Ethics of AI in global health research

Cape Town, 29&30 November 2022



Analysing a local imbalance of power ethics: University of Ghana vs. Data Commission

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Data is power; and whoever, whatever, controls data these days, wields power, or too much power. In conversations about the ethics of power relative to the governance of data, we give considerable attention to international imbalances of power, and how states, multinational organisations and peoples on opposite sides of the technology divide either exploit, or are exploited. I present, however, a case of a local or domestic imbalance of data power, and how it affects the conduct of Al-dependent bio-research at a local level. The domestic case I present on is from Ghana; and I present it as two tensions:

- Community engagement
- Institutional control

In October, 2021, the University of Ghana's School of Public Health, in collaboration with the International Food Policy Research Institute (IFPRI) advertised, and subsequently commenced the Accra Urban Adolescent Nutrition Study. The objective of the study was to describe the nutritional status, dietary intake, physical activity patterns, and food environment of about 1000 adolescents aged 12-19 years, from low- and middle-class households in 10 selected areas in the Greater Accra Region¹. A major component of the study required participants to wear a GPS/accelerometer-integrated belt to collect data on their physical activity and movement patterns for the period of the study, except when they were sleeping, after which their blood samples would be taken for analysis. The study had been approved by the Noguchi memorial Institute for Medical Research's Institutional Review Board, the Ghana Health Service, and the Ghana Education Service. Written informed consent and assent had also been obtained from both the parents/caregivers of the participants, and the participants themselves, prior to participation.

On the 8th of June, 2022, the Executive Director/Commissioner of the Data Protection Commission of Ghana, in a press statement, directed the University of Ghana to among other things, halt, with immediate effect, the said study, and conduct a Data Protection Impact Assessment (DPIA) to ascertain potential data risks which could have arisen from the conduct of the study since its commencement. The reason for the injunction? Some parents/guardians and teachers had raised concerns over the intrusive and sensitive nature of the data to be collected with the AI devices, and how these would be processed. The Commission investigated the concerns, and determined that the University of Ghana was not registered with the Commission as a data controller, and that it had breached a contract agreement with its sponsors (IFPRI), which required partners to comply with data regulations in their home countries.

The posture of the Data Commission, which has a mandate to "protect the privacy of the individual and personal data by regulating the processing of personal information", and "provide the process to obtain, hold and use or disclose personal information" has extensive powers to make the administrative arrangements it considers appropriate for the discharge of its duties, and investigate any complaint and determine it in the manner it considers fair. The DC's powers put it in a position of uncontrolled control over other data handlers, including the University of Ghana, and leave a lot of room for arbitrary government interventions and intrusions in the name of 'appropriate' and 'fair', with negative consequences, sometimes, for the conduct of bio-data-dependent research.

The concerns raised by some other parents/caregivers and teachers highlights a question of the ethics of community engagement: How much of community engagement should be done, the

extent and limits in the definition of 'community', and what communities should be engaged for the collection of AI data for research.

References

- 1. Press briefing, University of Ghana https://www.ug.edu.gh/sites/default/files/documents/Statement%20on%20the%20Accra% 20Urban%20Adolescent%20Nutrition%20Study_revisedc.pdf
- 2. Data Protection Act, 2012. Act 843

This paper was prepared for GFBR 2022. Further details on the meeting are available at www.gfbr.global.