research Ethics Committee (NHREC). These were situated in the wider context of African genomic initiatives such as H3Africa. Findings revealed fragmented regulations, legal ambiguities, infrastructural weaknesses and ethical dilemmas surrounding informed consent, community engagement and equitable benefit sharing. These limitations heightened risks of misuse, constrained data protection and restricted Nigeria effective participation in global genomic collaborations. The study recommended harmonisation of legislation, development of culturally adapted consent practices, investment in biobanking infrastructure, capacity building and establishment of stronger oversight institutions. Strengthening ethical system, fostering transparency and deploying secure technological tools were concluded to be essential for advancing responsible genomic research and safeguarding public trust in Nigeria.

Keywords: Nigeria, Genomics, data sharing, legal framework, ethical challenges, biobanking

Introduction

Over the past decades, genomic medicine transformed from a primarily research-oriented discipline into a cornerstone of precision healthcare, reshaped both clinical practice

and public health strategy. The sequencing of the human genome, completed in 2003 after the draft release in 2001, presented a new era in biomedical sciences by offering unprecedented Perspectives into the genetic composition of complex diseases and creating a foundation for integrating molecular data into routine medical decision-making.¹ This milestone enabled predictive and preventive healthcare frameworks in which diagnosis, treatment and prophylaxis could be tailored to an individual genomic profile. High-throughput sequencing technologies, together with advanced bioinformatics and biostatistics, facilitated large-scale studies of human genetic variation, producing extensive datasets that now underpin translational research in oncology, infectious diseases, pharmacogenomics and rare genetic disorders.² Genomic data thus emerged as both a scientific and economic resource, shaping national health priorities and influencing global health policies.³

The public health relevance of genomics is particularly significant in areas contending with the dual burdens of infectious and non-communicable diseases. By identifying genetic determinants of disease susceptibility, genomic medicine enabled population-level stratification, allowing policymakers to strengthen surveillance systems, design anticipatory interventions and optimize therapies based on population-specific profiles.⁴ In sub-Saharan Africa and Nigeria in particular, genomics advanced understanding of host-pathogen interactions, informed detection of drug resistance variants and guided vaccine and therapeutic development.⁵ Genomic epidemiology proved essential during the Ebola and COVID-19 outbreaks, with sequencing technologies enabling real-time pathogen tracking, outbreak source identification and global coordination of containment strategies.⁶ Beyond infectious diseases, genomics also supported stratified approaches to cardiovascular disorders, metabolic syndromes and cancers, underlining its dual scientific and policy relevance for Nigeria as a unique environment for genomic research considering its population size and unparalleled genetic diversity, described as among the most heterogeneous globally due to deep ancestral lineages.⁷ This diversity is vital for correcting the historical underrepresentation of African genomes in global datasets, which has implications for scientific discovery and equitable healthcare translation.⁸ Despite its potential, genomic medicine in Nigeria has been limited by infrastructural deficits, fragmented research efforts and the absence of a harmonized regulatory framework for data collection, storage and sharing.⁹

Nonetheless, institutions such as the African Centre of Excellence for Genomics of Infectious Diseases (ACEGID), the Nigerian Institute of Medical Research (NIMR) and the National Biotechnology Development Agency (NABDA), along with professional networks

¹ Collins; F.S.; Green; E.D.; Guttmacher; A.E.; Guyer; M.S.; “A vision for the future of genomics research”; 422; (2003); *Nature*; 835-847.

² Manolio; T.A.; Abramowicz; M.; Al-Mulla; F.; Anderson; W.; Balling; R.; Ginsburg; G.S.; “Global implementation of genomic medicine: We are not alone”; 11; (2019); *Science Translational Medicine*; eaat5014.

³ Shabani; M.; Knoppers; B.M.; Borry; P.; “From the principles of genomic data sharing to the practices of data access committees”; 23; (2015); *European Journal of Human Genetics*; 1553-1559.

⁴ Khoury; M.J.; Iademarco; M.F.; Riley; W.T.; “Precision public health for the era of big data”; 50; (2016); *American Journal of Preventive Medicine*; 398-401.

⁵ Olunwa; N.J.; Uduak; J.; Okafor; E.I.; Happi; C.T.; “Genomics and infectious disease surveillance in Africa: Advances and prospects”; 13; (2022); *Frontiers in Genetics*; 879231.

⁶ Happi; C.T.; Ugwu; C.A.; Olunwa; N.J.; “Genomic surveillance of COVID-19 in Africa: A new public health paradigm”; 8; (2020); *The Lancet Global Health*; e1003-e1004.

⁷ Tishkoff; S.A.; Reed; F.A.; Friedlaender; F.R.; Ehret; C.; Ranciaro; A.; Williams; S.M.; “The genetic structure and history of Africans and African Americans”; 324; (2009); *Science*; 1035-1044.

⁸ Fatumo; S.; Yakubu; A.; Oyedele; O.; Adebamowo; C.; “Promoting equitable global genomics: lessons from Nigeria”; 54; (2022); *Nature Genetics*; 12-15.

⁹ Yakubu; A.; Tindana; P.; Matimba; A.; Littler; K.; Munung; N.S.; “Model framework for governance of genomic research and biobanking in Africa”; 3; (2018); *BMJ Global Health*; e001276.

such as the Nigerian Bioinformatics and Genomics Network (NBGN), have built foundational capacity in research, training and advocacy.¹⁰ Nigeria participation in international consortia, especially the Human Heredity and Health in Africa (H3Africa) initiative, has expanded access to advanced sequencing, biobanking infrastructure and collaborative platforms, strengthening its contribution to the global genomic knowledge economy.¹¹ Despite these advances, Nigerian legal and ethical frameworks for genomic data governance remain inadequate. Constitutional provision under Section 37 of the 1999 Constitution recognize the right to privacy but do not address the unique vulnerabilities of genomic data, including its familial implications and potential identifiability across generations.¹²

The Nigerian Data Protection Regulation (NDPR) of 2019, modeled after the European Union General Data Protection Regulation (GDPR), marked an initial step toward comprehensive data protection and focused mainly on conventional personal information, leaving gaps in cross-border data transfer and accountability for genomic research.¹³ Other instruments, such as the National Health Act (2014), the National Code of Health Research Ethics¹⁴ and institutional review framework, provide general biomedical oversight but lack specific provisions for secondary data use, return of results and biobank governance. Informed consent remains problematic, as most participants lack understanding of long-term implications when contributing genomic data.¹⁵ The familial nature of genomic information risks inadvertent disclosure of sensitive details, such as predispositions to disease or kinship structures, raise potential for discrimination in employment, insurance, or social contexts.¹⁶ Broad consent practices often conflict with Nigeria socio-cultural norms, where communal decision-making and extended family influence research participation, underscoring the need for context-specific ethical frameworks.¹⁷ Addressing these concerns requires a nuanced framework that balances scientific innovation with individual and community protections. Conversely, the GDPR adequacy framework and Canada accountability-based Personal Information Protection and Electronic Documents Act (2000) provide useful benchmarks.¹⁸ Against this backdrop, this study examined Nigeria legal and ethical challenges in genomic data sharing, situating them in global bioethical and data sovereignty debates.

Genomic Medicine: An Overview

The development of genomic medicine has been shaped by scientific breakthroughs, technological innovation and translational ambition, fundamentally transforming biomedical

¹⁰ Gire; S.K.; Goba; A.; Andersen; K.G.; Sealfon; R.S.; Park; D.J.; Sabeti; P.C.; “Genomic surveillance elucidates Ebola virus origin and transmission during the 2014 outbreak”; 345; (2014); *Science*; 1369-1372.

¹¹ H3Africa Consortium; “Enabling the genomic revolution in Africa”; 344; (2014); *Science*; 1346-1348.

¹² Olatunji; O.; “The constitutional right to privacy in Nigeria: Lessons from comparative perspectives”; 19; (2019); *African Human Rights Law Journal*; 324-343.

¹³ Adeniran; A.I.; “Data protection in Nigeria: An appraisal of the Nigeria Data Protection Regulation 2019”; 40; (2021); *Computer Law & Security Review*; 105525.

¹⁴ Federal Ministry of Health; *National Code of Health Research Ethics*; Garki-Abuja; 2007. http://nhrec.net/nhrec/wp-content/uploads/2018/10/NCHRE_Aug_07.pdf, accessed July 28, 2025.

¹⁵ De Vries; J.; Bull; S.J.; Doumbo; O.; Ibrahim; M.; Mercereau-Puijalon; O.; Kwiatkowski; D.; Parker; M.; “Ethical issues in human genomics research in developing countries”; 12; (2011); *BMC Medical Ethics*; 5.

¹⁶ Nnamuchi; O.; “Biobank/genomic research in Nigeria: Examining relevant privacy and confidentiality frameworks”; 43; (2015); *Journal of Medical Ethics*; 776-904.

¹⁷ Tindana; P.; Molyneux; C.S.; Bull; S.; Parker; M.; “Ethical issues in the export, storage, and reuse of human biological samples in biomedical research: Perspectives from low- and middle-income countries”; 20; (2019); *BMC Medical Ethics*; 76.

¹⁸ Heyder; M.; “The APEC cross-border privacy rules now that we’ve built it, will they come?”; *International Association of Privacy Professionals*; 2014; <https://iapp.org/news/a/the-apec-cross-border-privacy-rules-now-that-weve-built-it-will-they-come>, accessed July 28, 2025.

research and clinical practice. Early origins in Mendelian genetics and the discovery of the DNA double helix in 1953 established the conceptual basis for molecular biology. The Human Genome Project (HGP), completed in 2003 after the draft publication in 2001, marked a transformative milestone by providing not only a reference sequence but also a platform for interrogating the molecular basis of complex traits, disease susceptibility and therapeutic targets with unprecedented precision.¹⁹ This achievement catalysed high-throughput sequencing, robust bioinformatics and international consortia, accelerating genomic data generation, analysis and application. As genomic technologies matured, applications expanded beyond monogenic disorders to encompass complex polygenic conditions, including cardiovascular disease, diabetes, cancer and neurodegenerative disorders. Next-generation sequencing (NGS), genome-wide association studies (GWAS) and multi-omics approaches enabled the dissection of complex biological pathways and disease phenotypes.²⁰

Precision medicine emerged, repositioning genomics as a clinical and public health imperative by integrating molecular observations into diagnostic, prognostic, therapeutic and preventive strategies.²¹ In oncology, identification of tumour-specific mutations supported targeted therapies such as tyrosine kinase inhibitors and immune checkpoint modulators, as well as molecular diagnostics, moving beyond uniform therapeutic regimens.²² In infectious diseases, genomic sequencing became essential for outbreak monitoring and antimicrobial resistance surveillance. During the 2014 Ebola outbreak and the COVID-19 pandemic, near real-time sequencing enabled pathogen tracking, outbreak source identification and coordination of containment strategies.²³ Pharmacogenomics further demonstrated how genetic variability influences drug metabolism and efficacy, improving dosing, reducing adverse drug reactions and enhancing outcomes.²⁴ The rapid expansion of genomic medicine also prompted ethical, legal and socio-political debates. Genomic data are sensitive, identifiable and longitudinally informative, raising concerns about privacy, consent, discrimination and equitable benefit-sharing.²⁵ Their predictive and familial implications sparked debates over “genetic exceptionalism” the idea that genomic data require unique regulation.²⁶

In the United States, the Genetic Information Nondiscrimination Act (GINA) attempted to address such issues, yet it has been criticised as inadequate and overly narrow.²⁷ Globally, disparities persist between high-income countries that have integrated genomic medicine into clinical workflows and low- and middle-income countries (LMICs) limited by infrastructure, regulation and funding.²⁸ In Africa, the Human Heredity and Health in Africa (H3Africa) consortium, launched in 2010, sought to counteract underrepresentation of African genomes by building capacity, biobanks and bioethics frameworks.²⁹ Institutions such as the African

¹⁹ Collins (n 1)

²⁰ McCarthy; M.I.; Abecasis; G.R.; Cardon; L.R.; Goldstein; D.B.; Little; J.; Ioannidis; J.P.A.; Hirschhorn; J.N.; “Genome-wide association studies for complex traits: consensus, uncertainty and challenges”; 9; (2008); *Nature Reviews Genetics*; 356-369.

²¹ Manolio (n 2).

²² Garraway; L.A.; Verweij; J.; Ballman; K.V.; “Precision oncology: an overview”; 31; (2013); *Journal of Clinical Oncology*; 1803-1805

²³ Happi (n 6).

²⁴ Relling; M.V.; Evans; W.E.; “Pharmacogenomics in the clinic”; 526; (2015); *Nature*; 343-350. Rothstein; M.A.; “GINA at ten and the future of genetic nondiscrimination law”; 48; (2018); *Hastings Center Report*; 5-7.

²⁵ Naveed; A.; et al.; “Privacy and ethical challenges in genomic data”; 16; (2015); *BMC Medical Ethics*; 70-81

²⁶ Evans; B.J.; Burke; W.; “Genetic exceptionalism and policy: Implications for genomic data sharing”; 36; (2008); *The Journal of Law, Medicine & Ethics*; 703-713

²⁷ Oppenheimer; B.; Bayer; R.; “Ethical challenges in global health research”; 90; (2009); *Health Policy*; 236-242

²⁸ Adebamowo; C.; Yakubu; A.; Fatumo; S.; Agwale; S.; “Genomics and health equity in Africa: Challenges and opportunities”; 19; (2018); *BMC Medical Ethics*; 45-57

²⁹ H3Africa Consortium (11).

Centre of Excellence for Genomics of Infectious Diseases (ACEGID) have advanced pathogen surveillance, training and sequencing, positioning the country as a continental leader.³⁰ The post-HGP era also ushered in integrative multi-omic approaches transcriptomics, proteomics, metabolomics and epigenomics enabling a systems-level understanding of disease aetiology and progression.³¹ These methods underpin precision strategies tailored to individual molecular profiles, improving clinical specificity.³²

Advances in computational infrastructure, cloud platforms and interoperable databases facilitated management of increasingly large and complex datasets, enhancing reproducibility and enabling longitudinal research.³³ Systems biology further integrated genetic, environmental and behavioural determinants of health, underscoring the complexity of genomic medicine.³⁴ Adoption of the FAIR principles Findable, Accessible, Interoperable, Reusable enhanced dataset harmonisation, while federated infrastructures such as VODAN and TWOC balanced data utility with privacy protection;³⁵ demonstrating how international genomic collaboration aligns with ethical and legal statutory requirements while advancing global health.³⁶

Data Sharing in Genomics: Global Perspectives

The emergence of genomic research in the twenty-first century transformed biomedical science, positioning the systematic collection, analysis and dissemination of genetic data as central to discovery and precision medicine. Genomic data sharing became indispensable for collaborative research across institutions and nations, while raising ethical, legal and social issues concerning autonomy, privacy and equitable benefits. International initiatives such as the Global Alliance for Genomics and Health (GA4GH) and Human Heredity and Health in Africa (H3Africa) established harmonised frameworks on consent, governance and oversight.³⁷ GA4GH developed normative and technical tools for interoperability, access control and transparent governance, while stressing participant rights and equitable benefit-sharing.³⁸ H3Africa localised these principles, promoting ownership, capacity building and culturally sensitive ethics to counter historical underrepresentation of African genomes.³⁹

The FAIR principles; Findable, Accessible, Interoperable and Reusable emerged as an operational standard for maximising utility without compromising ethics.⁴⁰ Findability relies on persistent identifiers, metadata and indexing, ensuring discoverability while protecting

³⁰ Gire (n 10).

³¹ Wilkinson; M.D.; Dumontier; M.; Aalbersberg; I.J.; Appleton; G.; Axton; M.; Baak; A.; Mons; B.; “The FAIR Guiding Principles for scientific data management and stewardship”; 3; (2016); *Scientific Data*; 160018

³² Beyan; O.; Choudhury; A.; van Soest; J.; Kohlbacher; O.; Zimmermann; L.; Stenzhorn; H.; Dekker; A.; “Distributed analytics on sensitive medical data: The personal health train”; 2; (2020); *Data Intelligence*; 96-107. Bonino da Silva Santos; L.O.; “Multi-omic integration in precision medicine”; 26; (2020); *Trends in Molecular Medicine*; 435-448.

³³ Landi; D.; et al.; “Computational infrastructures for multi-omic data”; 21; (2020); *Briefings in Bioinformatics*; 1312-1328.

³⁴ Katz; D.S.; Gruenpeter; M.; Honeyman; T.; “Taking a fresh look at FAIR for research software”; 2; (2021); *Patterns*; 100222; <https://doi.org/10.1016/j.patter.2021.100222>

³⁵ Beyan (n 32). van Soest; R.; Lamprecht; A.L.; Beyan; O.; “Federated data systems for health crises: Lessons from pandemics”; 1; (2018); *Data Intelligence*; 198-210

³⁶ Wimalaratne; S.M.; et al.; “FAIR principles for genomic data sharing”; 17; (2018); *Data Science Journal*; 1-10

³⁷ Kamdar; M.R.; Fernandez; J.D.; Polleres; A.; et al.; “Enabling web-scale data integration in biomedicine through linked open data”; 2; (2019); *NPJ Digital Medicine*; 90; <https://doi.org/10.1038/s41746-019-0163-5>

³⁸ Landi (n 33).

³⁹ Munung; N.S.; Mayosi; B.M.; de Vries; J.; “Equity in international health research collaborations in Africa: Perceptions and expectations of African researchers”; 11; (2016); *PLoS ONE*; e0161720.

⁴⁰ Wimalaratne (n 36).

confidentiality. Accessibility entails secure, auditable pathways for authorised users via authentication and data-use agreements, not unrestricted openness.⁴¹ Interoperability requires standardised file formats, machine-readable structures and controlled vocabularies such as OMOP, ICD-10 and Gene Ontology.⁴² Reusability demands documentation of provenance, workflows, dependencies and ethical constraints, extending dataset longevity and compliance.⁴³ The EU General Data Protection Regulation (GDPR) imposes stringent consent, accountability and transparency obligations on personal and genomic data.⁴⁴ Its “adequacy” principle restricts cross-border transfers to jurisdictions with equivalent rights. By contrast, the U.S. sectoral approach under the Health Insurance Portability and Accountability Act (HIPAA) regulates healthcare data but provides limited guidance on international transfers.⁴⁵

The Genetic Information Nondiscrimination Act (GINA) prohibits employment and insurance discrimination based on genetic information, reflecting debates on genetic exceptionalism.⁴⁶ In Europe, the European Genome-phenome Archive (EGA) applies tiered access and GDPR-compliant consent.⁴⁷ In the U.S., the Database of Genotypes and Phenotypes (dbGaP) emphasises institutional governance, controlled access and secondary use monitoring without statutory adequacy rules.⁴⁸ The principles governing the retention of DNA information in *Gaughran v United Kingdom App No 45245/15*⁴⁹ stressed that the indefinite retention of DNA samples and profiles without adequate justification violates the right to respect for private life. The decision illustrates the importance of proportionality, limited retention periods and effective oversight in genomic data repositories. African experiences revealed infrastructural gaps, uneven legal oversight and cultural diversity, requiring federated governance that balances global standards with local realities.⁵⁰ The community Advisory Boards (CABs) play a critical role in African genomic research by ensuring culturally appropriate engagement, monitoring consent and voicing participant preferences on secondary data use.⁵¹ Global frameworks such as GA4GH, FAIR, H3Africa, GDPR, HIPAA and GINA integrate training, capacity-building and infrastructural support to ensure local researchers and institutions benefit scientifically and technologically which collectively shaped the operational framework.⁵²

⁴¹ Wilson; R.; et al.; “Controlled access and consent management for genomic repositories”; 27; (2017); *Genome Research*; 214-223.

⁴² Kamdar (n 37).

⁴³ Katz (n 34). Bierer; B.E.; Barnes; M.; Jazic; I.; “Ensuring the ethical use of genomic data: Challenges and solutions”; 18; (2017); *Nature Reviews Genetics*; 641-653.

⁴⁴ Kuner; C.; *Transborder data flows and data privacy law*; Oxford; Oxford University Press; 2013. European Union; “General Data Protection Regulation (GDPR)”; L119; (2016); *Official Journal of the European Union*; 1-88.

⁴⁵ Health Insurance Portability and Accountability Act of 1996 (HIPAA, 1996); <https://www.cdc.gov/phlp/php/resources/health-insurance-portability-and-accountability-act-of-1996-hipaa.html>

⁴⁶ Rothstein (n 24).

⁴⁷ Wilkinson (n 31).

⁴⁸ Wilson (n 41).

⁴⁹ *Gaughran v United Kingdom App No 45245/15* (ECtHR, 13 February 2020).

⁵⁰ Rothstein (n 24).

⁵¹ Tindana; P.O.; Kass; N.; Akweongo; P.; “The informed consent process in a rural African setting: A case study of the Kassena-Nankana District of Northern Ghana”; 28(3); (2006); *IRB: Ethics & Human Research*; 1-6. Pratt; B.; Lwin; K.M.; Zion; D.; Nosten; F.; Loff; B.; Cheah; P.Y.; “Exploitation and community engagement: Can Community Advisory Boards successfully assume a role minimizing exploitation in international research?”; 15(1); (2015); *Developing World Bioethics*; 18-26.

⁵² Munung (n 39).

Genomic Medicine and Data Sharing in Nigeria

The evolution of genomic medicine in Nigeria reflected a paradigm shift in the pursuit of precision healthcare, shaped by scientific innovation, public health imperatives and ethical regulation. Nigeria genomic medicine trajectory has been gradual with early efforts centred on infectious diseases such as malaria, HIV and Lassa fever, showing the potential of genomics in addressing public health priorities.⁵³ Nigeria is recognised in the global genomic research community through participation in international consortia and the development of indigenous capacities to generate, manage and apply genomic data in clinically and socially relevant ways.⁵⁴ Participation in global initiatives such as the International HapMap Project enabled Nigerian researchers to contribute significantly to the understanding of human genetic diversity, thereby facilitating the design of population-specific interventions, pharmacogenomic applications and translational research adapted to local heterogeneity.⁵⁵ At the domestic level, institutions like the Institute of Medical Research and Training (IMRAT) at the University of Ibadan leveraged international funding to establish biobanks, training programmes and genomic competencies, ensuring Nigerian role as a central participant in global genomic science rather than merely a provider of raw data.⁵⁶

Data sharing in Nigeria involves intra-institutional access, inter-institutional collaborations and international partnerships, supporting genome-wide analyses, variant interpretation and the translation of findings into precision medicine interventions tailored to the nation diverse populations.⁵⁷ The legal basis for protecting genomic information in Nigeria is under established constitutional privacy principles. Nigerian courts in *Incorporated Trustees of Laws and Rights Awareness Initiative & Ors v National Identity Management Commission*⁵⁸ held that personal information receives constitutional protection and that its unlawful collection, disclosure, or processing infringe the constitutional right to privacy. Although these decisions did not concern genomic information specifically, they provide persuasive authority for treating genetic information as highly sensitive personal data requiring strict safeguards, particularly where international data sharing is involved. However, informed consent posed persistent challenges due to Nigerian linguistic diversity, variable literacy levels and culturally rooted interpretations of health and heredity. Unlike conventional biomedical research, genomic studies often required broad or open-ended consent for secondary and future uses, creating tensions between participant comprehension and scientific necessity.⁵⁹

The constitutional importance of informed consent and informational autonomy has also been recognised in Nigerian medical law. Nigerian courts in *Medical and Dental Practitioners Disciplinary Tribunal v Okonkwo* (2001)⁶⁰ affirmed that medical interventions affecting bodily integrity require the informed consent of the patient, reinforcing the broader

⁵³ Naveed (n 25).

⁵⁴ Akintola; S.; Callier; L.; Ogundiran; T.; “Personalizing medicine in Nigeria by tailoring the research process: Points to consider for genomic research”; 11(4); (2013); *Current Pharmacogenomics and Personalized Medicine*; 267-273.

⁵⁵ *ibid.*

⁵⁶ *ibid.*

⁵⁷ Egea; M.; Matteucci; I.; Mori; P.; “Definition of data sharing agreements”; (2015); In: Felici; M.; Fernandez-Gago; C. (Eds.); *Accountability and Security in the Cloud*; Springer International Publishing; 248-272.

⁵⁸ *Incorporated Trustees of Laws and Rights Awareness Initiative & Ors v National Identity Management Commission* (2021) LPELR-55623(CA).

⁵⁹ Gikonyo; C.; Bejon; P.; Marsh; V.; Molyneux; S.; “Taking social relationships seriously: Lessons learned from the informed consent practices of a vaccine trial on the Kenyan Coast”; 67(5); (2008); *Social Science & Medicine*; 708-720

⁶⁰ *Medical and Dental Practitioners Disciplinary Tribunal v Okonkwo* (2001) 7 NWLR (Pt 711) 206. <https://nigerianlawforum.com/case-law/dr-john-emewulu-nicholas-okonkwo-v-medical-and-dentalpract-2001/>

ethical principle that individuals should retain meaningful control over the use of their biological materials and associated information. While these decisions arose in clinical treatment rather than genomic research, they provide persuasive guidance for genomic consent practices. Institutionally, the Nigerian Biotechnology Development Agency (NABDA), established in Abuja, provided strategic direction for biotechnology research across health and agriculture, fostering an environment supportive of ethical data collection and dissemination.⁶¹ Ethical frameworks were operationalised through biobanks affiliated with H3Africa and the Institute of Human Virology Nigeria (IHVN), which together maintained more than 45,000 biological samples, including human tissues, pathogens and tuberculosis isolates, all preserved under international biobanking standards.⁶²

The regulatory approach adopted by Nigerian biobanks reflects the judicial and legislative emphasis on confidentiality and responsible handling of sensitive personal information. Nigerian courts and regional human rights jurisprudence in *Incorporated Trustees of Digital Rights Lawyers Initiative v Federal Republic of Nigeria* ECW/CCJ/JUD/02/23⁶³ held that effective privacy protection extends beyond preventing disclosure to ensuring adequate institutional safeguards for collection, storage and subsequent processing of personal data. These principles are particularly applicable to genomic repositories where the risk of re-identification remains significant. Community Advisory Boards (CABs), promoted by the National Health Research Ethics Committee, emerged as intermediaries between researchers and communities, providing platforms for ethical deliberation and advocacy.⁶⁴ CABs were intended to ensure that consent procedures reflected communal values, especially in contexts where genomic information implicated families or ethnic groups. Nevertheless, their effectiveness was limited by insufficient technical expertise, challenges in interpreting complex genomic datasets and ongoing tensions between local cultural values and international research imperatives.⁶⁵

Nigerian participation in multinational initiatives such as H3Africa was contingent upon regulated access agreements that ensured compliance with ethical standards, informed consent requirements and statutory provisions for secondary data use.⁶⁶ Nigerian genomic datasets carried immediate public health value, informing susceptibility studies for malaria, tuberculosis and sickle cell disease, while also advancing pharmacogenomic and chronic disease research.⁶⁷ Because genomic research frequently involved secondary analyses unforeseen at the time of collection, Nigerian realities of linguistic diversity, low literacy and cultural conceptions of heredity created significant barriers to comprehension.⁶⁸ Strategies such as translation, the use of visual tools and iterative consent processes were therefore institutionalised through the Nigerian National Code of Health Research Ethics,⁶⁹ which also

⁶¹ Nigerian Biotechnology Development Agency (NABDA); “Promoting biotechnology in Nigeria”; (2017); <https://allianceforscience.org/blog/2017/01/nigerias-2017-prospects-for-biotechnology/>

⁶² Nnamuchi (n 16).

⁶³ *Incorporated Trustees of Digital Rights Lawyers Initiative v Federal Republic of Nigeria* ECW/CCJ/JUD/02/23 (ECOWAS Community Court of Justice, 2023)

⁶⁴ Pratt (n 51).

⁶⁵ Strauss; R. P.; Sengupta; S.; Quinn; S. C.; et al.; “The role of community advisory boards: Involving communities in the informed consent process”; 91(12); (2001); *American Journal of Public Health*; 1938-1943

⁶⁶ Munung (n 39).

⁶⁷ Egea (n 57).

⁶⁸ Molyneux; C. S.; Peshu; N.; Marsh; K.; “Understanding of informed consent in a low-income setting: Three case studies from the Kenyan Coast”; 59(12); (2004); *Social Science & Medicine*; 2547-2559. Gikonyo (n 57).

⁶⁹ Federal Ministry of Health (n 14).

encouraged CABs to align practices with community values.⁷⁰ Genomic data, inherently identifying, carried residual risks of re-identification even when anonymised, particularly when cross-referenced with other.⁷¹

Ethical rights such as encrypted storage, restricted access and oversight by institutional review boards were employed, while transparency around risks of re-identification, withdrawal rights and disclosure obligations was emphasised to sustain trust.⁷² The judicial approach to privacy and confidentiality in Nigeria supports the argument that genomic information requires heightened protection because of its sensitive and potentially identifying nature. In National Industrial Court of Nigeria in *Adewunmi Akinola v Ocean Marine Solutions Ltd*,⁷³ the court held that medical information, including HIV status, falls within the sphere of private information protected from unauthorised disclosure. The court emphasised that an institution holding health information owes a duty of confidentiality and that disclosure without lawful justification may violate the individual's constitutional privacy protections. This principle is applicable to genomic repositories because genetic data can reveal not only personal health risks but also information concerning biological relatives and wider communities. Similarly, in *Tony Anozia v Mrs Patricia Okwunwa Nnani & Another*,⁷⁴ the Nigerian Court of Appeal acknowledged the privacy implications associated with compulsory genetic examination, rejecting attempts to compel DNA testing where such an order would improperly interfere with personal autonomy and privacy interests. Although the above case concerned parentage rather than research databases, its reasoning demonstrates judicial recognition that genetic information engages fundamental privacy concerns and cannot be accessed without appropriate legal justification.

Equity and access further shaped administration, as socio-economic disparities and unequal healthcare infrastructure influenced who could participate in research and who might benefit from outcomes.⁷⁵ Concentration of genomic research infrastructure in urban centres risked excluding rural communities, highlighting the need for inclusive strategies such as outreach, capacity building and equitable dissemination of benefits, including technology transfer and therapeutic tools.⁷⁶ Nigerian involvement in H3Africa also raised concerns about intellectual property, recognition of local contributions and the fair distribution of benefits, requiring frameworks that ensured equitable partnerships rather than extractive relationships.⁷⁷ These concerns reflect wider judicial and regulatory expectations that participation in health-related research must be structured around respect for human dignity, lawful processing and protection against exploitation. The importance of governance mechanisms is reinforced by the decision of the ECOWAS Community Court of Justice in *Incorporated Trustees of Digital Rights Lawyers Initiative v Federal Republic of Nigeria*,⁷⁸ where the Court considered obligations relating to privacy and protection of personal information in the digital environment.

⁷⁰ Parker; M.; Bull; S. J.; de Vries; J.; Agbenyega; T.; Doumbo; O. K.; Kwiatkowski; D. P.; "Ethical data release in genome-wide association studies in developing countries"; 6(11); (2009); *PLoS Medicine*; e1000143.

⁷¹ *ibid*

⁷² *ibid*

⁷³ *Adewunmi Akinola v Ocean Marine Solutions Ltd* (National Industrial Court of Nigeria, NICN/LA/461/2013).

⁷⁴ *Tony Anozia v Mrs Patricia Okwunwa Nnani & Another* (Court of Appeal, Owerri Judicial Division, CA/OW/29/2013) [2015] NGCA 15.

⁷⁵ De Vries; J.; Pepper; M.; "Genomic sovereignty and the African promise: Mining the genome for the benefit of Africa"; 38(8); (2012); *Journal of Medical Ethics*; 474-478

⁷⁶ Akintola (n 54).

⁷⁷ *ibid*.

⁷⁸ *Incorporated Trustees of Digital Rights Lawyers Initiative v Federal Republic of Nigeria* ECW/CCJ/JUD/02/23 (ECOWAS Community Court of Justice, 2023).

The decision supports the broader proposition that privacy protection requires not merely preventing disclosure but establishing institutional safeguards governing collection, processing and control of personal information. Concepts of personhood, communal ownership and familial responsibility influenced interpretations of consent and data rights, with some communities regarding biological samples as collective assets requiring approval from leaders or families.⁷⁹ The communal dimensions of genomic consent correspond with Nigerian ethical governance frameworks, which recognise that research involving human participants requires meaningful community engagement. The Nigerian National Code for Health Research Ethics provides for Community Advisory Boards (CABs) as mechanisms through which researchers may incorporate community concerns, cultural values and local expectations into research design and implementation. The Code recognises that Nigeria's ethnic, cultural and religious diversity requires participatory approaches capable of addressing community-level ethical concerns. Stigmas surrounding heritable disorders and infectious disease predispositions reinforced the need for confidentiality, while culturally adapted consent processes and CABs sought to address these concerns.⁸⁰

Legal Framework for Genomic Data in Nigeria

The management of genomic data in Nigeria operated at the intersection of constitutional rights, sector-specific health legislation, data protection directives and intellectual property regimes, collectively forming a multi-layered legal framework to regulate the collection, storage, use and sharing of genomic information while safeguarding individual and community rights. Nigeria participation in global genomics projects, such as the International HapMap Project and the Human Heredity and Health in Africa (H3Africa) consortium, heightened the urgency for robust regulatory mechanisms, as genomic information not only illuminated individual health profiles but also carried implications for relatives, ancestry and populations.⁸¹ This prompted the integration of constitutional rights, ethical codes, sectoral policies and intellectual property principles into a structured juridical framework aimed at balancing scientific advancement with legal and ethical accountability. The Nigerian Constitution of 1999 enshrined the right to privacy under Section 37, protecting communications, residences and correspondence although not explicitly referencing genomic data.⁸²

The Constitution privacy clause encompassed genetic information due to its sensitive nature and potential to reveal predispositions and familial linkages. Legal scholars underscored that acquiring or sharing genomic data without informed consent could constitute a constitutional violation, thereby embedding a consent-based model at the core of jurisprudence.⁸³ Although Nigerian courts have not yet directly adjudicated genomic privacy disputes, judicial interpretation of Section 37 demonstrates that privacy protection extends beyond physical spaces to personal information and individual autonomy. In *Nigerian Army v Mowarin*,⁸⁴ the Court of Appeal held that constitutional privacy protections are intended to safeguard personal dignity and autonomy against unjustified interference. This reasoning provides a foundation for extending constitutional protection to genomic information, which is inherently personal because it contains predictive health information, familial relationships and

⁷⁹ Tindana (n 51).

⁸⁰ Pratt (n 51).

⁸¹ Akintola (n 54).

⁸² Olatunji (n 12). Federal Republic of Nigeria; *Constitution of the Federal Republic of Nigeria*; (1999); Section 37, Cap. C23 LFN

⁸³ Nnamuchi (n 16).

⁸⁴ *Nigerian Army v Mowarin* (2015) 14 NWLR (Pt 1474) 451 (CA).

population-level characteristics. Similarly, in *Tony Anozia v Mrs Patricia Okwunwa Nnani & Another*,⁸⁵ the Court of Appeal considered the privacy implications of compulsory DNA testing and acknowledged that genetic information involves significant personal interests requiring legal justification before interference. The decision illustrates judicial recognition that genetic material is not merely biological evidence but information connected to identity, family relationships and personal autonomy.

In the health sector, the Nigerian National Code of Health Research Ethics (NCHRE), issued by the National Health Research Ethics Committee (NHREC) in 2007, set ethical and procedural benchmarks for biomedical research.⁸⁶ Central to this Code was the principle of informed consent, requiring participants to be fully apprised of both immediate and potential secondary uses of their samples. To address cultural and linguistic complexities, the Code institutionalised Community Advisory Boards (CABs), designed to reflect local social values and mediate between research protocols and community expectations.⁸⁷ CABs operated as participatory oversight mechanisms in matters of biobank governance, secondary data use and international collaborations.⁸⁸ While invaluable, their effectiveness depended on technical training and structured collaboration with researchers. The participatory role assigned to CABs reflects broader international and regional recognition that biomedical research involving genetic information requires community engagement beyond individual consent. In *Incorporated Trustees of Digital Rights Lawyers Initiative v Federal Republic of Nigeria*,⁸⁹ the ECOWAS Community Court of Justice emphasised that effective privacy protection requires institutional safeguards governing the collection, processing and protection of personal information.

Although, the case concerned digital privacy rather than genomic research specifically, its principles apply to genomic repositories because genetic datasets present heightened risks of identification, misuse and unauthorised secondary processing. Complementing health-sector ethics, the National Information Technology Development Agency (NITDA) guidelines provided directives on personal data protection, extending to genomic information.⁹⁰ Section 2 required explicit consent for data processing and imposed rights against unauthorised disclosure or modification. The legal significance of consent in data governance is reinforced by Nigerian judicial decisions concerning confidentiality of sensitive health information. In *Adewunmi Akinola v Ocean Marine Solutions Ltd*,⁹¹ the National Industrial Court recognised that medical information constitutes confidential personal information and that disclosure without proper justification may violate privacy rights. The decision is relevant to genomic data governance because genetic information is considerably more extensive than ordinary medical records, revealing not only individual health risks but also information concerning biological relatives. These rules applied extraterritorially to entities handling the data of Nigerian residents abroad, thereby aligning Nigeria with international standards, mandate accountability mechanisms such as compliance audits and impact assessments, operationalising constitutional privacy guarantees in both clinical and research contexts.

⁸⁵ *Tony Anozia v Mrs Patricia Okwunwa Nnani & Another* (CA/OW/29/2013) [2015] NGCA 15.

⁸⁶ Federal Ministry of Health (n14).

⁸⁷ Pratt (n 51).

⁸⁸ Strauss (n 65).

⁸⁹ *Incorporated Trustees of Digital Rights Lawyers Initiative v Federal Republic of Nigeria* ECW/CCJ/JUD/02/23 (ECOWAS Community Court of Justice, 2023).

⁹⁰ Belo-Osagie; U. U.; *Data Privacy Protection in Nigeria*; (2015); Elexica, Simmons & Simmons; http://www.uubo.org/downloads/SIMM0715001-Data_Privacy_Protection_in_Nigeria.pdf

⁹¹ *Adewunmi Akinola v Ocean Marine Solutions Ltd* (National Industrial Court of Nigeria, NICN/LA/461/2013).

The Freedom of Information Act (FOI Act, 2011), added complexity by granting public access to government-held records, potentially including health or genomic data.⁹² While advancing transparency, the Act created tension with privacy obligations. Scholars argued that genomic datasets, given their identifiability and community-level implications, required carefully calibrated disclosure protocols to balance FOI compliance with confidentiality and consent obligations.⁹³ Although Nigeria lacked a statute expressly regulating genomic ownership, principles of patent, trade secret and contract law influenced custodial rights over samples and data.⁹⁴ The absence of a specific genomic ownership statute means Nigerian governance relies on a combination of property, contractual and ethical principles. Comparative jurisprudence demonstrates the difficulty of treating biological materials as ordinary property. In *Moore v Regents of the University of California*,⁹⁵ the Supreme Court of California held that although patients retain interests relating to informed consent and control over personal medical decisions, removed biological materials may not automatically constitute personal property capable of ownership claims. While not binding in Nigeria, the decision illustrates the international legal challenge of balancing donor interests, scientific research objectives and commercial exploitation of biological resources. Biobanks and research institutions typically assumed custodial responsibility, overseeing storage and access, but acknowledged donors' residual rights, particularly when research yielded commercial or therapeutic applications.

The National Biosafety Management Agency (NBMA) Act of 2015, amended in 2019, introduced another regulatory layer, governing genetically modified organisms (GMOs) and gene-edited materials.⁹⁶ Although primarily concerned with biosafety, the Act had implications for genomic governance by requiring approvals, risk assessments and monitoring for studies involving recombinant DNA. These provisions intersected with NHREC ethical standards and NITDA data protection rules, demonstrating Nigeria integrated, multi-level governance model. This multi-layered approach reflects a regulatory model in which constitutional rights, administrative regulation and ethical oversight operate together. The ECOWAS Court's decision in *Incorporated Trustees of Digital Rights Lawyers Initiative v Federal Republic of Nigeria*⁹⁷ further demonstrates the increasing regional expectation that states establish effective institutional mechanisms for safeguarding personal data. For genomic research, this obligation extends beyond preventing disclosure to ensuring secure storage, controlled access, accountability procedures and lawful secondary use of biological. The Institute of Human Virology Nigeria (IHVN) managed several H3Africa-affiliated biobanks in Jos, Zaria and Abuja, maintaining over 45,000 biological samples under protocols aligned with NHREC, NITDA and NBMA standards.⁹⁸ Similarly, the Institute of Medical Research and Training (IMRAT) at the University of Ibadan developed standard operating procedures combining constitutional privacy protections, sector-specific legislation and international best practices, including consent, CAB participation and restricted access protocols.⁹⁹

⁹² Federal Republic of Nigeria; *Freedom of Information Act, Cap F36 LFN*; (2011).

⁹³ Jemilohun; B. O.; Akomolede; T. I.; "Regulations or legislation for data protection in Nigeria? A call for a clear legislative framework"; 3(4); (2015); *Global Journal of Politics and Law Research*; 1-16

⁹⁴ Nnamuchi (n 16).

⁹⁵ *Moore v Regents of the University of California* 793 P 2d 479 (Cal 1990).

⁹⁶ National Biosafety Management Agency (NBMA, 2019); *National Biosafety Management Agency Act*; (2019); <https://nbma.gov.ng/wp-content/uploads/2021/04/Amendment-of-NBMA-Act-2019.pdf>

⁹⁷ *Incorporated Trustees of Digital Rights Lawyers Initiative v Federal Republic of Nigeria* ECW/CCJ/JUD/02/23 (ECOWAS Community Court of Justice, 2023).

⁹⁸ Nnamuchi (n 16).

⁹⁹ Akintola (n 54).

Comparative Analysis Between Nigeria and Other Countries

The legal frameworks regulating genomic data in Nigeria, though progressively evolving, remain comparatively underdeveloped when assessed against international standards. This imbalance has significant implications for data sharing, research ethics and international collaboration. Nigeria has established a statutory foundation through the National Biosafety Management Agency (NBMA) Act of 2015, amended in 2019, which regulates genetically modified organisms (GMOs), gene editing and related biotechnologies.¹⁰⁰ This Act is supported by supplementary policies, including the National Biosafety Policy and the National Biosafety Guidelines on Gene Editing.¹⁰¹ Together, these instruments prescribe procedures for risk assessment, authorisation, monitoring and reporting of genomic activities. Despite such progress, Nigeria framework remains nascent compared to jurisdictions such as the United Kingdom, the United States and the European Union, where comprehensive instruments explicitly govern genomic data and its international transfer.¹⁰² In the European Union, genomic data governance is principally anchored in the General Data Protection Regulation (GDPR), adopted in 2016.¹⁰³

The GDPR enshrines strict protections for personal and sensitive data, including genomic information, requiring explicit and documented consent for processing and mandating security, accountability and restrictions on cross-border transfers.¹⁰⁴ Noncompliance carries significant financial penalties, ensuring enforceability. Compared with Nigeria reliance on agency oversight through the NBMA and institutional review boards guided by the National Health Research Ethics Committee (NHREC), the GDPR demonstrates the advantages of statutory clarity, enforceable rights and oversight structures that extend uniformly across public and private entities.¹⁰⁵ In the United States, genomic data governance rests on several complementary laws. The Genetic Information Nondiscrimination Act (GINA) of 2008 prohibits the use of genetic information in employment and health insurance, addressing discrimination risks in genomic research. Alongside, the Health Insurance Portability and Accountability Act (HIPAA) establish rigorous standards for health information management, including genomic data and grants individuals' rights of access, correction and consent for secondary use. Regulations issued by the National Institutes of Health (NIH) further mandate data-sharing protocols for federally funded research.¹⁰⁶ In contrast, Nigeria protections remain limited to constitutional privacy under Section 37 of the 1999 Constitution and NBMA oversight, without an equivalent statutory prohibition on genomic discrimination.

The coherence of U.S. instruments integrating privacy, consent and anti-discrimination provisions highlights gaps in Nigerian legislation and offers models for reform. The Human Heredity and Health in Africa (H3Africa) initiative illustrates efforts at harmonisation across low- and middle-income countries. Operating under a strict ethical framework, H3Africa promotes equitable collaboration, capacity building and adherence to internationally recognised principles, including informed consent, privacy and responsible data sharing.¹⁰⁷ Its

¹⁰⁰ NBMA (n 96).

¹⁰¹ *ibid*

¹⁰² Tripathi; L.; Dhugga; K. S.; Ntui; V. O.; Runo; S.; Syombua; E. D.; Muiruri; S.; Wen; Z.; Tripathi; J. N.; "Genome editing for sustainable agriculture in Africa"; 4; (2022); *Frontiers in Genome Editing*; 1-18.

¹⁰³ *Ibid*.

¹⁰⁴ European Union (n 44).

¹⁰⁵ Nnamuchi (n 16).

¹⁰⁶ Committee on Science, Technology, and Law; Policy and Global Affairs; National Academies of Sciences, Engineering, and Medicine, *International Summit on Human Gene Editing: A Global Discussion*, Washington (DC), National Academies Press (US), 2016, p. 1.

¹⁰⁷ Tripathi (n 102).

guidelines incorporate community engagement, benefit sharing and compliance with local regulations. Nigeria participation benefits from these standards, yet domestic instruments like the NBMA Act and NHREC codes often lack equivalent statutory force, creating misalignments in cross-border governance. The absence of codified enforcement for equitable benefit sharing and international data transfer limits Nigeria ability to fully operationalise H3Africa principles. In the United Kingdom and the United States, frameworks define rights over biobanked material and genomic datasets, often through patent law, data use agreements and formalised ethical reviews.¹⁰⁸ These structures ensure equitable recognition and incentivise participation in genomic research.

Nigeria, by contrast, has not explicitly addressed the proprietary status of genomic data. While the NBMA Act regulates GMOs and synthetic biology, it remains silent on IP rights and benefit sharing, creating ambiguities for public-private collaborations and cross-border projects.¹⁰⁹ Such gaps risk discouraging Nigerian researchers from engaging in international projects and raise ethical questions about fairness and recognition. In Nigeria, NHREC guidelines (2007) and institutional review boards employ Community Advisory Boards (CABs) to ensure socio-cultural sensitivity in participant engagement.¹¹⁰ These mechanisms encourage local trust but lack the enforceable standardisation seen in the GDPR or the NIH Genomic Data Sharing Policy, which mandate uniform consent templates, reporting requirements and oversight across institutions.¹¹¹ Nigeria reliance on decentralised approaches may lead to inconsistent practices and reduced interoperability in international collaborations. Integrating internationally recognised standards for broad consent, standardised information sheets and clear documentation protocols could enhance ethical robustness and global compatibility. While national policies provide important oversight, the globalised nature of genomic research requires harmonisation with instruments like the GDPR, GINA, HIPAA and H3Africa guidelines as these frameworks collectively illustrate the benefits of enforceable consent, robust privacy protections, anti-discrimination rights and equitable benefit-sharing mechanisms.¹¹²

Legal and Ethical Dilemmas in Genomic Data Sharing in Nigeria

The management of genomic data sharing in Nigeria is shaped by significant legal ambiguities, fragmented oversight and infrastructural deficits, all of which complicate the creation of coherent frameworks that safeguard participant rights while enabling scientific advancement. Nigeria has ratified global instruments such as the Convention on Biological Diversity and the Cartagena Protocol on Biosafety, but domestic implementation has been inconsistent, creating overlaps and gaps as follows:

1. Nigerian genomic research framework remained fragmented, with overlapping laws that created uncertainty over the collection, storage and sharing of genomic data. The Constitution guaranteed privacy (1999, Sec. 37) but did not address genomic information.¹¹³ The absence of an express constitutional reference to genomic information does not eliminate the possibility of protection through existing privacy principles. Nigerian courts have interpreted Section 37 as protecting personal autonomy and confidential information from unjustified interference. In *Adewunmi Akinola v Ocean*

¹⁰⁸ Committee on Science (n 106). Tripathi (n 102).

¹⁰⁹ NBMA (n 96). Nnamuchi (n 16).

¹¹⁰ Akintola (n 54).

¹¹¹ Committee on Science (n 106). Tripathi (n 102).

¹¹² Parker (n 70). De Vries (n 75).

¹¹³ Olatunji (n 12).

Marine Solutions Ltd,¹¹⁴ the National Industrial Court held that medical information is private information requiring confidentiality and protection against unauthorised disclosure. Although the dispute concerned HIV-related information rather than genomic data, the reasoning is applicable because genomic information contains even more extensive personal and familial health information. Furthermore, the ECOWAS Community Court of Justice in *Incorporated Trustees of Digital Rights Lawyers Initiative v Federal Republic of Nigeria*¹¹⁵ emphasised that privacy protection requires effective institutional safeguards regulating the collection, processing and protection of personal information. The decision illustrates the growing regional expectation that privacy rights must be supported by regulatory structures capable of addressing emerging forms of sensitive data, including genomic datasets.

2. While the NBMA Act (2015/2019) regulated GMOs, it offered little on human genomic data and instruments like the NITDA Guidelines and FOI Act intersected ambiguously.¹¹⁶ This regulatory fragmentation reflects a wider challenge in Nigerian data governance, where sector-specific legislation has developed without a comprehensive statute dedicated to genetic information. The judicial approach in *Incorporated Trustees of Digital Rights Lawyers Initiative v Federal Republic of Nigeria*¹¹⁷ demonstrates that effective protection of personal data requires clarity regarding responsibility for collection, processing, storage and disclosure. In the genomic context, uncertainty over whether genetic information should primarily be treated as health information, personal data, research material or biological property creates difficulties for regulators and research institutions.
3. Weak intellectual property protections complicated compliance and ethical oversight.¹¹⁸ The ownership and control of genomic resources remain legally complex because biological samples contain both personal interests and research value. Comparative jurisprudence illustrates the difficulty of determining whether contributors retain ownership rights over biological materials after donation. In *Moore v Regents of the University of California*,¹¹⁹ the court held that although patients possess important interests relating to informed consent and control over medical decisions, removed biological materials were not automatically subject to ordinary property ownership claims. The decision highlights the need for clear contractual and ethical frameworks governing Nigerian genomic databases, particularly regarding commercialization, benefit-sharing and recognition of local scientific contributions.
4. Skilled personnel in bioinformatics, genomic epidemiology and FAIR data management are scarce, slowing adoption of best practices.¹²⁰
5. Informed consent is hindered by cultural; linguistic and literacy diversity and genomic data pose significant risks of stigma and discrimination.¹²¹ The challenge of obtaining meaningful genomic consent is intensified by the fact that genetic information may reveal characteristics affecting families and communities rather than only individual participants. Nigerian judicial reasoning concerning genetic testing demonstrates recognition of the sensitivity of genetic information. In *Tony Anozia v Mrs Patricia Okwunwa Nnani &*

¹¹⁴ *Adewunmi Akinola v Ocean Marine Solutions Ltd (National Industrial Court of Nigeria, NICN/LA/461/2013)*.

¹¹⁵ *Incorporated Trustees of Digital Rights Lawyers Initiative v Federal Republic of Nigeria ECW/CCJ/JUD/02/23 (ECOWAS Community Court of Justice, 2023)*.

¹¹⁶ NBMA (n 96).

¹¹⁷ *Incorporated Trustees of Digital Rights Lawyers Initiative v Federal Republic of Nigeria ECW/CCJ/JUD/02/23 (ECOWAS Community Court of Justice, 2023)*.

¹¹⁸ Akintola (n 54).

¹¹⁹ *Moore v Regents of the University of California* 793 P 2d 479 (Cal 1990).

¹²⁰ De Vries (n 75).

¹²¹ Pratt (n 51).

Another,¹²² the Court of Appeal considered the privacy implications of DNA testing and acknowledged that genetic information engages significant personal interests requiring appropriate legal justification. Although the case involved parentage rather than research, it supports the proposition that genetic information requires heightened safeguards because of its implications for identity and familial relationships.

6. Community Advisory Boards promote participatory oversight; they often lacked the technical depth to evaluate complex genomic projects.¹²³
7. Divergences between Nigerian rules and global standards (GDPR, H3Africa principles) complicated cross-border research, as misaligned consent, data protection and benefit-sharing mechanisms risked inequitable outcomes favoring high-income countries.¹²⁴ Cross-border genomic collaborations raise questions concerning jurisdiction, control of data and equitable distribution of research benefits. The ECOWAS Court's decision in *Incorporated Trustees of Digital Rights Lawyers Initiative v Federal Republic of Nigeria*¹²⁵ reinforces the principle that personal data protection requires accountability mechanisms even where information processing occurs within broader digital networks. This principle is particularly relevant to multinational genomic initiatives, where Nigerian samples and datasets may be transferred to foreign institutions operating under different legal standards. Ensuring compatibility between Nigerian requirements, international frameworks and research governance principles is therefore necessary to prevent exploitative data flows and preserve participant trust.

Conclusion

Exploration of data sharing in Nigerian genomics revealed interaction between scientific advancement, ethical responsibility and regulatory oversight. Nigeria made progress through participation in the International HapMap Project, the H3Africa Consortium and establishment of agencies such as the Nigerian Biotechnology Development Agency and university-based research centres. These initiatives showed commitment to genomics in healthcare, public health and agricultural innovation. Legal and ethical infrastructure governing genomic data remained fragmented and ambiguous. Constitutional privacy provisions, National Information Technology Development Agency guidelines, Freedom of Information Act and sector-specific legislation offered partial rights but failed to regulate genomic research. Ethical concerns also included consent for long-term unspecified sample use, re-identification risks and stigmatization of individuals or communities. Weak infrastructure, limited expertise and absence of clear biobanking and data governance policies constrained compliance with national and international standards. Nigeria needs harmonised legislation, stronger ethical oversight, investment in infrastructure, human capacity, secure data technologies, public education engagement.

Recommendations

Based on the findings of the study, the following recommendations were advanced:

1. Develop a harmonised national legal framework specifically for genomic data that integrates domestic statutes with international standards to ensure clarity, enforceability and protection of participant rights.

¹²² *Tony Anozia v Mrs Patricia Okwunwa Nnani & Another* (CA/OW/29/2013) [2015] NGCA 15.

¹²³ Molyneux (n 68).

¹²⁴ Nnamuchi (n 16).

¹²⁵ *Incorporated Trustees of Digital Rights Lawyers Initiative v Federal Republic of Nigeria* ECW/CCJ/JUD/02/23 (ECOWAS Community Court of Justice, 2023).

2. Establish culturally adapted informed consent procedures that account for communal decision-making norms, linguistic diversity and literacy variations.
3. Strengthen infrastructure and human capacity by expanding biobanking facilities, improving data management systems and training personnel in bioinformatics, genomic epidemiology and data stewardship.
4. Introduce clear intellectual property and benefit-sharing policies for genomic data, particularly in the context of international collaborations, to ensure equitable participation and recognition of contributions.
5. Promote participatory involvement through Community Advisory Boards (CABs), genomic literacy programs and transparent stakeholder engagement in research design, data sharing and ethical oversight.