Evaluating Regulation of Data Science Health Research (DSHR) in Nigeria

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The use of data science in biomedical and health research enables large-scale multi-dimensional aggregation and analysis of heterogeneous data sources which could ultimately result in preventive, diagnostic and therapeutic benefit.

DSHR allows for the collection, analysis, and linking of information about people and their health to improve healthcare for everyone in unprecedented ways particularly in enhancing health research and drug development that may ultimately benefit low- and middle-income countries, like Nigeria where there are gaps in health care delivery and services. However, the governance and methodology and computational complexity of data science in health research raises novel ethical and legal challenges to which the legal framework of Nigeria is not prepared.

While it is undisputable that there is need for regulations and health research governance in order to protect subjects of DSHR from hazards arising from unaddressed legal and ethical concerns such as privacy and data protection and security, confidentiality, obtaining informed consent etc, it is doubtful whether the existing legal framework for health research in Nigeria effectively addresses these concerns.

Through an integrative review of literature, text, case law, existing laws and regulations and a thematic analysis was performed to determine their adequacy in tackling legal and ethical concerns in DSHR. Primary data were sourced using Nigerian Law Report and LawPavilion Law Report. Other secondary sources were accessed using Google Scholar, Jstor, PubMed, and Hein Online.

Preliminary findings suggest that though data science in biomedicine hold the potential for advancing health research, improving prevention mechanisms and optimizing healthcare delivery, yet several epistemic, legal scientific and normative challenges need careful consideration. For instance, legislative instruments were not developed with DSHR in mind, they do not adequately accommodate the attending legal and ethical concerns. These challenges have relevance for both the legal framework and the framing of criteria that should be employed when legal reform would be made both at institutional level and national levels. Based on this analysis, we provide some preliminary recommendations on how regulatory institutions in Nigeria could adaptively respond to those challenges.

It would be most desirable for the Nigerian Governments to overhaul the current pre-digital regulatory space to accommodate DSHR.