# Whose Data Is It Anyway?

## Navigating Data Privacy Rights, Institutional Interests, and IP in the Context of Health Research in Nigeria

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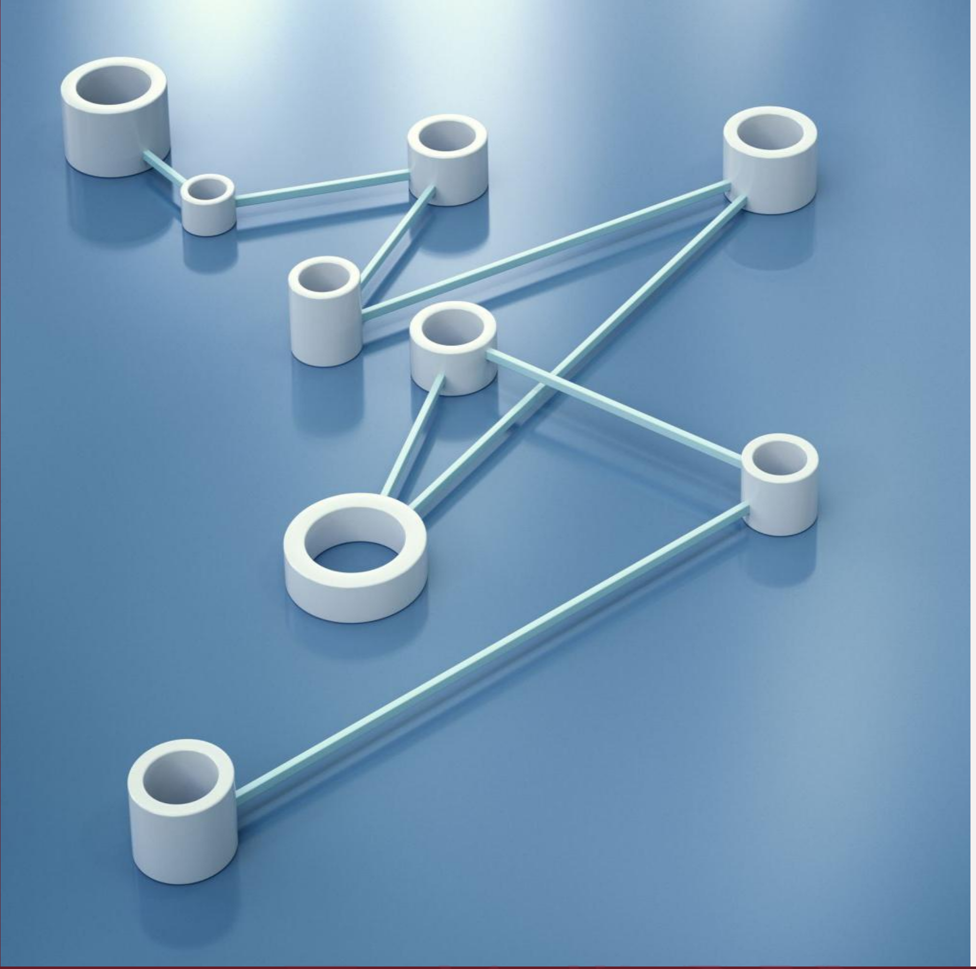


- The Problem: Health data is invaluable for research, but its ownership and use is not clearly defined.
- The Conflict: A potential clash of interests between multiple stakeholders: the data subject/research participant, the data controller (the research institution/funder/researcher), and the potential for commercial gain (IP).
- The Goal: To examine the legal basis for the claim of data ownership from three perspectives:

1. The data privacy rights of the data subject.
2. Institutional interests.
3. The intellectual property rights of researchers and companies, among others – patent, copyright and trade secret.

# Introduction

- Comprises a bundle of rights over a thing, including the rights to use, alienate, enjoy the fruits of, and dispose of.
- They are not absolute.
- Multiple stakeholders are involved in the context of health data.
- Key to data governance: Data ownership identifies accountability and responsibility for data.
- Overlaps with custodianship: actual possession of a thing may not amount to ownership.

# What Data Ownership may Entail

- 1999 Constitution guarantees privacy (s.37).
- Nigeria Data Protection Act (NDPA) 2023 is Nigeria's first comprehensive data protection legislation.
- Key rights of research participants over their personal data under the NDPA:
    - Consent: to give (Sections 25(1), 26(1), 30(1), 31(1)); to object (section 36); to withdraw (section 35)
    - Data portability: section 38 (defined as the right of the data subject to obtain data that a data controller holds on them in a structured, commonly used and machine-readable format and to re-use it for their own purposes – 2022 AU Data Policy Framework).
- The NDPA grants data subjects certain control over their data, but does it consider them as owners in a traditional legal sense?

- Article 42(1)(a) of the Nigeria Data Protection Act - General Application and Implementation Directive (NDP Act - GAID) 2025:

  > **Personal data, to all intents and purposes, belong to the natural person to whom it relates. Accordingly, it shall be construed as unethical to process data in a manner that the owner may object, taking into account, law, culture and faith.**

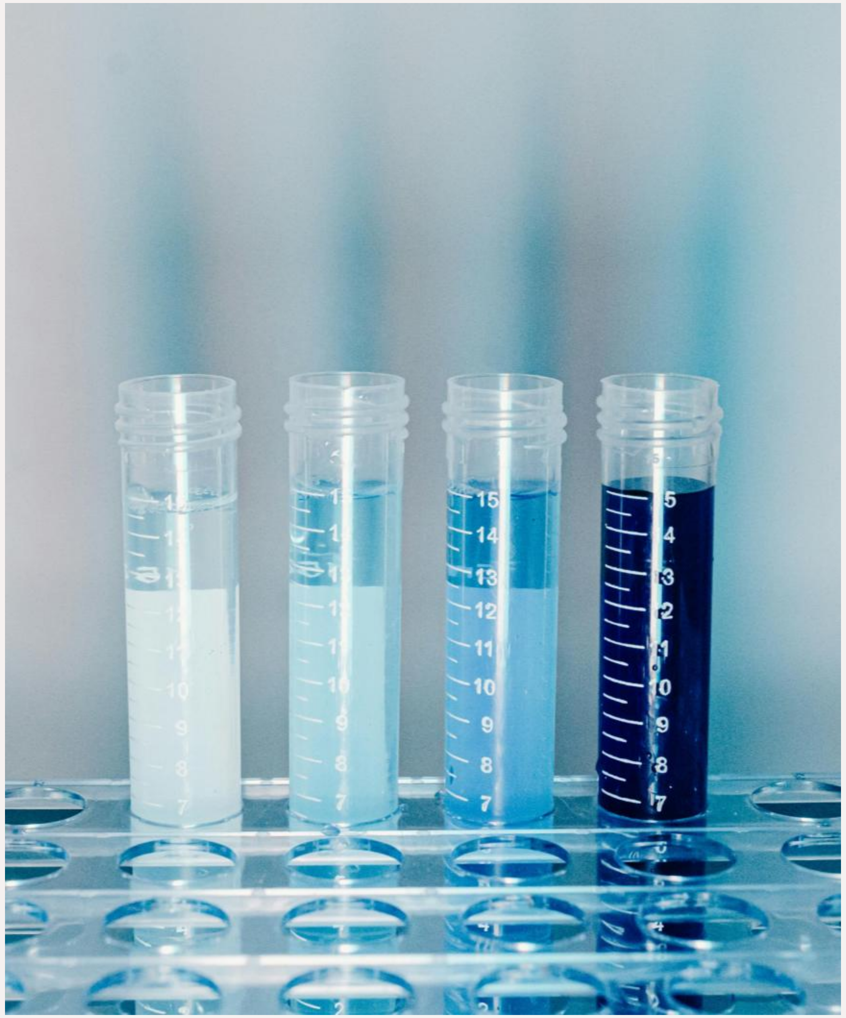
- NDP Act - GAID 2025 is issued by virtue of sections 6(c), 61 & 62 of NDPA - ***Kuda Microfinance Bank Ltd v. Amarachi Kenneth Blessing* (2025 CA Decision)**
- This aligns with the position under the AU Data Policy Framework 2022, and the 2020 South African court ruling (***Discovery Ltd and Others v Liberty Group Ltd*,** ZAGPJHC 67, 2000), which suggest that if the data is personal in nature, it is 'owned' by the data subject and a data controller may not exclude others from accessing the information.
- **Limitations**: Data protection laws are concerned mainly with the right of defence due to their protective nature, and it does not grant the power of disposal over the data to the individuals. As a result, data protection law is not directly concerned with the ownership of data, and it cannot be explicitly used for data ownership allocation (Asswad & Marx Gómez, 2021; Thaldar, 2024).

# Institutional Interests

- Universities, research institutions and hospitals generate and manage large volumes of health data, providing the basis for research and innovation.
- In practice, they generally treat data as an institutional asset – having invested in technical expertise, the necessary laboratory infrastructure, and other resources.
- Research policies often vest ownership of data in the institution, not researchers or participants - Usmanu Danfodiyo University Sokoto Research Policy 2020, para 5.5 (Ownership):

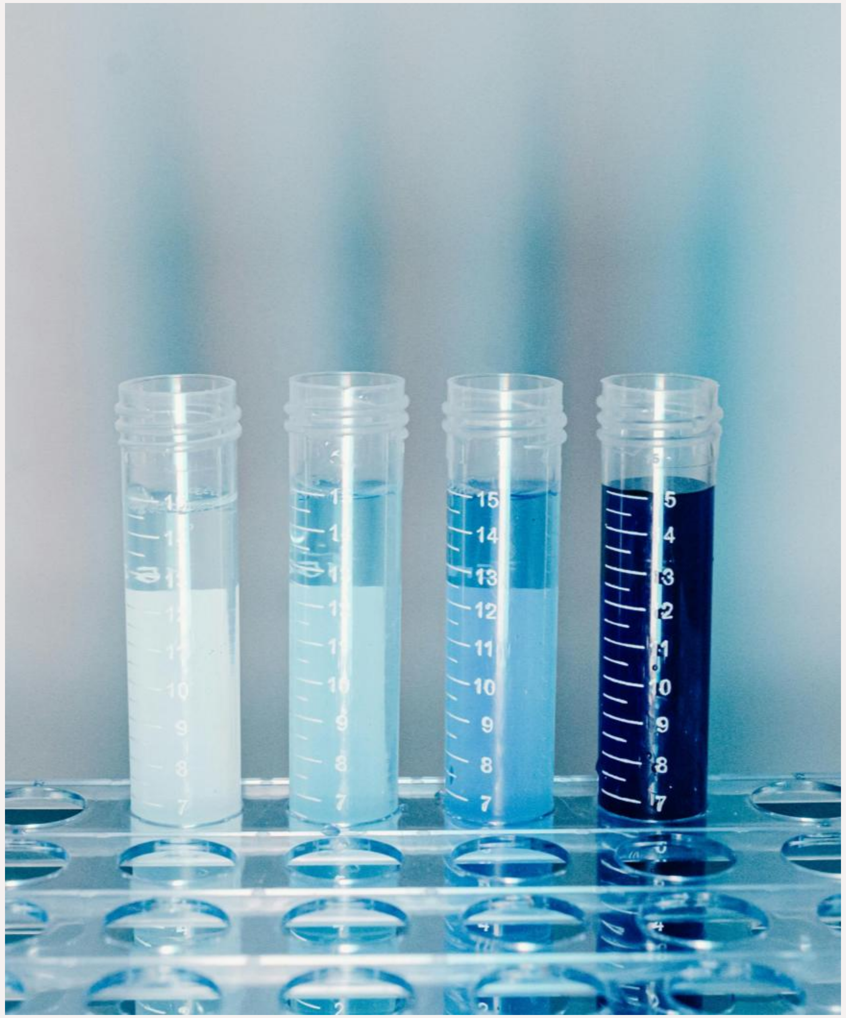
> **All data, notebooks, and research products resulting from any research conducted within the University and by University staff, students and/or visitors are the property of the University. These include any research carried out with the support of a grant given to staff, students and/or visitor of the University. Exemptions may be given in the case of contract research with an industry/third party but with the knowledge of the University.**

- Recognising ownership rights allows institutions to commercialise research outputs (say through patents) and exercise broad discretion to decide how data is used, shared, and stored for further research and innovation.
- However, are universities, research institutions and hospitals the true owners or mere custodians?



# Institutional Interests (cont.)

- With the shift to open science, global funders require data-sharing.
- Data-sharing conditions are often part of grant agreements (Shamseer et al, 2021).
- Some international partners seek clear ownership claims due to their commercialisation plans.
- Can conflict with local laws and participant expectations.
- General concerns: Without recognition of ownership rights, institutions and researchers may lack sufficient incentives to invest in large-scale, data-driven research.
- Particularly in Nigeria, where research funding is limited, institutions rely on international grants. Could the lack of ownership rights make them unattractive partners?



# The Rights of Researchers and the IP Dimension in Health Research Data

- Researchers also see themselves as owners of research data:

> 'researchers typically treat data as if they own them … feeling little compunction about taking a dataset from one institution to the next when they move, and/or publishing to open platforms without seeking institutional approval' (Dennis et al, 2019).

- The Labour Theory provides a basis for arguing in support of data ownership by researchers/health professionals. It is to the effect that every man has a natural property right to the fruits of his labour, for which the state owes the duty to protect and enforce.
- Often, researchers want to keep the data until they secure some form of intellectual property rights.
- The protection of intellectual property rights is to serve two twin objectives: private interests (protecting the rights of creators and inventors to ensure just rewards and recognition for their intellectual efforts, while incentivising further research and creativity/inventiveness) and public or societal interests in diverse works and inventions.

# The Rights of Researchers and the IP Dimension in Health Research Data (cont.)

**How IP Law Intersects with Health Data**

- Patents: inventions derived from health/genomic data.

  **Patents & Designs Act 1971, s 1(5): (5) Principles and discoveries of a scientific nature are not inventions for the purposes of this Act.**

- Copyright: publications, software, databases (original selection/arrangement).

  **Copyright Act 2022, s 2(5): The copyright in a compilation shall not confer any exclusive right in the pre-existing material or data.**

  **s 3: The following shall not be eligible for copyright —**

  **(a) ideas, procedures, processes, formats, systems, methods of operation, concepts, principles, discoveries or mere data.**

- Database rights: sui generis in some jurisdictions.
- Should raw data be IP?

# The Rights of Researchers and the IP Dimension in Health Research Data (cont.)

**Ownership Rights: Researchers vs Institutions**

- Copyright Act 2022

S 28(1) Except as otherwise provided in an agreement, copyright conferred by this Act, shall initially vest in the author.

(2) Where a person in the absence of an agreement to the contrary, creates a work under a contract for services, or in the course of employment by a government, a ministry, department or agency of a government or a prescribed international or inter-governmental organisation, the copyright in that work shall vest in that government, ministry, department, agency, prescribed international or inter governmental organisation.

# The Rights of Researchers and the IP Dimension in Health Research Data (cont.)

## Ownership Rights: Researchers vs Institutions

- **Patents and Designs Act 1971**

(l) Subject to this section, the right to a patent in respect of an invention is vested in the statutory inventor, that is to say, the person who, whether or not he is the true inventor, is the first to file, or validly to claim a foreign priority for, a patent application in respect of the invention.

(2) The true inventor is entitled to be named as such in the patent, whether or not he is also the statutory inventor, and the entitlement in question shall not be modifiable by contract.

(4) **Where an invention is made in the course of employment or in the execution of a contract for the performance of specified work, the right to a patent in the invention is vested in the employer or, as the case may be, in the person who commissioned the work**: Provided that, where the inventor is an employee, then--

(a) if- (i) his contract of employment does not require him to exercise any inventive activity but he has in making the invention used data or means that his employment has put at his disposal; or

(ii) the invention is of exceptional importance, he is entitled to fair remuneration taking into account his salary and the importance of the invention; and

(b) the entitlement in question is not modifiable by contract and may be enforced by civil proceedings.

**AI and Health Research: Ownership of Outputs**

- AI is increasingly used to process health/genomic data.
- Outputs may raise authorship/inventorship issues.
- Who owns AI-generated or AI-assisted work/invention?
- Nigerian and African IP laws are still silent on this.

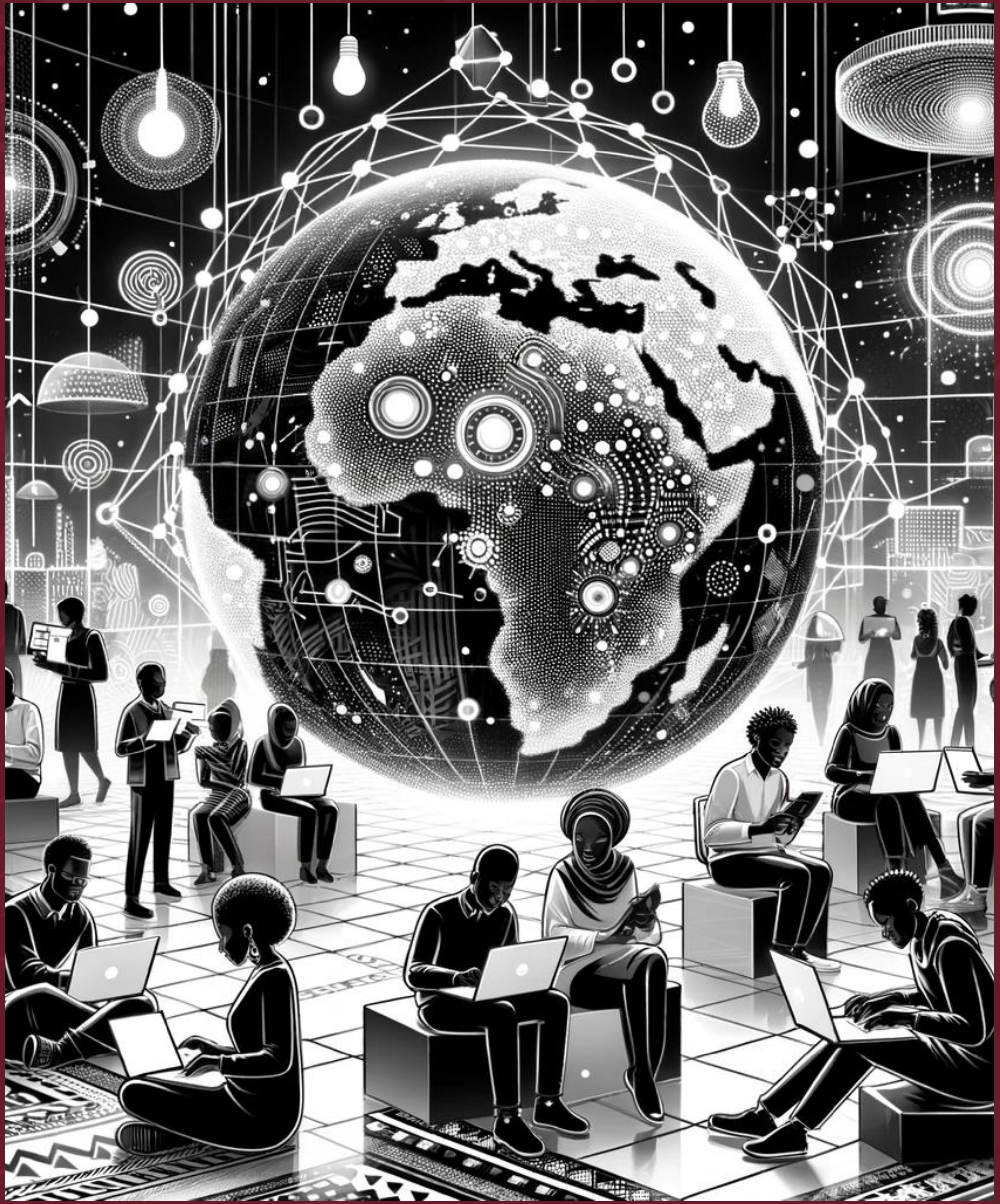
# The Rights of Researchers and the IP Dimension in Health Research Data (cont.)

# Conflicting Interests within existing data governance frameworks: A recap

- While proprietary models can serve as incentivising mechanisms, they may encourage biopiracy and restrict access (exclusive in nature).
- Open science promoting global data sharing vs the risk of exploitation, bias and discrimination against data subjects.
- Communities & participants demand control and value for their personal data.

# Conclusion and Recommendations

- **Fragmented Framework**: Current rules governing health data ownership in Nigeria – including data privacy rules, intellectual property (IP) laws, benefit-sharing principles, and institutional research policies – are fragmented and often raise conflicting interests among key stakeholders (data subjects/research participants, research institutions, funders, and researchers).
- **Implications:** This fragmentation undermines both effective access to personal data for health research and innovation and the protection of privacy, benefit-sharing, and institutional/researcher interests.
- **Reform Imperative**: There is a pressing need for policy and legal reforms to harmonise these frameworks. A complementary, coherent system is required that:
  - Guarantees data access for research and innovation;
  - Protects the privacy and benefit-sharing rights of data subjects;
  - Recognises and balances the legitimate interests of institutions and researchers.



# Conclusion and Recommendations (cont.)

- **Way Forward**: Adopt benefit-sharing frameworks for the use of personal information for health research and innovation.
- Integrate the prior-informed consent and benefit-sharing principles into the existing IP framework by amending the disclosure requirements in the context of patents.
- Legal clarity regarding data ownership: Institutions and researchers generating data are best positioned to be legally vested with ownership rights and held accountable. These ownership rights remain subject to privacy rules.
- Need to incentivise data-sharing and open science for public interest health research.