

My Data Our Health

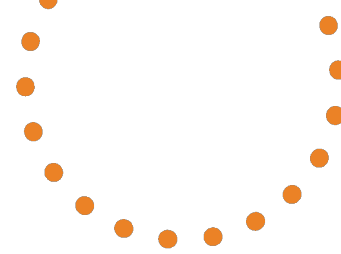
Launching a public conversation on data privacy and personal responsibility for collective well being

- On Data Privacy Day, Transform Health and partners launch a global campaign on health data and our rights called My Data Our Health.
- Effective sharing of health data offers tremendous potential to strengthen health systems and improve medical outcomes. Yet most people are unaware of how this data is collected, stored and used. There is currently no globally agreed regulation guiding countries on health data to protect individuals and foster trust in health data sharing.
- Through the My Data Our Health campaign, Transform Health is encouraging people to seek out their electronic health records and to find out more about the information they have access to.

28 January 2023

To mark Data Privacy Day, on 28 January, Transform Health is launching the My Data Our Health campaign, and inviting people and organisations to join us and to take part in the public conversation on the following questions:

- Who determines how our health data is collected, managed, stored and disposed of?
- What are the limits of this authority?
- How can we ensure this data is being used for public benefit purposes?
- How much access and control do and should individuals have over their health data?
- How can we ensure this ownership and control is respected and protected?



“Currently we have a system of health data extractivism where individuals hand over their data and then lose control over this most intimate information,” said Mathilde Forslund, Executive Director of Transform Health. “We need stronger regulation underpinned by ethical and human rights principles, that enshrine in law the rights and responsibilities of individuals in relation to their health data. My Data Our Health hopes to contribute to that outcome.”

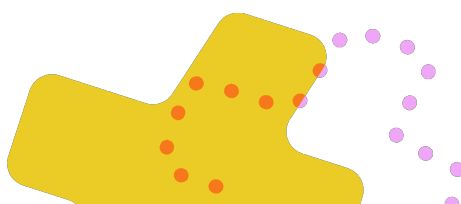
According to some estimates 30% of all data produced is generated by the healthcare industry¹. Yet most people are still unaware of how this data is collected, who is collecting it, where it is being stored, what it is being used for, and why. As individuals our rights to own and control our health data and our responsibilities to make this available to health planners and researchers, are not clearly defined or implemented in most countries.

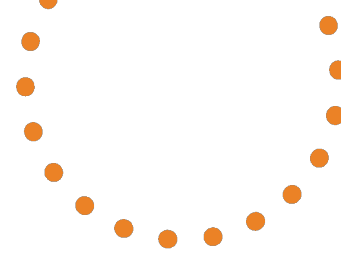
“At the heart of the My Data Our Health campaign is the issue of trust in those collecting and using our health data, and ensuring it is used to keep us healthy – now and in the future.” said Allan Ragi, Executive Director of the Kenya Aids NGOs Consortium (KANCO), a campaign partner. “Effective health data governance is necessary to create trust between individuals and institutions and between institutions – for example, to facilitate the sharing of data between healthcare organisations.”

Through the My Data Our Health campaign Transform Health aims to engage people and politicians in the discussion on how health data is collected, managed, used and disposed of. The campaign, through the [‘Where’s My Data?’ campaign action](#), is inviting people to go to their local health centre and request access to their electronic health records and digital health information. By highlighting individuals’ lived experiences, the campaign aims to put people in the driving seat when it comes to access and control of their data, and build health systems that are more responsive to their needs.

About Transform Health

¹ https://www.rbccm.com/en/gib/healthcare/episode/the_healthcare_data_explosion





[Transform Health](#) is a global coalition of organisations, individuals and institutions that advocate for the equitable digital transformation of health systems - to achieve health for all.

