

Ethical Considerations in Implementing the Data Advancing Wellness in Africa (DAWA) Project

J. Gakii Masunga, MBE, MS
Postgraduate Research Fellow
Harvard Medical School

GFBR Conference
29th -30th Nov. 2022



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DAWA Project Aims



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The **D**ata for **A**dvancing **W**ellness in **A**frica (**DAWA**, Swahili for “Medicine”) hence named aims:

- *To create an African Noncommunicable Disease (NCD) Big Data Commons, to collect and analyse big data to better understand the determinants of cardiometabolic disease and mental health outcomes across sub-Saharan Africa (SSA).*
- 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.
- 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.

DAWA Project Aims



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Big Data Collection

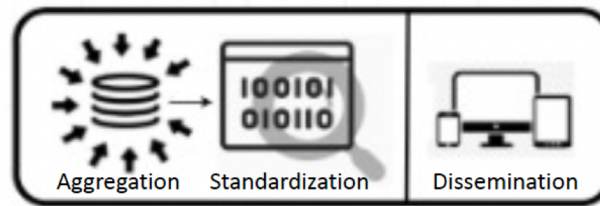
Medical Claims
Outcome Data



Smartphone App
Data from Patients
and Citizens



Publicly Available
Geospatial
Datasets



Integrating
and
Harmonizing data sources

DAWA Project Aims



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Data retrieved from Health Organizations Databases –
Understanding how data was collected may help mitigate bias:

- Data may exclude certain protected/sensitive groups eg. people from certain tribes or clans, those unable to afford care.
- Post-processing needs to be done to enforce fairness.

Prospective Data Collection considerations:

- Concerted effort must be made to ensure data collected is representative of the population by eg:
 - Actively enroll protected/sensitive groups.
 - Increase accessibility by providing voice enabled version of app so those who are unable to read can completed qx.



Importance of DAWA



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- There has been a surge in the burden of NCDs in SSA Africa (SSA) over the past two decades driven by increasing incidence of cardiovascular risk factors.
- According to the WHO NCD Progress Monitor, NCDs accounted for 37% deaths in 2019 in SSA rising from 24% in 2000.
- They are set to overtake communicable, maternal, neonatal, and nutritional diseases combined as the leading cause of mortality in SSA by 2030.
- There is therefore a need for reliable data about the distribution of NCDs and known risk factors, how they change over time, and how risk factors relate to NCDs outcomes.



Importance of DAWA



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- Large, long-term cohort studies in North America and Europe have been vital in determining disease etiologies, generating hypotheses for randomized controlled trials, and forming national health policy.
- Due to the combined effects of under-nutrition, infectious diseases, and other environmental factors, NCDs findings from other settings may not be applicable in SSA.
- Large prospective epidemiologic studies are therefore vital in determining NCD etiology and forming national health policies.
- Yet cohorts of this scale (hundreds of thousands of people followed for 20 or more years) do not exist in SSA.



Large Cohort NCD Studies

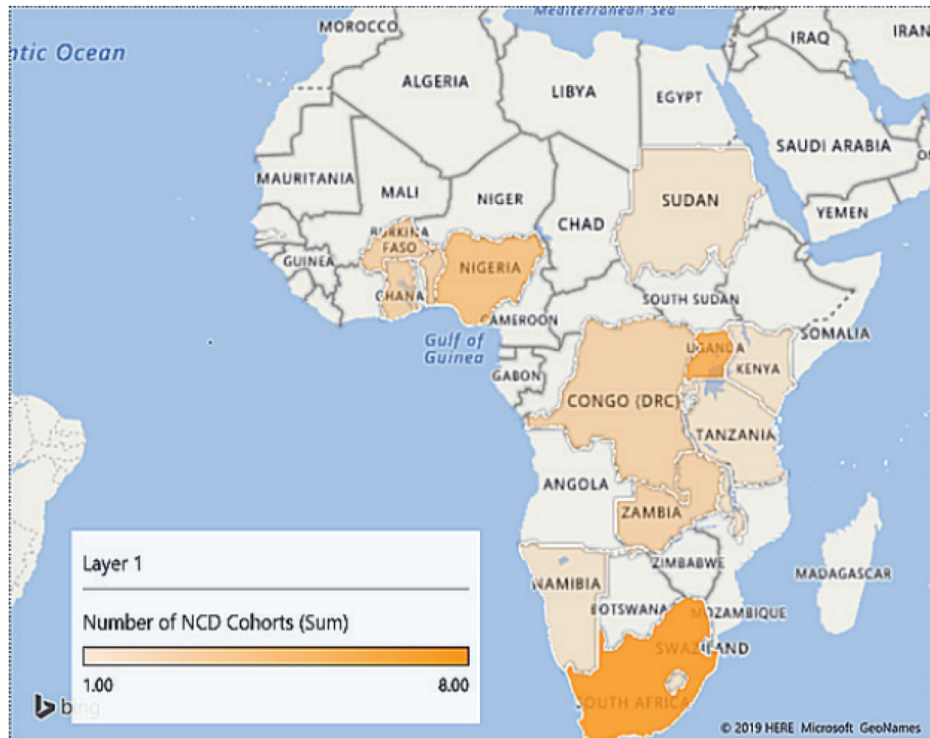


Figure 2. Map of non-communicable disease (NCD) cohorts found in SSA countries.

- Scoping review conducted to map the extent of current NCDs research from large prospective cohort studies in Sub-Saharan Africa.
- Inclusion Criteria:
 - At least one or more major risk factor other than age and sex.
 - Minimum of 500 participants.
 - 2 data collection points.
 - At least 12 months of follow-up.
- Total - 30 cohort studies from 18 countries. Majority from South Africa (27%) followed by Uganda and Zambia.

Feasibility of DAWA

- In 2008, feasibility of establishing a large-scale multicountry prospective study was explored.
- Pilot study conducted in four African countries.
- Participants randomly selected in the 4 countries.
- Sites used a 6-month follow-up.
- Consent and Data Collection:
 - SA and TZ – paper questionnaires, mail back complete.
 - UG and Nigeria – face to face/phone interviews.

COUNTRY	STUDY POPULATION
Uganda	Urban and Periurban Village Residents
Tanzania	Primary School Teachers
Nigeria	Health Care Professionals
South Africa	Teachers – Primary, Secondary and Intermediate schools

Feasibility of DAWA



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- Consent form and Qx translated into:
 - Kiswahili for TZ,
 - Luganda and Runyakitara for Uganda,
 - Afrikaans for SA.
- Qx collected:
 - Socioeconomic data
 - Infectious and NCD diagnoses
 - Mental health and injuries
 - Risk factors including smoking and alcohol use
 - Comprehensive Food Frequency Questionnaire (FFQ)



Feasibility Study Results



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- Total participants – 1415
- Median age was 41 years from 14 ethnic groups with 2/3 female
- 50% had access to clean-burning cooking fuel
- 70% had access to piped drinking water
- 92% had access to a mobile phone
- At 6-month follow-up, 68% completed the questionnaire (45% to 96% across sites)
- Majority sought medical care at public facilities or clinics

COUNTRY	TOTAL PARTICIPANTS
Uganda	497 Urban and Periurban Residents
Tanzania	229 Teachers
Nigeria	200 Nurses
South Africa	489 Teachers

Trust and Trustworthiness



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- Participants - will be asked to provide considerable data to be analysed that 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.
- To demystify AI in health research, the consent process should use easy to understand language to fill knowledge gaps



Trust and Trustworthiness



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- A study on data sharing in health research in Kenya showed that elaborating to research participants how the collection of their health data will benefit them was of primary importance to them.
- Additionally, regularly sharing with participants research outputs to show the impact of their contribution is a way to foster trust.
- Also, soliciting feedback on their experience with the data collection process and implementing changes based on this is paramount.



Fairness and Equity



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- DAWA 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.
- For DAWA to be successful, mutual trust and respect must be established among researchers, staff across these organisations and all other stakeholders involved in the project



Fairness and Equity



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- The widespread penetration of cellular phones across Africa makes conducting the DAWA project possible.
- However, the WHO Ethics and Governance of AI for Health report shows that women in LMICs have less access to cellular phones and the internet.
- 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.



Challenges & Opportunities

- Retention of research participants over the years – attrition due to competing priorities, no longer wanting to share personal data.
- Accuracy of data provided by participants – how to incentivize participants to share honestly?
- Participants' lack of trust in downstream users of data – these include policymakers, clinicians and public health practitioners, entrepreneurs
- Cohesion among research teams across the five countries