



# SEMINAR ON DIGITAL HEALTH DATA MANAGEMENT AMONG THE YOUTH IN UGANDA

**THEME:**

**Digital Health Innovation And Technology For Youth  
Empowerment**

30<sup>TH</sup> MARCH 2023 AT AHAKI



## Background

Digital Health initiatives must be guided by a robust strategy that integrates financial, organizational, human and technological resources. World Health Organization came up with the Global Strategy on Digital Health 2020-2025 with the aim of promoting healthy lives and well-being for everyone, everywhere, at all ages. This strategy is underpinned by global resolutions related to digital health and a specific resolution on digital Health solutions in the African region. Africa is in some ways poised to make use of these technologies through the rapid growth of mobile phone ownership and use. However, it is critical that Africa is not left out of new advances and it is equally important to approach new innovations thoughtfully.

The use of Internet, email, social networking sites and mobile phones is rapidly expanding in the African Region. Between 60% and 80% of people in the Region are estimated to be using mobile phones. These tools and platforms are creating opportunities for the effective use of digital health solutions, applications and services to improve national health systems.<sup>1</sup>

The lives of adolescents and young adults (AYAs) have become increasingly intertwined with technology. National surveys show approximately 92% of teens go online daily and 95% of teens report having a smartphone or access to one.<sup>2</sup>

As technology is increasingly available, to managing health and well-being, the potential for using these platforms to extend health care delivery and advance patient engagement and education is highly demanded.

---

1 <https://www.afro.who.int/health-topics/e-health>

2 <https://www.pewinternet.org/2015/04/09/teens-social-media-technology-2015/>

## Objectives of the Seminar

1. To contribute to the understanding and contesting of the digital inequalities related to digital health data management in Uganda.
2. To share experiences on the strengths and challenges faced by youth in using digital technology for collective action.
3. To propose an ideal mechanism for digital health data management, benchmarking on experiences of the youth.

## Outcome

Promote deeper interest in digital health data management and innovation

## Methodology

The seminar employed a range of participatory methodologies such as presentations, plenary discussions and experience sharing to create a range of experiences and knowledge on digital health systems.





The opening remarks were made by Mr. Baguma Christopher the Director of Programmes, Ahaki who thanked everyone for their attendance and to the experts for sparing time to share their views and experiences on health apps.

He gave a contextual discussion of the intention of the seminar which was to create more ideas and experiences that will inform the dissemination and final report. He highlighted on the confidentiality issues in terms of privacy, data security, ownership as part of the things we need clear guidance on-going forward in the day's discussion.

How best can we contribute to the regulatory frameworks that can make sure that any user is safe with their data as well as issues of service providers and how they keep data. But also reminded participants that digital information is not only IT but it entails many areas i.e., policy, regulatory among others key components and the need to pave way to create a legal framework for the country in terms of accessing e-Health and usage.

**Figure 1:** Mr. Baguma Christopher, the DOP, Ahaki giving his opening remarks

## SESSION TWO



### Expert panel Discussion

The panel discussion was moderated by Ms. Joyce Nabaliisa, the M&E officer at Afya na Haki. The panel comprised of:



#### **Mr. Ddembe Andrew, Chief Executive Officer, Mobiklinic Uganda**

Andrew is a health equity advocate, entrepreneur and innovator. He is a lawyer that focuses on health law matters. He represents Uganda in the AU-EU Youth hub project, a brain child of the African Union and European Union that collects youth experts. Andrew is the founder and CEO of Mobiklinic Uganda, a digital health organisation that uses both physical and digital means to empower community health systems. Mobiklinic was awarded innovation of the year 2020 by CEO Summit and also selected as fastest rising social enterprise in Africa by the ACT Foundation of Nigeria.



### **Dr. Miiro Chraish, Pharmacist at Mulago National Referral Hospital**

Dr. Chraish is a passionate researcher in digital health technologies. He has four years of experience in health information systems in pharmacovigilance, community health services and HIV/AIDS care. He worked with National Drug Authority, in Uganda to implement IT enabled pharmacovigilance projects across the country. Dr. Miiro has also led research collaborations with HEPI, Fvital of Japan and SimPrints International in community health systems in last mile areas.



### **Ms. Lillian Nalwoga, Programme Manager, The Collaboration on International ICT Policy for East and Southern Africa (CIPESA)**

Lilian has seven years of ICT policy research and advocacy experience. She has facilitated and coordinated ICT policy workshops- including coordinating the East African Internet Governance Forum in 2011 and 2015. She is also the president of the internet society (ISOC) Uganda and an advocate for digital apps. Lillian holds a master's degree in Digital Media and society from Uppsala University, Sweden.



### **Mr. Agaba Benedict, Health Informatics Specialist at the Ministry of Health, Uganda**

Benedict is a health informatics specialist, with eight years of experience in health information technology and working in the health space. He has a master of science in Health Information Technology from Mbarara University, Uganda. Benedict works on the HIV/AIDS program under the division health information, Ministry of Health, Uganda.

## OVERVIEW OF DIGITAL HEALTH APPS

Over 65% of the youth in Uganda use smart phones. Some of the digital health apps being used in Uganda include M4RH, Rocket health, Mobiklinik app, Tele medicine, M health, and Remote patient monitoring among others.

There is need for digital health because of the human resource gap in the country. Digital health apps services have bridged the gap of service inequality especially in the rural areas where there is lack of trained human resource. This can be statistically justified by the ratio of 1 doctor: 20,000 people of which these doctors prefer the urban centres to the rural areas. Digital apps are especially needed in situations of pandemics and outbreaks, not forgetting the demand principles, and intellectual property rights as standards for developing these apps. These standards must be prioritised.

The first line of contact with Uganda's healthcare system is the Village Health Teams (VHTs), however, it has been long since the VHTs received formal training, then the issue of distances, and traditional birth attendants who are not part of Uganda's healthcare system have greatly impacted on the need to equip and strengthen community health systems.

“

*Many people are still struggling to use digital platforms; there is need for investment and mobilisation geared towards digital health literacy to enable smooth use of digital platforms for people to enhance their health.”*

**Mr. Andrew Ddembe**

Mobiklinik's part of work is the skill set and creation of an interface with the respondents. The Mobiklinik app is used by VHTs and doctors, to call for first hand ambulances, first aid, and integrated referral. Mobiklinik doesn't work in isolation, they work with health facilities to deal with ideal problems and universities such as Clarke International University to train VHTs.

## How is health data managed?

“

*Most health Apps developers are mainly concerned with the functionality of the apps. The MoH is mandated to protect the consumers.”*

**Mr. Benedict Agaba**

The health informatics specialist took the team through the steps of data flow from the lowest level to national level. He emphasized the need for capacity building especially for the data persons at the lower level but this deals with health. However, for health data that is collected through the health apps, it is directly harvested to the central depository at the Ministry of Health.

Therefore, there is a lot of data privacy and confidentiality as personnel interact with the data.

Health care practitioners have expertise in data protection. Data is always secured. Therefore, whichever information shared must be confidential. Primary data can be easily recovered by reaching out to the primary source and getting clear information. Though, whichever data one collects is part of the optimisation process so the data backup is quite one thing that is incorporated in these health apps.

In case of data breach, the MoH has a fully-fledged department to monitor and that is the Standards Compliance and Patient Protection Department (SCAPP) to handle any kind of complaint. But also, all media platforms such as twitter, Facebook and others are avenues for one to get feedback.

## Are there policies in place specifically for health apps?

There are no specific policies for health apps, however, there is continued reference to existing legislations for guidance. The Ministry of Health is drafting guidelines to ensure that a clear mechanism is put in place for the actors. There are laws and innovations like the Data protection Act 2019 which is associated with the challenge of alignment with digital health aspects and the ignorance that exists among the population.

Other sources of legislations currently in use include; The NITA Act 2009, The Registration of persons act 2015, The Electronic Transactions Act 2011, Computer Misuse Act 2010, Electronic Signatures Act 2011, Uganda Communications Commission Act 2013, UNC-



Science and technology Act, Copy right Act and many others. Although all these laws don't directly speak to digital health, they inform any developer of such apps who may intend to register persons for Ugandan citizenship.

## **What are the criteria for qualification of the app for usage by the people?**

The ministry of Health under the established structures and within the line department has criteria and basics that it looks at, such as; research made by the developer on the particular aspect to avoid malfunction, the developed app is then presented to the Digital Health Sub Committee which then checks for the relevance of the app and whether it is essential and what gap it is trying to address. After approval then it's recommended to the health information and innovation research technical team and these may make some recommendations then send to the top management for final approval. Involved bodies include National Information Technology Authority (NITA)-Uganda and the line regulator such as Uganda Medical and Dental Practitioners' Council (UMDPC).

## **Do you think that the policy environment is favourable to the current digital innovations?**

Several policies are in place such as the laws and the data protection office that looks at the oversight of data flow in the country. But these haven't been able to regulate digital health information. And a lot of hackers on the globe something we need to be cautious of not to happen in the health sector. As a country the need to look at the issue of digital health tracing and the ability to use apps to advance our health can then proper.

“

*The youth need to appreciate how digital health works. They need to get involved in the spaces and identify platforms for more information to aid their innovations and refine existing policies”.*

**Dr. Miiró Chraish**

On the issue of the use of these apps, many people face hardships to use these apps and the ability to operate them. But when we talk about young people, they are able to operate such gadgets. The issue then becomes how are we able to see that the security designed for these apps is effective and worth to share health related issues of patents and safety with the data.

## What is the role of CSOs in terms of digital innovations?

A number of awareness has been made and focused on the policy and making people understand how to use technology for evidence-based research and do ground advocacy and capacity building.

“

*Civil Society Organisations have actively created awareness on meaningful use of the internet and digital platforms as well as providing evidence-based research to contribute to shaping favourable policies regarding digital health data management”.*

**Ms. Lillian Nalwoga**



**Figure 2:** Panel session with experts and the moderator Ms. Joyce Nabaliisa, M&E Officer, Ahaki



## Plenary

On the issue of the criteria for developing these apps for a particular place and not the entire country, the panellists remarked that this relates to the audience and in most cases the funder but also the need dictates the target population to service within the health sector. But many players usually have their target areas, population like AMREF, Vision Fund, Mild May etc.

On the issue of where data that's stored and generated from smart watches and the kind of apps is kept, the panellists remarked that this is a grey area but once you subscribe to such a service provider then you need to read the policy guidelines and rules before you sign up for such an app. Read through and sync before you sign up for these apps but most likely many people do not read these ToRs. In regards to data loss and misappropriation of data by a health provider, this depends on a case-by-case scenario. Each person/ service provider is personally liable.



## SESSION THREE



### 🔴 Youth Panel

The youth led panel discussion and engagement was moderated by Mr. Nsubuga Acksam, an Associate in the Advocacy Capacity Enhancement Department at Afya na Haki together with Mr. Jessy John Nabundesi from Community Health Advocate – Wakiso. The discussion featured youths from various organisations who attended the seminar and these included; Nkoobe Fatiha from CEHURD, Florence Nabukenya from PHAU, Nabatanda Gloria from Smart Youth Network Initiative and Kiganda Willian from CHAWD. A number of views from the youth were shared in regards to digital health data management which took a Focus Group Discussion (FGD) form of interaction that included the following ;

### **Experiences sharing and challenges faced using digital health apps as a youth**

The youth panelists shared positive experiences and challenges faced while using these digital health apps and the issue of confidentiality. That whereas youth are eager to embrace digital innovation, there is need for securing their data. This can come in terms of regulation oversight and better policy frameworks and this speaks to the standards created to have trust in such digital health systems.



*Most young people are not devoted to reading; health apps developers need to summarise the information, clarify and make it accessible in languages even a layman can understand”.*

**William- Community Health Advocates Association of Wakiso.**

## Major highlights from the discussion:

- a) The content that forms part of the privacy terms which are expressed in hard, technical terminologies and lengthy paragraphs and opined that these need to be summarised for ease and maybe put in graphics.
- b) Another youth shared experience on access to such digital health data with his vast experience as a community activist in Wakiso, he noted about the need to increase awareness among youth on the use and accessibility of the health apps. There is need for training especially on the usage and language. Youths suggested that the languages could be translated to various languages in the country.
- c) But again in terms of liability, accuracy and safety, where does liability fall when one follows the apps for example the menstrual apps and the user for example conspires but also where some complaints can be lodged.
- d) The issue of service delivery in terms of using internet and the restrictions related to access some of the information since some times these apps require payments and restriction to operate in particular countries. How then can the government be able to give a hand for effective usage of such health information.

The youth highlighted some fears like the safety of the information being shared hence an issue on privacy needs to be addressed since information is shared and stored on foreign store servers.

- e) There was a growing concern on how best can countries like Uganda domesticate or create better formidable guidelines and frameworks, it was argued that much as these regulations are from the EU, most of these have been domesticated and these supplement to the already existing laws operating within the country and those yet to be enacted.

## Do you think these health innovation have a great impact towards the improvement of our health?

The youth panelists highlighted that some of this information is relevant but the usage turns out to be interpreted in a more negative way.

### Plenary

In terms of how to deal with the issue of privacy and access to health information, it was observed that all persons operating within Uganda dealing in data are mandated to register with the data protection unit.

On the issue of how misinformation is handled at the MoH and the authenticity of such data for the users; experts highlighted that quality and educated people who understand the concepts and proper information fed onto the systems need to be engaged.



**Figure 3:** The Panel session with youth and the moderator Mr. Aksam Nsubuga, ACE Associate, Ahaki

## Low Hanging Fruits

1. We can better the issue of frameworks through access to trainings and innovations for many to think about such basic information on health, making sure that the developed frameworks be used and creation of awareness rather than creating more legislations, policies and guidelines.
2. Train health workers on how to best use these systems i.e., Ministry of Health dashboards but also empower health facilities to know, use these innovations and be able to access these systems.
3. The population and the youth should embrace technology and know how it works in order to appreciate these digital health apps and make good use of them. *"In order to embrace technology, you should know how it works"* one of the panelists highlighted. The need to know how it works, what are the opportunities, get into the spaces about these discussions and then what role do you want to play?
4. Appreciating the innovations put in place and build on them to create more ecosystems and with favourable policies we can make the health system better.
5. The question about awareness, safety, how to operate the apps or the usage all these should be the questions addressed to the policy framework that should be put in place.

## Emerging Issues

1. The urgent need for a policy framework to deal with the guidelines to be followed since there is no direct law regulating the digital health apps an example are the illegal apps operating with in the country.
2. There is need to shape ideal mechanisms for digital health data management benchmarking on experiences of the youth so as to better serve them.
3. Acquiring contemporary understanding of digital health data management in Uganda through advocacy campaigns especially in the context of digital literacy and documentation
4. There is an urgent need for digital literacy as a means of improving the use of digital health apps.
5. There is need to deal with misinformation and disinformation in the region (Africa) so as to create confidence amongst the population that is consuming the digital platforms.
6. Developers of digital platforms should consider confidentiality as a means of protection of data and make use of the available regulatory frameworks as they develop apps.
7. The role of CSOs in Advocacy, evidence generation, awareness creation and capacity building.
8. Regulators have to involve the community in the policy formulation and awareness of laws.
9. Over regulation hinders innovation especially when it comes to digital apps. When the sector is over regulated, it may kill innovation and creativity.
10. Training of health practitioners on data protection both at the lower levels and the national levels on management of digital data and information.
11. What solutions can be put in place to solve the issue of the social structures that tend to make workers abandon rural areas to work in urban centers?
12. The efficiency of the data accessed by the digital health users on the various platforms stood out firm.



Plot 6105, Valley Road, Canaan Sites Nakwero  
Gayaza-Kalagi Road  
Tel: +256 (0) 414 660 733  
Email: [info@afyanahaki.org](mailto:info@afyanahaki.org)  
Website: [www.afyanahaki.org](http://www.afyanahaki.org)

**ahaki**  
Afya na Haki  
Harnessing Africa's Potential

  
**WARWICK**  
THE UNIVERSITY OF WARWICK

  
**wellcome**