

# Overview of Governance Framework for Data Science Health Research in Nigeria

**Oluchi Maduka (PhD)**

Postdoctoral Fellow

Center for Bioethics and Research, Ibadan  
Nigeria



**THE GEORGE  
WASHINGTON  
UNIVERSITY**  
WASHINGTON, DC



DS-I Africa



# The BridgELSI Team



T. Ogundiran



C. Adebamowo



S. Akintola



A. Jegede



S. Callier



S. Adebamowo



C. Caga-Anan



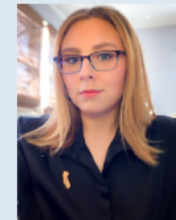
O. Adeyemo



O. Maduka



A. Akintola



J. Kukucka



# Data Science Health Research

- has enormous potential for discovery and optimization of healthcare
- raises several ethical, legal, and social (ELSI) challenges
  - The content and quality of the consent given by individuals
  - Benefits and harms to individuals participating in DSHR
  - Ownership of data
  - Privacy

This is particularly important in Low- and Middle-Income Countries (LMIC) like Nigeria where legal protections and ethical regulations are evolving.

# What is BridgELSI doing ?

## BridgELSI Project

Bridging Gaps in the ELSI of Data Science Health Research

Review of existing legal and ethical oversight for DSHR in Nigeria as a foundation for development of novel ethical oversight of DSHR in the country.





# Objectives of the BridgELSI Project

1

Evaluate current governance framework for Data Science Health Research in Nigeria

2

Survey the knowledge, attitude and practices of key stakeholders to current and emerging ELSI of data science health research in Nigeria

3

Engage with key stakeholders to develop novel Governance Framework

4

Implement training and mentoring in Data science and General Research capacity building for DSHR and ethics committees

# Methodology for Objective 1

Evaluate current governance  
framework for Data Science Health  
Research in Nigeria



Legal research & analysis  
approaches



Text analysis



Case law research



Primary and secondary data



Identified specific themes in these  
laws

# The Questions

What are the laws,  
that provide a legal  
and ethical framework  
for oversight of DSHR  
in Nigeria?

Do these laws and  
regulations provide  
sufficient framework  
for governance of  
DSHR in Nigeria?

What are the gaps?

deidentified health  
data

secondary use of  
identifiable health  
data

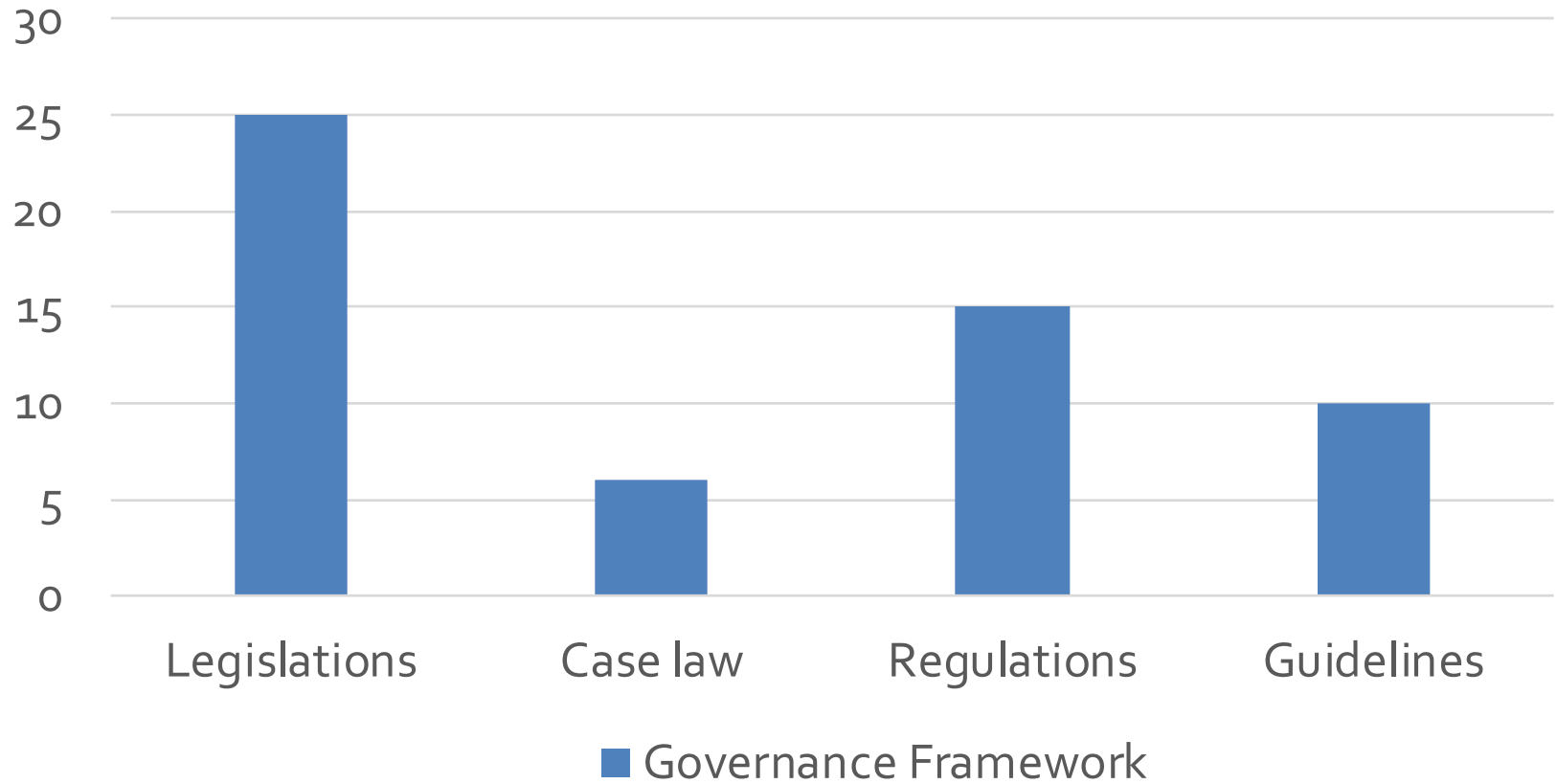
commercialization of  
data

Commercialization of  
tissue

## Specific Themes



# Extant Governance Framework





Question	CFRN	NHA	NCHRE	NDPR	NCME	CRA
Secondary use of existing identifiable health data in health research?	✗	✗	✓	✓	✗	✗
Govern what happens to deidentified health data used in research?	✗	✗	✓	✓	✓	✗
Commercialization of tissue?	✓	✓	✓	✗	✓	✗
Commercialization of data?	✓	✗	✓	✗	✗	✗

## FINDINGS

CFRN – Nigerian Constitution

NHA – National Health Act

NCHRE – National Code for Health Research Ethics

NDPR – Nigeria Data Protection Regulation

NCME – Nigerian Code of Medical Ethics

CRA – Child's Right Act

	CFRN	NHA	NCHRE	NDPR	NCME	CRA
Consent	✓	✓	✓	✓	✓	✓
privacy	✓	✓	✓	✓	✓	✓
Cultures, groups & communities	✓	✓	✓	✗	✓	✓
Rights of data subject	✓	✓	✓	✓	✓	✓
Dignity	✓	✗	✓	✓	✓	✓
Discrimination	✓	✓	✓	✓	✓	✓
Publicly available data	✓	✗	✓	✓	✓	✗
Anonymization/ de-identification of data	✗	✗	✓	✓	✓	✓
Ethics Review	✗	✓	✓	✗	✓	✗
Use of secondary or existing research data	✗	✗	✓	✓	✗	✗
Public health	✓	✓	✗	✓	✓	✗
Data collection	✓	✓	✓	✓	✓	✗

## FINDINGS

CFRN – Nigerian Constitution

NHA – National Health Act

NCHRE – National Code for Health Research Ethics

NDPR – Nigeria Data Protection Regulation

NCME – Nigerian Code of Medical Ethics

CRA – Child's Right Act

Nigeria has a robust research ethics framework

Data privacy and protection fall under several laws and regulations

The laws provide guidance particularly in relation to data subject rights, privacy and confidentiality, consent of research participants, protection of cultures, groups and communities, commercial uses of data, and protection from discrimination.

However, there are gaps or deficiencies regarding the ethical review of DSHR and the use of anonymized data, de-identified data, and publicly available data for health research

# RECOMMENDATIONS

- There is a need for the development of new governance frameworks for DSHR.
- That builds on existing laws and includes broad stakeholders' engagement.
- This ensures the protection of participants, researchers, and their products, and enhances trust and buy-in by the general population.

# Acknowledgements

We acknowledge the support of staff of the Center for Bioethics and Research, Nigeria

## **FUNDING**

Research reported in this publication was supported by the National Institute Of Mental Health of the National Institutes of Health under Award Number U01MH127693. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.





Thank you for listening