








QUESTIONNAIRE

Contact Details

Please provide your contact details in case we need to contact you in connection with this survey. Note that this is optional.

Type of Stakeholder (please select one)	<input type="checkbox"/> Member State <input type="checkbox"/> Observer State <input checked="" type="checkbox"/> Other (Civil Society Organisation)
Name of State Name of Survey Respondent	Kenya The Kenya Legal and Ethical Issues Network for HIV & AIDS (KELIN) 
Email	nwere@kelinkenya.org ; twafula@kelinkenya.org ; and timalingat@kelinkenya.org
Can we attribute responses to this questionnaire to your State publicly*? *On OHCHR website, under the section of SR health	<p><u>Yes</u> No</p> <p>Comments (if any): This submission has been made by KELIN with support from the following organisations:</p> <ol style="list-style-type: none"> 1. Positive Young Women Voices (PYWV) 2. Ringa Women Fighting Aids Group: 3. Y+ Kenya 4. Ambassador for Youth and Adolescent Rep Health Programme (AYARHEP) 5. Jinsiangu 6. Youth Advisory Council <div style="display: flex; justify-content: space-around; align-items: flex-end;"> <div style="text-align: center;">  <small>RINGA WOMEN GROUP FIGHTING AIDS</small> </div> <div style="text-align: center;">  <small>Y+ KENYA ORGANIZATION OF YOUNG PEOPLE LIVING WITH HIV</small> </div> <div style="text-align: center;">  <small>YAC Youth Advisory Council Nairobi Metropolitan Services</small> </div> <div style="text-align: center;">  <small>AYARHEP Ambassador for Youth & Adolescent Reproductive Health Program</small> </div> </div> <div style="display: flex; justify-content: space-around; align-items: flex-end; margin-top: 10px;"> <div style="text-align: center;">  <small>Positive Young Women Voices</small> </div> <div style="text-align: center;">  <small>JINSIANGU</small> </div> </div>

Background

Within the framework of Human Rights Council resolution 42/16, the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, has identified digital innovation, technologies and the right to health as one of her priorities during her tenure (See [A/HRC/47/28](#) paras 78-86). In compliance with her mandate and in line with this priority, she has decided to devote her next thematic report to the Human Rights Council, to be held in June 2023, to this theme.

Objectives of the report

The Special Rapporteur underlines that technological developments in health care have proven to be an instrumental element in the provision of health care and have improved people's quality of life. She acknowledges that innovation and digital technologies have improved ability to store, share and analyse health information, increased provider capabilities and enhanced patient access to health-care services, of which some have been instrumental to handling, inter alia, the COVID-19 pandemic.

However, while new technologies and artificial intelligence could transform weak health systems in low-resource settings, there are legitimate concerns about human rights abuses that digital technologies enable in the area of health care, for example on issues related to privacy, equality and autonomy, with greater risks for youth, marginalised people, and criminalised groups.

In the forthcoming report, the Special Rapporteur intends to consider the benefits of increased use of digital technologies in the planning and delivery of health information, services and care, as well as the extent to which digital technologies may open or restrict access to specific groups. She will also focus, inter alia, on the possible positive and negative effects of artificial intelligence, as well as on the effects of the rise of web platforms and social media, on access to health information and services. She will also consider racism, embedded in the global health-care system, which makes digital health-care solutions susceptible to absorbing those same faults.

In so doing, and by adopting the anti-coloniality¹ and anti-racism frameworks, the report will focus on factors that need attention to achieve equitable digital health, which include accessibility, affordability, acceptability and quality, among others.

Questionnaire

The questionnaire can be downloaded below in English (original language), French and Spanish (unofficial translations). [Responses can address some of the questions or all of them, as feasible or preferred.](#)

- Download the questionnaire (WORD): [English](#) | [Français](#) | [Español](#)

How and where to submit inputs

Inputs may be sent by e-mail by 15 November 2022.

¹ Coloniality is a concept coined by Walter D. Mignolo around 1995, refers to the living legacies of European colonialism in social orders and knowledge systems, which created racial hierarchies that enable the social discrimination that has outlived formal colonialism. See [A/HRC/47/28](#) para 9.

E-mail address	ohchr-srhealth@un.org
E-mail subject line	Contribution to HRC report - SR right to health
Word limit	750 words per question
File formats	Word or PDF
Accepted languages	English, French, Spanish

Treatment of inputs/comments received

Please note that all responses will be published on the official webpage of the Special Rapporteur by default unless it is indicated that the submission and/or the supporting documentation should be kept confidential.

Key Questions

You can choose to answer all or some of the questions below. (750 words limit per question).

The Kenya Legal and Ethical Issues Network for HIV & AIDS (KELIN) is a non-governmental organization based in Kenya that advocates for a holistic and rights-based approach to health service delivery and for the full enjoyment of the right to health for all, including the vulnerable, marginalized, and excluded populations. KELIN has employed a people-centered approach by engaging and capturing the views and experiences of a cohort of young people in all their diversity. The responses in this questionnaire are drawn from interviews with over 75 young people in Kenya during the Digital Health and Rights Project (DHRP) research study, two virtual consultations with representatives from 6 youth-led organizations working on health and human rights in the country, and available literature on the topic.

Recommendations

1. Governments in partnership with health technology developers and global health key stakeholders should build digital literacy for young people to facilitate better access and use of DHTs while at the same time equipping them with the necessary skills to manage inherent online risks.
2. Governments in partnership with health technology developers and global health key stakeholders should develop national, regional, and global governance frameworks and safeguards that will provide young people with adequate data protection while maximizing opportunities for them to benefit from the use of digital health and improve their general well-being.
3. Governments should strengthen the development of digital health innovations in accordance with the WHO principles of transparency, accessibility, scalability, replicability, interoperability, privacy, security, and confidentiality as outlined in the Global Strategy on Digital Health (2020-2025)
4. Governments in partnership with health technology developers and global health key stakeholders should develop national, regional, and global digital health frameworks in the form of comprehensive digital health strategies to regulate the processing of personal data and better coordinate and harmonize digital health technologies
5. Digital Health Developers should engage young people in the design and implementation of digital health technologies to improve access and utilization of digital health services
6. Digital Health developers should design digital health innovations with young people's rights and well-being at the center and over private and commercial interests.

7. Digital health developers should respect, safeguard, and uphold young people's right to privacy as well as their right to information sharing and access.

1. What are benefits of increased use of digital technologies in the planning and delivery of health information, services and care? Consider the use of digital technologies for healthcare services, the collection and use of health-related data, the rise of social media and mobile phones, and the use of artificial intelligence specifically to plan and deliver healthcare. Please share examples of how such technologies benefited specific groups. How have digital technologies contributed to availability, accessibility, acceptability and quality of healthcare? Has the use of artificial intelligence improved access to health information, services and care? Please comment on existing or emerging biases in health information, services and care.

Young people face considerable challenges as they transition into adulthood including mental health issues, challenges with their changing bodies, sexual and reproductive health issues, and substance abuse among others. This is a critical period of life to offer access to adequate, comprehensive, and quality health information and services that will contribute to their present and future well-being². Digital Health Technologies (DHTs) offer great potential in improving the ability to access information, diagnose and treat diseases more accurately and efficiently.

Improved access to quality health information and services

“I use an application called Aunty Jane. It is an application by TICA and Nena na Binti where you can call in and ask questions on SRHR and a counselor on the other end will give information, direct you to a facility and even send the product I want to where I am or my house. This is very good because this platform helps you gain information via the phone instead of going to a health facility” (DHRP Kenyan Participant)

As technology becomes ever more present within healthcare systems, digital natives including young people have gained increased and diversified access to healthcare information, services, and adequate referral and linkages. In 2019, (WHO) developed recommendations on using targeted client communication (TCC) to convey health information tailored for specific audiences. Such information might be conveyed through text messages, voice, apps, or social media³. WHO Guidelines recommend the transmission of information through these channels only if potential concerns about data privacy can adequately be addressed. Artificial Intelligence (AI) technologies have changed where people access health care. Health AI technologies are increasingly distributed outside regulated healthcare settings such as the workplace, the education system, or social media, thus improving access to healthcare services. Digital health interventions have also been identified as critical avenues to enhance healthcare access for young LGBTQI+ people. Speaking on the subject during consultative meetings, a young woman said *“Young people can easily access information and services at their own comfort”*, while another added, *“Some people are not comfortable with going to the hospital hence digital technologies offer a good opportunity for such people to access information at their own convenience.”*

²See “WHO 2020- Youth-centered digital health interventions: a framework for planning, developing and implementing solutions with and for young people”, available at <https://apps.who.int/iris/bitstream/handle/10665/336223/9789240011717-eng.pdf>

³ See “WHO Guidelines and Recommendations on Digital Interventions For strengthening Health Systems, available from <https://apps.who.int/iris/bitstream/handle/10665/311979/WHO-RHR-19.6-eng.pdf>

DHTs increase efficiency in health care service delivery and offer real-time access to patient data which leads to improved prognosis and quality of treatment. As digital natives, young people are not just beneficiaries of DHTs but are also the change drivers who can help find the right digital tools that are meaningful for their context, and determine which services are functioning and which are not appropriate⁴. They are the experts in understanding what health information young people require and what technologies they are using. As a result, they can contribute to customizing solutions to meet their specific health needs. In turn, this might increase the accessibility and uptake of digital health solutions. As conveyed by a participant from the KELIN-led consultative discussion, *“Young people are able to share feedback digitally and this is able to progressively improve the quality of digital health platforms and assist to hold facilities accountable for the quality of health services.”*

Many African countries still criminalize same-sex partnerships to mention a few Nigeria, Somalia, Kenya, and Burundi making such persons live in fear of attacks, imprisonment, and even the death penalty⁵. The persecution and criminalization of LGBTIQ in such contexts hinder them from accessing health services and engaging with healthcare providers due to stigma and discrimination and fosters a culture of societal homophobia and transphobia. As such they are at risk of experiencing human rights violations such as violence, involuntary medical procedures, and denial of health services. Digital health technologies have reduced contact time with healthcare providers and provided mechanisms through which health information and services can be sought anonymously. This is particularly important for adolescents, young people, and criminalized populations as it offers the opportunity to access information and services at their own convenience and enables them to access filtered information without having to disclose their identities. In Kenya, a young participant from the digital health and rights project said *“For me, being online is convenient. Also, there is privacy because when you go to the health facility, you don’t know who I am going to find there, I don’t know how they are going to treat me and sometimes maybe my issue is a bit confidential, and I don’t know how to communicate but online there is privacy. I can also use a pseudo name like “Hi, my name is Atieno from Nairobi” yet am in Kisumu.”* A second participant from the DHRP study also says that *“We prefer to ask the internet those questions like STIs, menstruation, pregnancy. If you ask such questions [of a nurse] you’re deemed as an irresponsible or immoral young person.”* – 23-year-old man, Ghana

As young people continue growing up in a digital world, their interaction and experience with DHTs are an important determinant of their well-being. DHTs offer enormous potential for improving young people lives through increasing their access to information and services and providing opportunities for communication and learning. However, poorly designed and governed DHTs may undermine young people’s rights and expose them to multiple forms of risk and harm.

2. How might the use of digital technologies for health either include or exclude specific groups? What is the benefit or harm to particular groups that face discrimination on the basis of sex, age, gender, poverty, class, nationality, disability and the rural and urban divide, religion, political or other opinion, national or social origin, birth, health or other status. Please share examples of ways in which specific groups of people have been either included or excluded in the collection and use of digital data related to health and how this has affected planning and financing of services.

⁴ See “Youth-centered digital health interventions: a framework for planning, developing and implementing solutions with and for young people.”, available at <https://apps.who.int/iris/bitstream/handle/10665/336223/9789240011717-eng.pdf>

⁵ See “Criminalization and stigma limit LGBTQ access to health care in Africa”, available at <https://www.devex.com/news/criminalization-and-stigma-limit-lgbtq-access-to-health-care-in-africa-99725>

DHTs enable the availability and continuity of health services, however not everyone has equal opportunity to access and benefit from them. Rapid digitalization of health information and services pose increasing risks of inequality which may cause disadvantages for some young populations including those disadvantaged by economic status, health, social or cultural conditions. The WHO global strategy on digital health 2020-2025 instructs the appropriate use of technology to ensure there is digital health equity. Elements that impede vulnerable and marginalized populations from benefiting from DHTs must be identified and addressed in order to achieve digital health equity.

The digital gender and age divide

Gender disparities, intersecting and combined with other social differences such as socio-economic status, age, ethnicity, race, rural-urban divide, living with disabilities and low literacy levels continue to determine the extent to which different men, women, and gender diverse people are able to access, use and benefit from DHTs⁶. According to the International Telecommunications Union (ITU), 62% of men against 57% women are using the internet globally, showing that significant disparities in internet access and usage still exist. Only 24% of women use the internet compared to 35% males in Africa. (ITU, 2021). This digital gender divide has further been exposed by the COVID-19 pandemic. Women are less likely to use social media applications and mobile data prices remain highest in SSA⁷. Many SSA women and especially those living in marginalized communities face disproportionate digital exclusion, particularly due to socio-cultural reasons. The digital gender divide persists even when access is granted. SSA women have less access to education, hence are more likely to have lower literacy levels and are less likely to work in the formal job sectors. Gender norms have also been attributed to limiting women's educational attainments which perpetuates illiteracy and consequently the ability to navigate digital tools. Technology is also viewed as a man's domain. Such gender stereotypes discourage girls from pursuing STEM subjects which affect their participation in digital spaces. During consultations, a youth representative said, *"I was in a mixed school, but the computer classes were only for the boys..., the girls in my school were left behind in terms of digital technology..."*. As such, to bridge the gender digital divide, African governments must urgently execute administrative and pragmatic measures, policies and laws to address the sustained cultural norms in employment, education and income.

On the other hand, age also remains a key barrier to the use of online services and a substantial factor of digital exclusion. Generally, and specific to health-related use, the younger populations use the internet more frequently⁸, making it logical to believe that their health is likely to improve when large-scale digital transformations happen in health care. Young people living in LMICs, typically with limited resources and low social status, can be greatly disadvantaged by the backdrop of limited resources and inequitable access to healthcare services.⁹ Concerns regarding access for some adolescents and young populations remain in SSA, with discussions with the youth highlighting several barriers that face youth, particularly in SSA, including lack of access to adequate education, multiple barriers to school completion, economic constraints, and social-cultural factors. Such barriers affect phone ownership and internet access for young people and

⁶ See: " Digital health and rights: context in three countries : Ghana, Vietnam, Kenya 2021 [Mjwana, Nomtika; Imalingat, Tara; Kpodo, Irene; Pham, Trang](#) ", available at https://repository.graduateinstitute.ch/record/299380?_ga=2.122198222.411083115.1667762787-770674288.1665561298

⁷ GSMA report 2021. The Mobile Economy Sub Saharan Africa available at <https://www.gsma.com/mobileeconomy/wp-content/uploads/2022/10/The-Mobile-Economy-Sub-Saharan-Africa-2022.pdf>

⁸ See <https://journals.sagepub.com/doi/full/10.1177/20552076221074485>

⁹ See "Sub-Saharan Africa-the new Breeding ground for global digital health", available at https://www.researchgate.net/publication/340163034_Sub-Saharan_Africa-the_new_breeding_ground_for_global_digital_health

even where there is access there are challenges with low digital literacy skills inhibiting young people from fully utilizing and benefiting from DHTs. Young people especially those between the ages of 12-25 years with diverse sexual and gender identities such as those identifying as gay, lesbian, transgender, bisexual, intersex or queer (LGBTIQ+) also face considerable risks of physical, mental, and sexual health challenges compared to their peers.¹⁰

The rural - urban divide

“Not everyone has access to a smartphone or the internet. We must realize that some young people, for example, those in rural areas and those from low social economic status are not able to access maybe a smartphone. They can be left out from digital health platforms because of this” (DHRP participant)

Available data shows that 81% of people living in developed countries use the internet compared to 40% in developing countries, and 15% in the least developed countries. Digital divide disconnect goes beyond the connected and the unconnected, reaching deeper levels such as how individuals use information and communications technology, quality of their experience online, what digital devices they have access to, and the availability of the content in their own language. Rural populations in LMICs are 40% less likely to use mobile internet compared to the urban settings. Data further reveals that about 90% of young people unable to access the internet live in Africa or in the Asia-Pacific region¹¹. Also, risks associated with digital technology such as artificial intelligence have been reported to be greatest in areas where the health systems are weakest, usually the LMIC.¹² Most applications are developed with a focus to target persons living in urban settlements or cities. Infrastructure in rural contexts does not support access to and use of digital health technologies and does not also offer opportunity for developers to develop applications for these kinds of contexts. Cost has been recorded as a hindrance to eHealth access in Cameroon where the poor with low income find it difficult to access digital health services¹³. A participant during the consultation said that *“Of course there are limitations for those who are deep in the rural areas who do not have phones or the internet.”*

People living with disability

Globally, there are about 240 million children living with disabilities, 10% of them living in Eastern and Southern Africa¹⁴. Most young people living with disabilities form part of the world’s poorest and marginalized populations and experience multiple forms of inequality and discrimination. Though many existing assistive technologies for people with disabilities are based on the use of technology providing improved communication and learning opportunities, the use of technology offers opportunity as well as potential barriers for people with disabilities¹⁵. Many people suffer various forms of disabilities including mental, physical and skill-based disabilities that may limit them from accessing DHTs and hence impact on their quality of life. Content developed for digital health platforms in most cases does not also consider persons living with disability. For example, DHTs that are designed to provide visual information inherently discriminate against people who are visually impaired as they cannot receive, perceive, or interpret it. A joint commitment is required in the form of policy and clear guidelines and

¹⁰ See “Effectiveness, Acceptability, and Feasibility of Digital Health Interventions for LGBTIQ+ Young People: Available from, <https://doi.org/10.2196/20158>

¹¹ See “Youth-centered digital health interventions”, available at <https://apps.who.int/iris/bitstream/handle/10665/336223/9789240011717-eng.pdf>

¹² Williams, Carmel. "A Health Rights Impact Assessment Guide for Artificial Intelligence Projects." Health and Human Rights 22.2 (2020): 55, available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7762915/>

¹³ See “Digital Health in Low Resource Settings” from, <https://medwinpublishers.com/IQHE/digital-health-in-low-resource-setting-overview-of-telehealth-market-in-cameroon.pdf>

¹⁴ See Young people with disabilities in Eastern and Southern Africa demand to be treated as equals UNICEF 2021 available at <https://www.unicef.org/esa/stories/young-people-disabilities-demand-be-treated-equals#:~:text=There%20are%20240%20million%20children,in%20Eastern%20and%20Southern%20Africa.>

¹⁵ See “Barriers and facilitators to use of high technology augmentative and alternative communication devices: a systematic review and qualitative synthesis, available at <https://pubmed.ncbi.nlm.nih.gov/22369053/>

standards that encourage the inclusiveness of people living with disabilities in DHTs. An example mentioned during the consultative meetings was like; “*Persons with disability have been excluded – e.g. those with hearing/ visual impairment*”. *The kind of format and how we put the message on sexual reproductive health, sometimes I don’t feel like they can really get to understand it...*” “*Digital techs do not consider the need of disabled people*”

People living with HIV/AIDS and TB

There are many benefits of DHTs to people living with HIV/AIDS and affected by TB. For example, a variety of digital health innovations including the use of text messages, social media and websites have been used to improve linkage and retention to care for HIV/AIDS patients. These approaches have been associated with increased HIV testing and treatment adherence among men who have sex with men and other key populations. For example, in South Africa HIV positive young people who faced challenges in accessing care were reported to have responded well to a smart phone application built to deliver HIV lab results, information, support, and appointment reminders¹⁶. Countries like Zambia, Mozambique and Zimbabwe have used data visualization tools to enable program planners zero in on districts where adolescents and young women are at highest risk of HIV acquisitions¹⁷. The discussions held with young people alluded that DHTs can help promote adherence to healthcare for those living with HIV/AIDS and TB. However, limitations in terms of access especially for young people must be observed. Many young people especially in sub-Saharan Africa do not own mobile phones and may not have access to the internet hence not able to access HIV and TB related digital health information and services.

3. Please share examples of how the use of artificial intelligence in health has improved access for specific populations or reproduced or exacerbated existing inequalities. How have specific populations – including women, gender diverse people, Black and indigenous people, and others – been excluded both in the development and use of artificial intelligence? How has the development and use of artificial intelligence reinforced or exacerbated existing biases? Please share examples of positive steps or inadequate attention to address the need for training, support, and involvement of underrepresented groups in the development of new technologies.

Big data and artificial intelligence are powerful technological tools that enable analysis and prediction of complex health care data and expedite diagnosis and screening interventions¹⁸. Use of AI particularly in Africa can assist in the elimination of inefficiencies like shortage of healthcare staff, misdiagnosis, and reduce recovery time. Evidence has shown that medical artificial intelligence (MAI) used in Kenya enhanced the quality of health-worker-patient connections with a high number of symptoms brought forth¹⁹. Most recently, AI applications in Africa have only had a few cases and tests. South Africa has successfully used a logistic classifier-based system to forecast the duration of health workers in public service²⁰. It is however critical to protect against issues like breaches in privacy. Ethics must be the key doctrine for an AI framework.

¹⁶See “Improving linkage to and retention in care in newly diagnosed HIV-positive patients using smartphones in South Africa: available at <https://pubmed.ncbi.nlm.nih.gov/30938681/>

¹⁷ See “UNAIDS. Thematic segment background note: What do the regional and country-level data tell us, are we listening and how can we leverage those data and related technology to meet our 2025 and 2030 goals? UNAIDS Programme Coordinating Board, UNAIDS/PCB (49)/21/34, December 2021, available at”

https://www.unaids.org/sites/default/files/media_asset/Summary_Meeting1_PCB49_Thematic_Segment_WG_EN.pdf

¹⁸ See <https://www.gsma.com/mobilefordevelopment/wp-content/uploads/2020/11/Digital-Health-June-2020.pdf>

¹⁹See “Artificial Intelligence for Healthcare in Africa, “, available from <https://www.frontiersin.org/articles/10.3389/fdgth.2020.00006/full>

²⁰See “Artificial Intelligence for Healthcare in Africa, “, available from <https://www.frontiersin.org/articles/10.3389/fdgth.2020.00006/full>

Artificial intelligence (AI), if unchecked, has the potential to amplify existing forms of discrimination which might affect people's right to health and to be free of discrimination²¹. The use of AI assists us to find valuable patterns and draw insights that may be used to make predictions or aid us in making critical decisions. However, the data generated from AI may reflect societal biases that shape their generation, collection, availability, synthesis, and analysis. AI insights are based on data correlations that could be reflective of societal biases for example of gender disparities in society. This is primarily problematic in the health sector where such biases may disproportionately harm those who may be already facing discrimination²². During the consultative meeting, a participant mentioned that *"the data that is being used is biased, Information from certain groups is excluded for example that of women and black people"*

The use of AI in health is also related to concerns regarding the external risk of privacy breaches. De-identification or anonymization of patient health data might be compromised with regards to the ability of new algorithms being able to successfully re-identify data. This could cause increased risks to patients' data that is under private custodianship²³. The establishment of an ethical framework on DHTs is critical for the advancement of rights, minimizing harm and regulating DHT developers. The adoption and implementation of human rights standards and norms that encompass ethical principles into law and provide opportunity of being enforced is thus of paramount importance.

4. How has the rise of web platforms and social media increased access to health information and services, or conversely, increased risk of misdiagnosis or other harms? Please share examples of ways in which social media and web platforms facilitated innovation in access to evidence-based health information and services, or created new threats of discrimination, mental health harms, or online or offline violence.

The rise of web platforms and social media

"My Dad was Diabetic and in social media, there is a platform for diabetes management. I used that group to get specific information. It's a Facebook page, they tell you... What the condition entails and what you can take or the medications available for treating the condition. It's an open forum so if you have any questions or concerns you ask and get the answers." (DHRP Participant)

Many healthcare professionals can now access a myriad of social networking and sharing sites to enhance patient interaction including care and education. Healthcare providers can use Facebook, Twitter, YouTube, blogs, among many sites to better patient health outcomes, improve health information to the community and motivate patients²⁴. For example, mobile phones have been used for Polio campaigns in Somalia, and to build and share of information with Men Who have Sex with Men (MSM) in Ghana²⁵. In Kenya, Love matters, a Facebook page has reached more than 1.8 million followers providing easy to access information on sexuality and sexual health for young people. Since 2012 the platform has offered comprehensive rights-based information on sexual and reproductive health and rights. The platform engages young people with information

²¹ See "Artificial intelligence and human rights: Opportunities and risks," available at

<https://www.hhrjournal.org/2020/12/viewpoint-participatory-machine-learning-using-community-based-system-dynamics/>

²² See "Machine Learning Using Community-Based System Dynamics. Health and human rights, 22(2), 71–74", available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7762892/>

²³ See "Privacy and artificial intelligence: challenges for protecting health information in a new era. BMC Med Ethics 22, 122 (2021)". Available at <https://doi.org/10.1186/s12910-021-00687-3>

²⁴ See <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4103576/>

²⁵ See <https://www.comminit.com/1a/content/engaging-social-media-health-communication-africa-approaches-results-and-lessons>

and links them to necessary service provision from local health providers²⁶. The One Impact digital mobile platform has also been used by many African countries and beyond to provide people living with TB information and access to support services. It also facilitates people affected by TB with virtual spaces to report challenges for rapid response and resolution. The platform offers comprehensive community empowerment, community engagement and community-led monitoring solution that puts people at the heart of the TB response²⁷.

5. How has the right to privacy been impacted by the use of digital technologies for health? Please share examples of ways in which data gathered from digital technologies have been used by States, commercial entities or other third parties to either benefit or harm groups regarding the right to health.

Concerns about access, use and control of health data have increased with the widespread use of DHTs. As such, there have been calls for systematic oversight of health data at global and national levels. Appropriate safeguards must be placed to maintain privacy of health data and especially in the context of DHTs. Most DHTs are developed by private companies who are influenced by competing and profit-making goals that do not prioritize the safety of users.

Young people are worried that information gathered through digital health platforms is being collected and used or sold off to third parties without their knowledge and consent. The young people encouraged the use of people centered models and models that are developed using a human rights framework. Developers should also be deliberate in including different groups of people and ensure that the AI algorithms are as inclusive as possible. Protecting the digital security and safety of adolescents and young people is critical but challenging. Most young people are vulnerable as they connect to health platforms using their mobile devices and have experienced non-consensual and inappropriate access to their health data²⁸. A participant from the DHRP said: *“I use Google a lot but the challenge that comes with Google is the cookies and they are trackers. So, when you log in to a site and they tell you do you accept cookies? And you accept the cookie gives Google permission to access your information with a third-party which is not okay. So, most of the time I actually miss out on a lot of information because I don’t like accepting the cookies. I might be searching for something on Google and then when I accept the cookies, I see the same thing that has been searching for on Instagram or when I log in to Facebook it doesn’t sit right with me because they’re already sharing my information very fast which I don’t think is the main point I just need the information I don’t need something that I’m asking about to be everywhere”*. Another participant from the DHRP said *“Sometimes you never know who is checking your information. Some sites in Google have no privacy. For instance, you search information on Facebook, and the next minute you see suggested pages. So you are like, Okay, how did they know? So you will be searching for information like abortions, and maybe you are tempted to check that page on social media, Facebook will be telling your friends that you liked the page. “Linda (pseudo name) liked this page” (laughing)...and they will be like why is she liking the page? Maybe there are symptoms they have already seen in me so people will be discussing how am liking certain pages.”*

The privacy settings in DHT policies may be difficult for young people to understand, navigate and even interpret. There is a lack of awareness about privacy settings and young people most

²⁶ See “Love Matters Kenya”, available at : <https://www.rnw.org/network-members/africa/>

²⁷ See: One Impact Digital Platform <https://stoptbpartnershiponeimpact.org/>

²⁸ See “Adolescence: a foundation for future health, The Lancet, “available at [https://doi.org/10.1016/S0140-6736\(12\)60072-5](https://doi.org/10.1016/S0140-6736(12)60072-5).
<https://www.sciencedirect.com>

often do not change their privacy settings from the provided default settings²⁹. Adolescents and young people may not understand that digital health platforms may be linked to other platforms, but security policies and agreements presented in the primary platforms are lacking and may leave health data accessible to others. As alluded to by a participant in the DHRP

"I have an issue with the consent forms. You find that they may be too big to read. Also, a person may be accepting information yet their privacy may not be guaranteed. Consent forms may sometimes be too small or too big to read. The fonts used may not be appealing to the eyes. Second thing, there are issues around Facebook where many people don't know how to keep their privacy or put their information private. You might think you are talking to this guy yet many people have access to that information. So the issue of limited technology and information is a major challenge to many people." A second participant from the project indicated that *"If I could design a health app, I would make the consent form as brief as possible so that majority can read it because some people read terms and conditions and agree without reading the whole thing."*

People are not only using various digital health applications to access health information, but also to better understand their bodies and their fertility. However, individuals continue to be agitated at the likelihood that very personal health information provided to these apps can be utilized unpredictably. For example, data privacy concerns have been raised concerning the applications that support women through pregnancy. A report by Privacy International (PI) shows that 61% of pregnancy apps transferred data to Facebook immediately a user logged into the app and that most of the companies undertook no adequate precautionary measures to protect the data that users entered into the apps.³⁰

Whereas aggregated data is capable of monitoring real-time population flows, recognizing potential transmission hotspots, and informing other public health insights like travel restrictions, vulnerable users can be harmed through the identification of their physical locations. Recent analysis of Google store COVID-19 related apps has reported that only 16 apps explicitly stated their commitment to de-identify user data. Additionally, digital health tools could be securitized in a manner that exceeds public health intentions. For instance, the governments of Kenya, Israel, Turkey and Mexico among other countries have been reported to capitalize on the COVID-19 pandemic to analyze telecommunications data guised under "contact tracing." The abuse resulting from data misuse, privacy violations, and the consequences of the digital health surveillance measures transcend only damaging of the public trust but can also cause fragmentation of responses resulting from competing actors promoting different digital tools³¹. Therefore, all parties that use personal data for unintended purposes should be governed through normative and legal frameworks to ensure data protection and deter alternative use thereof. Health data should be treated with high safety and security standards.

6. What are current strengths or weaknesses of digital health governance at national, regional and global levels? Please provide examples of laws, regulations or other safeguards that that have been put in place to protect and fulfil the rights to health, privacy, and confidentiality within the use of digital technologies for health? Do restrictive laws or law enforcement create any specific challenges for persons using digital technologies to access health information or services?

DHTs have been acknowledged as a building block to universal health coverage. When properly implemented, digital health solutions within a health system can accelerate better quality, efficient and accessible health care. This however can only be achieved with good digital health governance. Many countries particularly those in sub-Saharan Africa lack comprehensive and holistic approaches to digital health and ones which require sound governance for successful

²⁹ See "Youth engagement in Digital Health", available from <https://www.medicusmundi.ch/de/advocacy/publikationen/mms-bulletin/digital-health-a-new-era-of-global-health/kapitel-3/youth-engagement-in-digital-health-a-critical>

³⁰ See <https://privacyinternational.org/long-read/4804/how-digital-health-apps-can-exploit-users-data>

³¹ See Sekalala, Sharifah, et al. "Analyzing the human rights impact of increased digital public health surveillance during the COVID-19 crisis." *Health and Human Rights* 22.2 (2020): 7., available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7762901/>

nationwide sustainable rollout. The lack of clear governance frameworks and structures may result in fragmentation, wastage of resources, duplication of efforts, nonstrategic investment decisions, and a lack of common standards.³²

Despite the known benefits of DHTs, evidence shows slow digital health transformation at national levels of many LMICs, as technological tools for training, data sharing and communication remain under-utilized.³³ Many countries lack the enablers in place to augment digital health benefits to enhance health outcomes for their citizenry. In fact, most countries lack a clear roadmap to digital health maturity, leading to consistent disorganization and divisions at all levels, preventing countries from maximizing their investments in DHTs. One leading challenge encountered by healthcare institutions is their low capacity to attract and retain tech-savvy professionals, more particularly, digital health professionals. Most healthcare staff and users, particularly those residing in rural areas, lack computer skills. On the other hand, the doctors and the nurses feel that the ICT component of health care is an additional component to their already overwhelming technical work. In Cameroon, there is neither provisional management of digital health skills nor a capacity-building framework developed by the country's ministry of health, clearly showing a shortage of competency and resources in implementing digital health at all levels in the country.

The youth consulted in this submission reported that good digital health governance should facilitate efficiency, effectiveness, accountability, equity, and inclusiveness. A participant from the DHRP said *“There is a need to meaningfully engage in our case young people in the planning, design, implementation, and monitoring and evaluation of digital health technologies.”* Several challenges facing the governance of digital health were also discussed. These included the lack of or inadequate legal frameworks governing digital health. They also mentioned that there is a lack of a harmonized process in the development and management of DHTs. Platforms offer information and services that may be fragmented and that may not serve adequately the needs of youth. Recommendations were made on the need to harmonize DHTs to facilitate faster and more efficient access to services and commodities online.

“I would encourage the government to conduct monitoring and evaluation of digital services and also encourage the government officials to organize digital safety workshops for the people, develop easy-to-access platforms that consider the needs of different sub-populations, then they should be cognizant of the language because as we are discussing here, we are speaking from a point of privilege where all of us have like uuh, smartphones and have an access to data. But then we don't know if we are just developing this app for people in the cities, the people in Nairobi, Kisumu, whatever, but what happens to people at the grassroots level. So, the government official to put all these things into consideration so that at least no one is left behind.” (DHRP participant)

There is therefore a need to develop clear guidelines and set standards on how DHTs should be developed. Developing a registry of digital health applications so that they can be scaled up, and controlled is important. Most importantly, countries need well-structured and scalable digital health fixes, reassuring policies, increased funding opportunities, and a viable local capacity.

7. What steps have been taken by Governments, commercial entities or third parties to uphold the rights to privacy, confidentiality, non-discrimination and equality in the development and use of digital technologies for health? Please share examples of where meaningful public consultations and participation were included in the development of the adoption of laws, policies and strategies developing digital technologies in the area of health.

³² See “Transforming Health Systems Through Good Digital Health Governance available from <https://www.adb.org/publications/transforming-health-systems-good-digital-health-governance>

³³ See https://www.ghspjournal.org/content/6/Supplement_1/S41

[Digital Health for Africa](#) partnership was launched in 2017 by ITU and WHO to improve the use of digital technologies and reinforce public health care service delivery in Africa. Improving health equity requires incorporation of best emerging practices such as building diverse and inclusive teams. Such diverse teams are capable of sharing a broader range of perspectives which lead to innovative and broadly accessible tools. For instance, the Unite Us, a digital health technology company, recruits individuals from each community it enters to ensure local culture tailor made solutions. Also, other entities such as [Savvy Cooperative](#) collaborate with patients to understand their journey, which allows them to design greatly sensitive products

During the [Africa Health 2021](#), a separate panel discussion on [Telemedicine opportunities and challenges in Africa: policy and regulatory perspective](#), the business lead East-West Africa described the approach by Amazon Web Services(AWS) to work with partners and local organizations to ensure that data protection laws and virtual discussions safeguard both patients and practitioners. On health data theft during the discussion, the Chief Technology Officer (CTO) from Nigeria, said that the Nigeria Data Protection Regulation (2019), whereas was a positive step, did not sufficiently address delivery of healthcare details such as data storage. The CTO called upon development of regulations that address data protection, equity and quality in Nigeria. The Lagos State Ministry of Health observes compliance with Nigeria data protection guidelines and are currently working on how to address effective digital health.

In Kenya, individual data privacy is addressed by the Data Protection Act 2019; requiring compliance from all data handlers and processors. The Office of the Data Protection (ODPC) is mandated to oversee the implementation of this Act. Further, the ODPC has shown why data protection impacts assessment and has put in place mechanisms for organizations to adhere to the Data Protection Act³⁴. Kenya also has geolocation-based legal requirements for Telehealth licensure, while critical aspects regarding mobile apps are centered on the Intellectual Property rights granted to the product developers. Also, digital platforms processing personal data are required to adhere to [Article 31 of the Constitution](#) which guarantees personal data privacy to all Kenyan citizens. Kenya has also domesticated the Budapest Convention on Cybercrime as the Computer Misuse and Cybercrimes Act; imposing cyber security regulations on personal information data handlers³⁵.

In 2021, the Kenya ICT Action Network (KICTANet) disseminated its findings from report titled, [Public Participation: An Assessment of Recent ICT Policy Making Processes in Kenya](#), which examined the extent to which the public had participated in the law-making process of three ICT policies; which included the Computer Misuse and Cybercrimes Act 2018 and Data Protection Act of 2019. The findings showed that the public was meaningfully involved in the structuring of the Data Protection Act, highlighting heightened public interest in privacy issues and data protection. The public was intrigued by the government’s decision to introduce [Huduma Namba](#) adding to the global trend towards the adoption of data protection laws following the European Union’s adoption of the GDPR. Additionally, there were county meetings where political will on data protection was notable. However, it was realized that the public was limited to contribute to the Cybercrime Act³⁶.

From written submissions, one participant noted from a regional perspective that, “*East African Community (EAC) gives recommendations for member states to reform their legal frameworks on data protection and privacy based on international best practices.*”

³⁴ See “Data Governance Framework”, available from <https://kilimo.go.ke/wp-content/uploads/2022/04/MoALFC-Data-Governance-Framework-2022.pdf>

³⁵ See https://tripleoklaw.com/wp-content/uploads/2021/01/DIGH20_Chapter-18_Kenya.pdf

³⁶ See “Public Participation – Recent ICT Policy Making Processes in Kenya”, available from <https://www.apc.org/en/news/kictanet-launches-report-public-participation-recent-ict-policy-making-processes-kenya>