The COVID-19 pandemic has spurred on digital innovations, but unfortunately not everyone benefits equally. The rapid onset of these digital innovations has highlighted the lack of awareness of digital rights amongst their users. Although the problem of digital inequality spans all generations, the impact on young people is one that shouldn’t be ignored, particularly in areas such as education and health.

Youth researchers Trang, Nomtika, and Tara, are exploring how digital rights, particularly digital rights in health, impact young people. Digital Health and Rights Advisory Group (DRAG), who are conducting a participatory action research project in the field of digital health and rights.

The research (January 2021-2022) will look at the impact of digital health technologies on the rights of young adults (ages 18-30) in Kenya, Vietnam and Ghana using the HIV sector as a case study. The project uses digital ethnography and qualitative research methods to conduct in-country field research to inform policy recommendations for national and global health decision-makers, and the campaigns of youth and civil society networks.

Trang, Tika, and Tara’s insights and experiences of research in the digital space and how young people shape their own destiny in relation to their digital rights guide this chapter.
“Equitable access is key to maximising the positive impacts that digital technologies can bring for people and society. Level of education and income are cited as the main predictors of ability to access digital technologies.”

Digital rights are human rights

“Digital technologies are used to socialise, to work, to play, to communicate, to learn, and to explore. In short, they affect every aspect of a young person’s life. To be a 21st century citizen means being digitally literate.” - Trang, Vietnam

Digital innovation is moving fast, and so is its impact on human rights. While wide availability of digital technology has benefited many during the pandemic - from social media allowing us to keep in touch with family and friends, to healthcare apps improving access to appointments, testing and vaccination - concerns are growing over how these technologies may impact the most vulnerable and marginalised in society. Fundamentally, these concerns centre around issues of access, data, and privacy.

Equitable access is key to maximising the positive impacts that digital technologies can bring for people and society. Level of education and income are cited as the main predictors of ability to access digital technologies. The digital divide, however, is particularly bad for women and girls. Women and girls experience the digital divide strongly both in relation to access to technologies, but also in lack of access to digital education and subsequent job opportunities in the digital sphere.

The COVID-19 pandemic has also exposed the risks of the digital divide to ongoing health and wellbeing. The pandemic, however, has also enabled youth to mobilise in new ways. In the UK the organisation Students for Global Health (SfGH), a student led network advocating for health equity and partners of DRAG have felt these effects directly. Anu, Director of SfGH, describes how the pandemic has affected activism with the organisation “We are able to work with organisations not just nationally but internationally, providing us the opportunity to find new ways to engage with civil society.” In Vietnam, Trang said, “Young civil societies are doing a great job [...] They are contributing a great part to the work of preventing the epidemic as well as supporting members of the community, especially people living with HIV or transgender people.”

The data issue

Data is often seen as something neutral, however it is anything but. Marginalised and criminalised populations are often ignored in data collection - or missed due to the aforementioned inequities in access to digital technologies - meaning that the data gathered about them
is lacking, false, or of poor quality. This missing data often means less or inadequate funding and support for these groups because they are not identified and their needs are not measurable.

Although digital innovation provides an opportunity for more equitable data gathering efforts, it also poses risks. As artificial intelligence comes to the forefront, inaccurate data means that AI learns to replicate existing inequalities rather than mitigate them.³ This is a risk also acknowledged by our youth researcher, Tika, who said we must be aware of the agendas being pushed and profits being gained by those institutions gathering our data, because “they could further risk, marginalise, discriminate, and even exacerbate existing human rights violations.” Personal data, and the insights it provides about individuals and demographics, can also be packaged and sold to the highest bidder. Our youth researcher, Trang, elaborated: “Children and young people have a right to know about who is holding and profiting from their information, what their information is being used for and whether it is being copied, sold or traded.”

For marginalised or criminalised communities, privacy violations pose significant risks to their access to healthcare, freedom from stigma and discrimination, and even their life. For example, efforts to gather information on sexuality - whether it be through dating apps, social media or for healthcare purposes - pose a risk depending on the cultural and legal context of the country in which an individual lives.

Digital rights in health

“Most people whose rights are often marginalised online are also not well-versed in workings of digital technologies as a result of existing systemic barriers.” - Tika, Kenya

Digital solutions are becoming increasingly common within health systems and are often seen as the solution for saving money and improving health outcomes. Decision makers in health are moving quickly to try and capitalise on developments. However, a lack of meaningful regulation at national and international levels persists. This leaves people of all ages vulnerable to the problems of access and privacy.

Rules grounded in human rights need to be in place so that people are protected wherever digital technologies or AI are being used and able to hold governments, the private sector, and others to account.”
“Education, empowerment, understanding local context, and digital literacy are key for understanding existing digital rights legislation and identifying where particular populations may be at risk of losing their digital rights.”

These new tools often gather intrusive personal data in ways that can have ongoing connotations for young people. Youth rarely have input into the policy decisions that shape what kinds of data are gathered about them, by whom, and how that data is used or managed. Trang points out that, “For sensitive groups such as LGBT people, people living with HIV, and people who use drugs, the confidentiality of their information, as well as their health status, is extremely important.”

Setting youth up for success

“This group [youth] is not homogenous and carries a wealth of experience [...] So, young people need funding, resources, ears that will listen and act, and spaces across sectors to be broadened.” – Tika, Kenya.

So, what do we as young people need to continue mobilising effectively? Education, empowerment, understanding local context, and digital literacy are key for understanding existing digital rights legislation and identifying where particular populations may be at risk of losing their digital rights.

The digital space provides unique opportunities for civic engagement with young people. Such forms of engagement may include acts of participatory politics such as youth creating and circulating photos, memes and videos to their network. However, Trang highlights that a barrier to digital civic engagement is a natural cautiousness and lack of trust from young people, who do not necessarily view the internet as an open and transparent space for political expression.

Digital technologies can help our communities to thrive. We need research and processes that work with young people to identify the risks they face. We need funding that supports digital literacy amongst young people and that enables youth-led initiatives in developing, implementing, and monitoring digital technologies. Most importantly, we as youth need a seat at the decision-making table. By doing so, we can both protect young people and their communities from harm and unleash the power of youth in development.
