HARNESSING HEALTH DATA FOR PUBLIC GOOD: ETHICS, GOVERNANCE, AND LESSONS FROM THE UK LLC MODEL FOR AFRICA NATIONS.

Author: Olayemi Amusile[1,2] Supervisor: Rachel Calkin[1]

Affiliations: 1. Uk Longitudinal Linkage Collaborations, University of Bristol Room G.08, Canynge Hall 39 Whatley Road Bristol BS8 2PS, United Kingdom.

2. Commonwealth Scholarship Commission in the United Kingdom

Introduction

The UK Longitudinal Linkage Collaboration (UK LLC) is the national Trusted Research Environment (TRE) for the UK's longitudinal research community, supporting secure, ethical access to linked health and administrative data. Initially established as a COVID-19 resource, it now serves broader public-good research. With robust governance and transparency, UK LLC provides a model of responsible data use. Led by the Universities of Bristol and Edinburgh, it enables secure access to linked health, social, behavioural, and economic data from over 325,000 participants across more than 20 UK Longitudinal Population Studies.

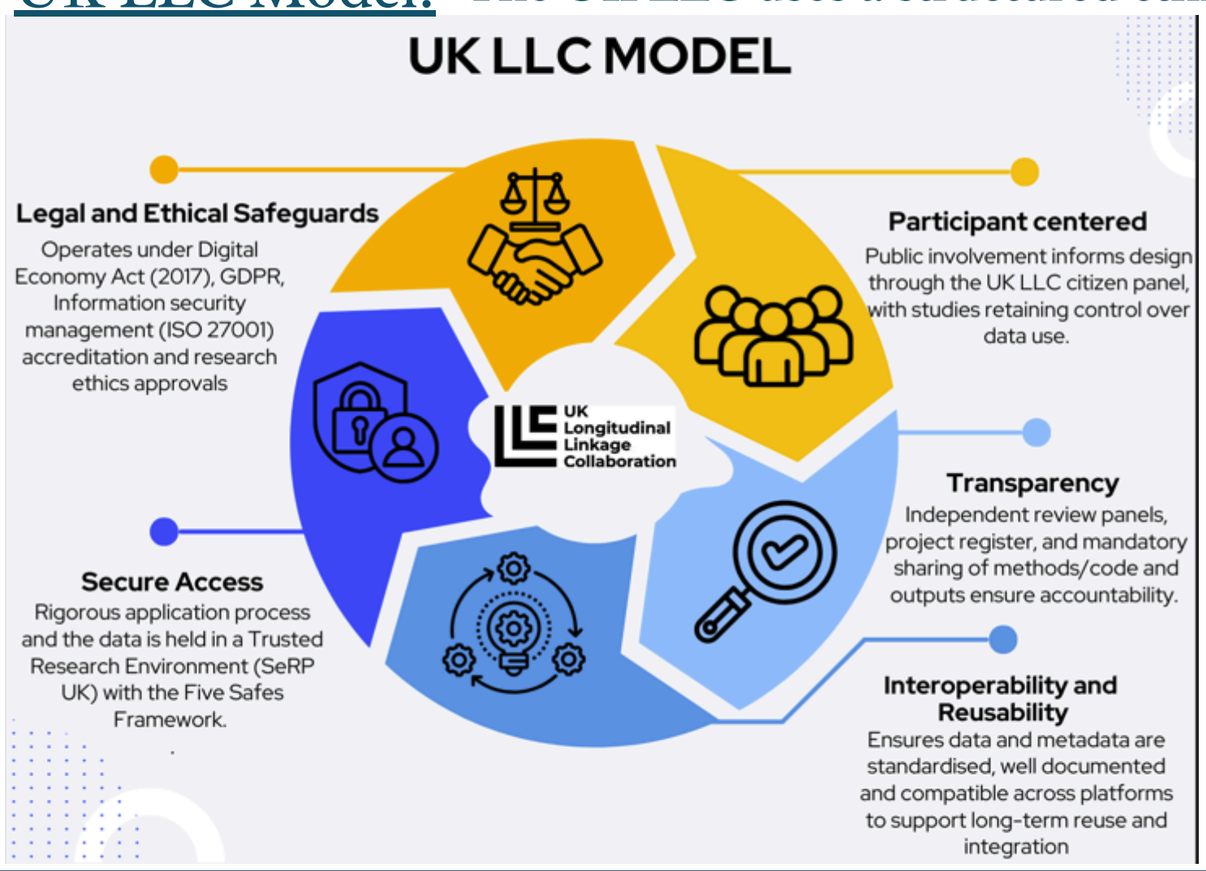
Objective

To explore how ethics and governance are embedded in the UK LLC platform and identify transferable lessons for health data systems in African countries.

Methodology

Figure 1. Practical steps

UK LLC Model: The UK LLC uses a structured ethics and governance framework



Lessons for Africa

African countries TREs and longitudinal initiatives show promise but can learn from the UK LLC in governance, researcher accreditation, and rigorous ethical and scientific review.

Many lack secure TREs, formal safe-output checks, transparency, and reproducibility practices, while public-benefit alignment and comprehensive use of the Five Safes framework are limited (Safe People, Safe Project, Safe Data, Safe Settings and Safe Outputs, Safe People).

Adopting UK LLC–inspired practices could enhance data security, ethical oversight, collaboration, and research impact.

Conclusion

The UK LLC offers a strong model for ethical and secure use of health data that supports public research and informs policy. African countries can adapt similar frameworks to strengthen their health data systems. A key priority is ensuring ethical governance and transparency, participants must understand how their data is collected, stored, and used in order to build trust and support long-term engagement.

References

1. UK Longitudinal Linkage Collaboration. (2024). UK Longitudinal Linkage Collaboration (UK LLC): The National Trusted Research Environment for Longitudinal Research. International Journal of Population Data Science, 9(1). https://ijpds.org/article/view/2468/6167

2. UK LLC: Trusted Research Environment for Longitudinal Data." UK Longitudinal Linkage Collaboration, https://ukllc.ac.uk/. . Accessed 26 Aug. 2025