

Enhancing Fairness in digital health by improving representation in healthcare data

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In a Nutshell

Over the last 20 years, **Artificial Intelligence (AI)** has increasingly been applied in healthcare to enhance diagnosis, patient monitoring, and personalized care. However, there is growing concern that AI might worsen existing socio-economic inequalities and biases. This research focuses on improving AI fairness by fostering real-world data collection in Africa, specifically addressing breast and general cancer care in Nigeria.

The study **seeks to understand under what conditions patients are willing to share personal data**, emphasizing factors like perceived benefits, stigma, and transparency. It also investigates how AI and digital tools can enhance healthcare access and where these technologies can be integrated into patient care.

A **mixed-method approach** was used: interviews and desk research in phase one, followed by quantitative surveys in phase two. Initial findings reveal significant barriers in Nigeria, including limited AI awareness, poor healthcare access, mistrust, and stigma. Successful initiatives, such as collaborative frameworks between public and private sectors, NGOs, and digital health providers, highlight the potential for enhancing healthcare access and improving data representation.

Key recommendations include:

- **Stakeholder Collaboration:** Governments, private entities, and NGOs should unite to address Africa's unique challenges through innovative data-sharing approaches.
- **Community Engagement:** Involving local communities and trusted organizations can enrich datasets and align health solutions with local needs.
- **Policy Reforms:** Policymakers should invest in healthcare infrastructure, drive systemic reforms, and support robust data systems to enhance global health equity.

The research calls for public education campaigns about AI, transparent governance mechanisms, and capacity-building initiatives for healthcare providers to foster trust and improve AI integration.

Conclusion

Stakeholders must collaborate to empower patients in data sharing, ensure equitable representation in AI healthcare models, and leverage technology to bridge healthcare gaps. This approach is critical for achieving global health equity and addressing biases in AI-driven healthcare systems.

What we do and why it matters

This research aligns with the E4S Center's mission by tackling key challenges at the crossroads of **technological innovation, inclusivity, and resilience**. It explores ways to improve algorithmic fairness in healthcare through real-world data collection in Africa, particularly in Nigeria, thereby contributing to a more **inclusive economy** and comparing the findings with developed countries such as Switzerland. The study identifies strategies to reduce socio-economic inequalities and empower marginalized communities through equitable representation in AI-driven healthcare models.

The project also advances **economic resilience** by addressing gaps in healthcare access and data-sharing trust. It offers actionable recommendations for fostering collaborative frameworks involving governments, NGOs, and private sectors to strengthen healthcare systems.

Furthermore, the research demonstrates findings and recommendations how AI can generate economic, environmental, and social value by enhancing healthcare access and outcomes in underrepresented regions. It aligns with E4S's mission by proposing policies, community engagement strategies, and education initiatives to ensure sustainable and ethical use of AI technologies.

The recommendations target diverse stakeholders: **policymakers** to create equitable data-sharing frameworks; **healthcare providers** to build trust and reduce stigma; **technology developers** to design inclusive AI systems; **NGOs and community leaders** to drive awareness and community engagement; and **private sector entities** to invest in public-private partnerships. Together, these groups can empower patients, enhance data representation, and ensure AI fosters a fairer, more inclusive, and resilient healthcare ecosystem.

How we do it and main findings

For the project, we followed a two-step approach. Regarding the used methods (interviews and surveys), a clarification with the Ethics Committee (canton of Zurich and Vaud) were conducted, and a declaration of non-jurisdiction was issued

Phase 1 – Explorative qualitative interviews and desk research

Between fall 2023 and spring 2024, qualitative interviews were conducted with representatives from the Nigerian healthcare ecosystem to explore patient data collection, willingness to share data, and perceptions of AI. Roche Nigeria facilitated participant recruitment. Interviews were held online via Zoom, with a one-page project overview and informed consent sent prior. Seven participants represented pharmaceutical companies (2), healthcare providers (1), the National Health Insurance Authority (1), and patient advocacy organizations (3). Interviews were analyzed using qualitative content analysis, with findings supplemented by relevant literature.

The main findings from the interviews were two-fold. First, they highlighted key challenges in achieving fair data representation for AI in the Nigerian healthcare including limited awareness regarding the adoption of AI, poor healthcare access, lack of trust in sharing data and disease-related stigma potentially reducing data sharing willingness by avoiding care. Secondly, the interviews highlighted existing innovative public-private-NGO partnerships, yielding key

recommendations for stakeholders to enhance patient data sharing and equitable AI data representation, including multi-stakeholder collaboration, community engagement, and evidence-driven policy development.

As a further result of phase 1, the following research model was developed.

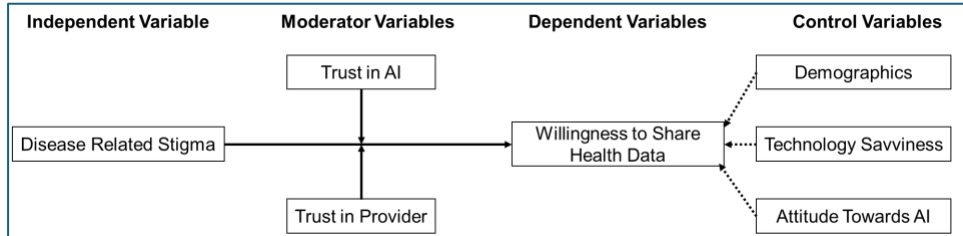


Figure 1: Research model

Phase 2 – Quantitative approach – survey

The first objective of phase 2 was to enhance the understanding of the identified aspects of our model (see Figure 1: Research model) and their impact on data sharing willingness by particularly focusing on the influence of disease related stigma (in our case focusing on cancer) and the role of trust in AI and healthcare providers as moderating factors.

The second objective was to evaluate the model in two distinct socio-economic contexts to establish a foundation for comparative analysis. The study compares Nigeria, representing a developing country, with Switzerland, representing a developed country.

The survey conducted in Switzerland (N = 162 participants) was carried out as part of a master's thesis, and the results were analyzed with R and subsequently triangulated through additional interviews (N = 12). First findings from the Swiss context revealed that stigma minimally affected Swiss citizens' willingness to share health data. However, trust in AI and healthcare providers emerged as critical moderators. High trust levels significantly increased data-sharing willingness, particularly under stigma. Willingness varied by scenario presented to the participants, being highest for diagnoses with family doctors and notably lower when AI was involved (family doctor using AI and AI app solely).

Due to extensive coordination for conducting the survey in Nigeria, this survey's launch was delayed. By mid-December, 162 participants have completed the survey. The results will be analyzed in the coming months.

Call for action

The integration of AI into healthcare in Nigeria highlights the transformative potential of public-private partnerships in addressing critical healthcare gaps. Our study emphasizes the need for diversifying healthcare data, particularly from underrepresented populations, to reduce biases in AI models and improve their effectiveness. Key findings and recommendations are as follows:

Diversification of Data: Stakeholders must prioritize the collection of healthcare data from diverse populations in Africa to mitigate AI biases and enhance model accuracy.

Public-Private Partnerships: In resource-limited settings, collaboration between governments, pharmaceutical companies, research institutions, and NGOs is essential to bridge data gaps. These partnerships offer mutual benefits, where governments facilitate data access and infrastructure, while private entities gain valuable insights into disease patterns and treatment outcomes, leading to innovative solutions.

Nigerian Collaborative Frameworks: The success of collaborative frameworks in Nigeria offers valuable lessons. Stakeholders must unite in their efforts, with a focus on innovative data collection strategies tailored to Africa's unique challenges. Engaging local communities and trusted institutions can enrich datasets and ensure digital health solutions are relevant to the population. Policymakers must use these insights to drive long-term healthcare reforms, investing in infrastructure and data systems.

The success of these partnerships relies on inclusivity, strategic collaboration, and long-term investment. By embracing these principles, stakeholders can create an equitable healthcare system in Africa, leveraging AI to improve health outcomes and drive global health equity.

“The common characteristics of successful collaborative frameworks in Africa include a commitment to inclusivity, a strategic approach to partnership, and a focus on sustainable infrastructure and community engagement. By embracing these collaborative approaches and focusing on inclusive data collection and sharing, stakeholders can create a healthcare environment in Africa that harnesses the full potential of AI to deliver improved health outcomes for all.”

- Yash Shreshta

Learn more

2024, Bridging the Digital Health Gap: An agenda for public-private access to Inclusive Data in Healthcare, Submitted to Communication Medicine,

The impact of perceived stigma on the data sharing behaviour of patients: A comparative study of Switzerland and Nigeria, WIP

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