

MY DATA OUR HEALTH

Personal health data is the most crucial part of someone's identity as it affects most aspects of their lives including the services they receive. However, we share our data frequently whenever we are seeking services at health facilities or even accessing health information online about certain ailments. There are health application forms and apps that collect personal data during registration before a client gets the services or information they seek. sharing health data raises a concern about individual privacy due to trust issues in health workers handling and collecting the information. This makes the patients or clients have no confidence in the security of their data which results in them concealing or filtering information for fear of their data being leaked or used wrongly.

There is limited information on how personal health records are handled, who controls them, and how they will be used after collection both now and in the future. Most people will be willing to share their information if it will be used for the greater good of their health or the public through diagnosis, treatment, or research. No explicit information is however available on how the data will be used and concern on consent in case the data might be re-used in the future is wanting. It is crucial to inform the client on how the data will be used and seek their consent in case of future re-use.

In Kenya, it is normal to give your information without questioning how it will be used because, for the longest time, we have not been demanding to know. Most health practitioners do not seek consent while extracting data from clients. Perhaps the public does not just put much attention to what might happen in case of a breach. Mostly, they are not aware they can access their health records anytime they want. The limited knowledge of data governance makes the public not demand action from policymakers to legislate laws and policies that govern health data privacy. This in turn makes the government put less effort into the law implementation since it seems less prioritized by the public.

There are several laws and guidance on health data governance in Kenya. The healthy policy promotes the use of technology in healthcare but requires medical institutions and practitioners to maintain high confidentiality of patients' privacy. Article 35(b) of the Kenyan constitution states that any citizen has the right to access information held by another person and is required to exercise or protect any right. The federal law also sets guidelines for how health practitioners can handle data. Also, it dictates and limits who can access the medical practitioner's health records. You cannot access any other person's health record until you provide proof of identity, because health practitioners are required to keep a patient's record confidential. This is information that a lot of the public is not aware of.

Health records are strictly to be used to support research, help create new drugs, and plan and provide patient care. They are only to help in the goodwill of the health field, the patient, or the public. When data is mishandled it affects public health interventions. It means no more funding for the health field since there is no research being carried out from the data recorded. To some extent, key and marginalized populations can be discriminated against based on their health records.

Data governance is an issue that needs prioritization and more conversations around it. We should not turn a blind eye to how important part of our life our health records are. There should be efforts to sensitize everyone from the media, policymakers, and medical practitioners to the public on data governance, who controls it, and its accessibility. There should be enough legislation on health data



governance for everyone to understand what the law states and how better they can be upheld whereas more laws should be enforced to protect the patient's confidentiality including a framework to engage the communities at the grassroots level on the health data governance and protection.

Our key call to action is to call for the government of Kenya to prioritize the health data governance framework, to initiate conversations on a global health data governance guide with World Health Organisation (W.H.O) in WHOA76 that can be domesticated into different nations including Kenya.

Article by Sharon Sitati

Volunteer NivalishePad Initiative.