MY DATA, OUR HEALTH CAMPAIGN

Communique from the National Consultation on Health Data Governance

Tamarind Tree Hotel, Nairobi | 2 July 2026

On 2 July 2026, the Health NGOs Network (HENNET), in collaboration with KELIN and under the broader Transform Health Kenya Coalition, convened a National Consultation on Health Data Governance at the Tamarind Tree Hotel in Nairobi. The consultation brought together civil society organisations, youth and women led organisations, health workers, researchers, media, and government representatives to reflect on their lived experiences of health data systems in Kenya and to shape a shared civil society position on how these systems should be governed.

The consultation was held as part of the My Data, Our Health campaign, a civil society initiative advancing accountable, inclusive, and rights-based health data governance under the Digital Health Act 2023 and the Data Protection Act 2019. Participants responded to a structured reflection covering their awareness of health data, their personal and professional experiences, and their views on access, privacy, equity, data quality, and the use of data for decision making. This communique captures the collective voice that emerged.

What participants told us

Awareness is growing, but it is uneven. Participants came with a wide range of understanding. Some described themselves as well versed in the policies and laws that govern health data, while others said they were still learning. A striking number told us they understood the subject far better by the end of the day than when they arrived, a clear sign of the appetite for this conversation and the value of creating spaces for it. Across the room, participants understood health data as the personal information collected during care, including weight, blood pressure, diagnoses, treatment, and medical history, gathered at facilities and by Community Health Promoters, stored in both paper and digital systems, and used for patient care, planning, disease surveillance, and policy.

Experiences with the new systems are mixed. Many participants have interacted with digital health platforms such as Taifa Care, the SHA platform, KHIS, and facility level electronic medical records, in their roles as patients, health workers, researchers, peer monitors, and Community Health Promoters. Several praised the speed and convenience the systems bring, describing faster service and accurate records that follow the patient from one visit to the next. Others pointed to persistent frustrations, including frequent system downtime, slow applications, lost data, and the fact that records from years past were never migrated into the new systems. The experience in rural facilities was described as slower and more difficult than in urban and private settings.

Patients still cannot easily reach their own data. One of the strongest and most consistent messages was that ordinary people struggle to access their own health information. Participants noted that access depends heavily on who you are, with health workers and researchers finding it far easier than patients and members of the public. Several described the frustration of having a legal right to their records on paper while lacking any practical,

patient facing way to actually retrieve them. This gap between the right and the reality was raised again and again.

Trust and privacy remain fragile. Confidence in how health data is secured ranged widely, from those who felt fully assured to those who were openly worried. Recurring concerns included cyber security and the historical vulnerability of government systems to attack, uncertainty about what happens to data once it is collected, and the sense that data is sometimes used without the knowledge or consent of the person it belongs to. Some participants noted that they trust secure digital systems more than paper records, which can be lost, damaged, or seen by the wrong people.

Systems are not yet inclusive. Participants were clear that health data systems do not yet serve everyone equally. They pointed to a divide between well-resourced urban hospitals and rural facilities still relying on paper, and to the exclusion of persons with disabilities, the elderly, people with lower literacy, and communities in informal settlements and remote areas. True equity, they stressed, will only come when every facility has the same tools and every population is included in both data collection and decision making.

Data quality reflects the pressure on the system. Where data is automated, participants felt the margin of error was smaller. Where records are still manual, they described errors, omissions, and delays, often the result of overstretched health workers rushing to record details for large numbers of patients. The result, several noted, is data that does not always reflect the true situation on the ground.

Data is not yet fully used to improve services. While many agreed that health data supports planning and decision making, participants gave pointed examples of data that is collected but not acted upon. One noted that data on post abortion cases points clearly to unintended pregnancies, yet family planning commodities remain in constant stock out. Others observed that services can remain poor even where the data is available, and that the country has not yet used its data for predictive planning and forecasting.

A shared call to action

From these reflections, a clear and shared set of priorities emerged. Participants at the National Consultation call on the Ministry of Health, the Digital Health Agency, the Office of the Data Protection Commissioner, county governments, and Parliament to:

- Guarantee patients the right and the practical means to access their own health records, through simple, patient facing digital tools.
- Strengthen the implementation of the Digital Health Act 2023, with particular attention to interoperability, so that Taifa Care, KHIS, the SHA platform, and other systems can talk to one another and present a complete patient record.
- Invest in digital health infrastructure in rural and underserved areas, including connectivity, devices, and reliable systems, so that no community is left behind.
- Reduce system downtime and stabilize the platforms that health workers and patients now depend on.
- Strengthen data security, privacy, and transparency, and make clear to every person how their data is collected, stored, used, and protected.

- Ensure meaningful consent and engagement at every stage, from collection through analysis to decision making.
- Make the systems genuinely inclusive of persons with disabilities, the elderly, people with lower literacy, and communities in remote areas and informal settlements.
- Invest in training and capacity building for health workers on data management and data quality.
- Raise public awareness of health data rights and responsibilities through sustained community sensitization.
- Close the gap between what the data shows and the services people receive, and build towards predictive planning that anticipates health needs.
- Progressively increase domestic financing for health data systems and reduce reliance on donor funding, so that Kenya owns and localizes its own health data infrastructure.
- Close the remaining gaps in the legal framework governing the collection, access, and use of health data.

The way forward

These are not abstract policy demands. They are the voices of the people who use, build, and depend on Kenya's health data systems every day. The My Data, Our Health campaign will carry this collective position forward into continued engagement with the Ministry of Health, the Digital Health Agency, the Office of the Data Protection Commissioner, Parliament, and our partners across the Transform Health Coalition, and into the position papers and policy dialogues ahead. Health data belongs to the people. Governing it well is a shared responsibility.

Participating organisations

The following organisations contributed to this consultation and to the collective position captured above:

- HENNET (Health NGOs Network)
- KELIN
- Ministry of Health
- Huawei Kenya
- Nairobi City County
- Nairobi County Inspectorate Department
- AHF Kenya
- North Star Alliance
- Medecins Sans Frontieres (MSF)
- Y+ Kenya
- Young Professionals for Development (YPD)
- Talk Africa
- Kenya Student and Novice Nurses Association (KESNNUR)
- Youth Alive! Kenya
- AWR

- AYARHEP
- COGWIN
- Manee Kenya
- Kenneth and Jacob's House
- Violet Mbiti Foundation
- Miss DYMS Initiative
- AGJK
- Digital Advocacy
- Health Business Magazine
- Coalition of Grassroots Women Initiative
- SKHAT
- The Standard Group
- Jenga Afrihub
- RYV
- CHP