

## **Africa Health Data Governance, is it about Sharing, Hoarding: Who does it Serves:**

**Moderated:** Benjamin Akinmoyeje, PhD Research student

**Rapporteur:** African Rapporteur Network (AFN)

**Lead Discussants:**

- Dr. Ime Asangansi eHealth4everyone Founder
- Taiwo Peter Akinremi, Data Protection Specialist (DAPT)

**Benjamin Akinmoyeje**, (PhD student who moderated the African Health Data session), welcomed the stakeholders on the call together with **Taiwo Peter Akinremi** (Data Protection Specialist with Data Analytics Privacy Technology Limited). Benjamin noted that the discussion of African's digital data is now at the front page of both national and regionally. Most discussion have been concentrated on having stronger data protection, privacy framework to limit data sharing and its protection. The health sector in general is known to generate a lot of data and a lot of these data are stored in silo. However, health data is probably the most affected by the current web of data regulations and privacy. Benjamin raised that data should be more beneficial to patients, but the argument is that with all massive regulations, privacy, and all these guidelines; are there no missing opportunities to get insights that can improve patient outcomes. As a round table discussion, a question was put to the table by Benjamin that are these regulations patient focused, how should health data in Africa be governed. Looking at regulations that are patient centered, could we have something different.

**Dr Ime**, (founder of eHealth4everyone) said this is a crucial conversation. It impact our ability to have robust health data infrastructure that helps all the players in the healthcare systems, from decision makers, governance and down to health workers and patient. Dr Ime put forward that protection is largely about protecting data. There are many regulations inherited from human rights approaches which include confidentiality that needs to be maintained. Research should be done in a way that data is reusable, and data should not be used without permission. However, it has its own drawbacks. Dr.Ime noted that sharing is a concern and sometimes there are conflicts with protection and sharing. However, regulation that promotes both protection as well as sharing is important. We have data protection policies, but we don't have data sharing policies for example in Nigeria. Therefore, there is for data sharing policies because people are protecting their own side of data especially among the doctors.

**Taiwo Peter Akinremi**, (Data Protection Specialist (DAPT)) loudly raised that Nigerian protection regulation is one step ahead in regulating their environment but however the focus is the African health data. Like the previous speaker, there is need for data sharing policy. As data protection practitioner, during audit exercise, how organization share data is a major concern and who they share it with. Taiwo said many organizations don't know the impact of data sharing. For

instance, in the health sector, there is hoarding of data which calls for sharing awareness. Taiwo also noted that patient should be at the center of data sharing.

As the round table discussion evolved, there are concerns as to whether putting protection first help the patient? It was noted that most patients are not really concerned about their data but rather what their data can do for them, in terms of more insights that can allow physicians to care for them. A question was raised as to whether we should have regulations that encourages decent or ethical sharing of data instead of people hoarding data. It was noted that with respect to African health data the first thing that need to be done is to identify what constitutes health data as that will inform what to share and the system that needs to be developed. It was raised that data are more sensitive to regulation than others, identifiable content such as name, date of birth and any information that can be used for tracking is generally more prone to regulations compare to aggregate data like total number of people with malaria. While there are regulations that regulates patient data, there is challenge of trained health workers, hence, need for health works on how to protect data and health information. It was noted that existing regulations have helped the healthcare workers to maintain compliance with the regulations. However, not so much for aggregated data and how it should be hosted. Also, data collection tools possess challenge of the uniqueness of local contest. It was noted that there is little to no compliance in the health sector, however, the regulation has really prompt the awareness. Another key finding is that health workers don't know how to share and the data they are hoarding, hence, the need for health sector to be driven by enforced regulation. The discussion noted that NDPR data breaching fine is not motivating enough. As mentioned, data sharing should come with advantages and incentives including the implications of not sharing should be boldly written. The discussion noted that data sharing comes with skills such as ability to anonymize and pseudonymize data. In the African setting, the main challenge is how do get people embrace sharing which can contribute to the global and national good. The discussion reflected that patient suffers the most if the data breached. Patient should be at the data center sharing process. Touching on data governance in Africa, it was identified that Leadership and governance are one of the main challenges, not just for data but also for many other things that we face on a day-to-day basis. Leadership and governance are required to provide a vision, provide the incentives, get everybody on the table so that there is knowing that patient is the most important person and roles are clearly identified. Data Governance leadership is how the data is managed, providing oversight for example is best practice to have a governance committee in big hospitals that oversees and reviews data protection and sharing management practices. In Nigeria there is a national data governance, but it is not operational, it is not executing its functions. A data governance rules are not being followed. NITDA by law are mandated to oversee data governance across all sectors, it can also be curious and eager to know how the interplay within the data governance between the regulatory bodies of data governance generally and the sectorial players. NITDA should liaise with the ministry of health. It was noted that leadership and governance are irregular and has been dormant for years. It was submitted that the only entity that can drive it is the user, so we have to bring the patient to the conversation and that needs to be user centric, and patient driven. To get people interested in their data and discussion there is need for webinar like this and capacity building to address the knowledge gap such as in-service training, school curriculum, sponsored training and awareness program. Another challenge identified are the big players that determined the destination of data

which make it hard for end users and local player to play-in. The way to fight the power asymmetry is through legislation. While there are issues and challenges, progress has been recorded across the continent and various African countries over the past 10 years in these various aspects. As the cyber space is becoming a more dominant role in our lives, some things are going to happen in future, a politician's data is going to be leaked and is going to create an opera that is going to be a major thing and these types of things make the politician more aware of these things. The round table discussion noted that data sphere is about introducing and looking at the concept of data governance in an arrangement where multiple players are brought on board to decide the destiny of data in a contextualized manner. There is call for new model, different frameworks, and different initiatives for the sake of data dividends for all stakeholders. And need for more advocacy to stakeholders that make all these laws, and ensure funding is made available for related data research. In conclusion, the workforce needs to be educated right from university to retiree. And infrastructure, internet to host data need to be addressed to encourage locally hosting of information.