

Ethics of AI in global health research

Cape Town, 29&30 November 2022



Case study

Ethical considerations in implementing The Data Advancing Wellness in Africa (DAWA) Project

Joan Gakii Masunga, MBE, Postgraduate Research Fellow, Harvard Medical School, Boston, USA

Brief description of the research project

The **Data for Advancing Wellness in Africa (DAWA)**, Swahili for “Medicine”) hence named **The DAWA Project** aims to build innovative technologies to collect and analyse big data, employed to better understand the determinants of cardiometabolic disease and mental health outcomes across sub-Saharan Africa (SSA), while advancing the health and wellness of Africans everywhere.

The specific aims of the DAWA project are:

1. *To create a tool, an African NCD Big Data Commons, for the generation of timely health information and wellness products at varied levels of complexity, be it in the patient, practice, policy and/or economic frameworks.*

The integration and harmonisation of data sources from various health organisation databases, geotagged smartphone devices as well as environmental and geospatial datasets from public sources will allow for the creation of an African NCD Big Data Commons. This will allow complex levels of data to be subsequently mined and enable us to deliver public health gains through the insights that big data analytics can leverage. This platform will be enhanced using automated data retrieval and harmonisation techniques and validated for future real-time collection and update of data into the Big Data Commons.

2. *To study the multifactorial determinants of, and outcomes from, cardiometabolic disease and mental illness in SSA using big data and its analytics.*

Data science will allow precise identification of high-risk populations, and comprehensive understanding of the study of diseases, including the interactions between behavioural, social, environmental, and economic determinants of health risk factors. The results can improve population surveillance and thus improve and target interventions for health promotion and disease prevention.

Background

Cardiometabolic diseases and mental illness continue to present a formidable burden of disability and premature mortality in sub-Saharan Africa. These populations also face disparities in healthcare and an ever-increasing cluster of behavioural, social, environmental and economic risk factors. Countries across SSA vary extensively in respect to their social and economic development and historical trajectories, each with their own specific health challenges and outcomes. Interventions and health promotion activities touted from traditional epidemiological studies from the US and Europe have been limited by the lack of African data available and variables studied and have not impacted sufficiently at the population level. These methods also pose significant timeliness and efficiency barriers from research to implementation, efficiency limitations and lack of spatial resolution. Currently, major impediments to advancing our battle in non-communicable disease (NCD) prevention and control in SSA are:

- a. The power to find unexpected associations, though potentially without substantive relevance
- b. The capacity to assess complex interactions with more complicated variable selection
- c. The potential to design dynamic interventions.

The DAWA project is being initiated to address these issues in collaboration with four African institutions located in South Africa, Nigeria, Tanzania, Uganda and three US institutions located in Boston, Massachusetts. This will provide an ecosystem comprising data scientists, engineers, software technicians, global health experts, epidemiologists, biostatisticians, and community representatives to advance data science applications for curbing the NCD burden. It will also further develop much needed human capacity to strengthen data science and computational thinking platforms on the African continent.

Ethical issues and commentary on each issue

Trust and trustworthiness

1. The DAWA project will collect considerable data to be analysed from participants that will be used by at least four distinct groups of stakeholders namely, health care providers, researchers, entrepreneurs and policy-experts. This data will include sensitive health information which raises questions of autonomy and privacy. Situated in the context of historical exploitation of the African continent, questions of trust, privacy, protection, and autonomy are paramount. For this project to be impactful, participants need to trust the researchers and staff requesting their personal data. It is therefore imperative that the research team establish trust and transparency with the participants¹. One way to do this is by elaborating how the collection of their health data will benefit them. A study on data sharing in health research in Kenya showed that research participants deem this to be of primary importance as they consider sharing their data for research². Additionally letting the researchers from the respected local institutions who have established relationships with the community members lead the project may help allay fear and apprehension of potential participants.

Fairness and equity

2. Identification and mitigation of algorithmic and data bias has received considerable attention in High Income Countries as AI use has become more widespread and societies have had more time to identify the problems. In Low-and Middle-income countries, however, because adaptation is still not widespread, the efficiency gains from AI interventions receive a lot more attention than the potential risks. Therefore, in implementing the DAWA project, bias identification and mitigation needs to be thought about pre-emptively³.

3. The DAWA study also seeks to elucidate underlying moral viewpoints within participants that may inform their health-seeking, political, and communal behaviours. The philosopher John Mbiti defines African personhood in a relational and communal context where having a sense of duty to others is normative⁴. It is therefore unwise to assume that Western individualistic moral viewpoints inform the behaviours and thought processes about justice and fairness of Africans. It is also equally misguided to assume that just one theory could be generalized to the entire continent⁵. Therefore, this study seeks to understand the underlying values specific to each cultural context to begin to understand what the epidemiological results mean in this context.

4. The DAWA project will be a collaboration between four institutions based in Africa and three based in the US. There is an undeniable power differential between the institutions which could alter in-group relations and participant willingness and disclosure. These factors could affect knowledge generation and production and therefore must be critically examined. One example of how this could present is for researchers from the US based institutions to replicate research designs from their home institutions that may render the study irrelevant for the target populations where the study is being conducted. For DAWA to be successful, mutual trust and respect must be established among researchers and staff across these organisations and all other stakeholders involved in the project.

5. The widespread penetration of cellular phones across Africa makes conducting the DAWA project possible. However the WHO Ethics and Governance of Artificial Intelligence for Health report shows that women in LMICs have less access to cellular phones and the internet⁶. Concerted effort to ensure that women are sufficiently recruited to participate in the study is therefore needed to ensure that they are represented in the datasets.

Conclusions and recommendations

For the DAWA project to be impactful, it is important to incorporate the perspectives of all the relevant stakeholders pertinent to this project in the design and development of AI systems, to ensure that the issues that are relevant to them are captured. Another important exercise to demystify AI in health research is to hold focus groups with proposed study participant groups to gauge their level of understanding and provide subsequent education to fill knowledge gaps.

Definitions of sensitive/protected groups need to be widened for an Africa specific context, so that such identifier data is collected proactively, and used for auditing later for potential bias. For example, whereas in the West, race is a significant sensitive feature, in Africa other sensitive features may include tribe, clan and religion. After identifying these potential dimensions of discrimination, conscious effort can then be made to ensure data collected covers all these groups.

In addition, in stipulating the type of projects that can utilize the data from DAWA, methodologies to document the provenance, creation, and use of machine learning datasets such as “datasheets for datasets”, should be encouraged to avoid discriminatory outcomes. This is an example of a best practice that can be embedded to inform the technical design and development of AI for health research and to mitigate potential unforeseen risks. Further, the machine learning community has in recent years developed various definitions of fairness. Examples include individual fairness and group fairness. Specific metrics include demographic parity, equality of opportunity and equality of odds. Depending on specific applications, a collaborative effort between researchers and subjects will be needed to identify the most applicable metrics on a case-by-case basis.

Finally, international bodies such as the WHO should consider instituting rules and regulations to guide the implementation of AI research in LMICs by external parties. Establishing of regulatory frameworks of operation should not be left to the goodwill or trustworthiness of researchers, global tech companies and their AI developers. A globally established framework will ensure that local populations are not exploited and that their rights and benefits are prioritized and served⁷.

References

1. Kerasidou A. Artificial intelligence and the ongoing need for empathy, compassion and trust in healthcare: La inteligencia artificial y la continua necesidad de empatía, compasión y confianza en la atención sanitaria. *Intell Artif Besoin Constant Empathie Compassion Confiance Dans Sect Santé*. 2020;98(4):245-250. doi:10.2471/BLT.19.237198
2. Jao I, Kombe F, Mwalukore S, et al. Research Stakeholders' Views on Benefits and Challenges for Public Health Research Data Sharing in Kenya: The Importance of Trust and Social Relations. *PLOS ONE*. 2015;10(9):e0135545. doi:10.1371/journal.pone.0135545
3. Gebru T, Morgenstern J, Vecchione B, et al. Datasheets for Datasets. Published online December 1, 2021. doi:10.48550/arXiv.1803.09010
4. Mbiti JS, Mbiti. *African Religions & Philosophy*. Heinemann; 1990.
5. Atuire CA. African perspectives of moral status: a framework for evaluating global bioethical issues. *Med Humanit*. 2022;48(2):238-245. doi:10.1136/medhum-2021-012229
6. World Health Organization. *Ethics and Governance of Artificial Intelligence for Health: WHO Guidance*. World Health Organization; 2021. Accessed October 1, 2022. <https://apps.who.int/iris/handle/10665/341996>
7. Kerasidou A. Ethics of artificial intelligence in global health: Explainability, algorithmic bias and trust. *J Oral Biol Craniofacial Res*. 2021;11(4):612-614. doi:10.1016/j.jobcr.2021.09.004

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