

Health for all in the digital age

# COALITION BRIEF

# **Introducing Transform Health**

Transform Health is a coalition of organisations dedicated to achieving health for all in the digital age.

Transform Health was formed in 2018 by a group of organisations who saw the need for a concerted, long-term effort to harness the transformative benefits of digital technology and data in support of the Sustainable Development Goal target of universal health coverage (UHC) by 2030.

Transform Health campaigns for and collaborates with the individuals, communities, governments, organisations, and institutions that are most affected by the lack of access to equitable, affordable, and high-quality healthcare. We are committed to promoting youth and women's participation and leadership and to promoting the perspectives, concerns and needs of marginalised groups so that everyone can benefit from the digital transformation, and access and control their own data to improve their health outcomes.

Transform Health is currently governed by seven founding partners - Fondation Botnar, Joep Lange Institute, Medicus Mundi Switzerland, PATH, PharmAccess Foundation, the Partnership for Maternal, Newborn and Child Health (PMNCH) and Women Deliver - and representatives from the Youth Experts: Tech 4 Health platform.

# Why has Transform Health been established?

In 2015, world leaders committed to providing quality health services to all through extending universal health coverage (UHC) to everyone by 2030. These commitments were reaffirmed in 2019 at the United Nations (UN) High-Level Meeting on UHC, and in the associated political declaration. Yet, whilst most parts of the world have seen an expansion in access to health services and coverage of key interventions over the last two decades, on current trends the SDG target will not be met:

Around half of the world's population still lacks access to essential primary health care.

At least 400 million people do not even have access to the most basic health services.

Globally, the proportion of the population impoverished by out-of-pocket health spending is increasing.

If progress towards UHC is not accelerated, billions of people will continue to be subjected to poor, unreliable and relatively expensive health services, increasing their vulnerability to communicable and non-communicable diseases. In the digital age, technology and data have the potential to be harnessed to help accelerate progress toward achieving UHC and provide all of humanity with protection from poor health.

#### Closing the digital divide

Digital technology, applied in an ethical and equitable manner, particularly in support of primary health care, has the capacity to address the widening health gap and accelerate progress towards UHC. Digital technologies are transforming all aspects of our lives, spurred by the increased availability of data and use of advanced analytical capabilities. The digital transformation of health offers opportunities for countries to achieve UHC by 2030 through strengthening health systems, supporting individuals to manage their own health and enhancing the quality and coverage of health services. The digitalisation of other sectors such as environmental health and education is also compounding the availability of data that can be used to address determinants of health.

### What is digital health?

According to the World Health Organization, 'digital health' is "the field of knowledge and practice associated with any aspect of adopting digital technologies to improve health, from inception to operation". The field of digital health is continuously evolving and incorporates many areas including the application of information and communication technology (ICT) to health, health informatics, telemedicine, mHealth and eHealth. Digital health also includes the use of emerging technologies such as wearable devices, internet of things (IoT), artificial intelligence, genomics, blockchain, virtual reality and big data analytics to transform healthcare. Non-digital components required for health systems to use data and digital tools in service of health goals, such as skilled health workforces, are an equally important part of 'digital' health.

The digital age offers unprecedented possibilities to improve health and well-being, but many people are unable to reap its benefits:

- Although 93 per cent of the world's population live within physical reach of mobile broadband or internet services, only 53.6 per cent of the world's population use the internet.
- An estimated 3.6 billion people are unconnected, most of them living in the least developed countries.
- The gender gap in internet use is growing with more men than women accessing the internet in two out of three countries.
- Lack of ICT skills is a barrier to effective use of digital technologies across the world.

Digitalisation and use of digital technology is already a key and growing part of most health systems. However, national governments and international health partners are not yet fully unlocking the potential of the digital transformation to scale up primary health care and support the expansion of UHC. Digital health innovations are not being driven by the needs of those communities who experience the greatest burden of disease or who are being left behind in the effort to achieve global health goals by 2030. In many countries and regions, particularly those with weak health systems, digital technology is being implemented in a piecemeal fashion, based on external programmes and priorities rather than being driven by needs on the ground. Many digital approaches also fail to address the lack of access to technology and digital skills needed for individuals and communities to take full advantage of new innovations. This results in weak country ownership and poor uptake of many initiatives.

Transform Health has been created to address these issues. By working together, we can harness the digital transformation to achieve health for all.

# The opportunities and risks for health in the digital age

Transform Health believes that digital technology and data, if effectively and equitably deployed, are enabling forces that can strengthen health systems and help people to attain and maintain good health and wellbeing. The application of digital technology and the use of data to support the needs of individuals and health systems is extensive and will continue to grow due to the rapidly evolving nature of the field.

For example, digital tools and approaches can:

- Generate data that improves the efficiency and effectiveness of core pillars of the health system such as health information, finances, supplies and logistics.
- Facilitate targeted health messages to individuals to promote public health messages, generate demand for services and broaden contact coverage.
- Help health workers update their knowledge and skills and deliver more effective care through fast access to clinical protocols, decision-support mechanisms and consultations with other health workers.
- Empower frontline health workers by enabling them to provide communities with timely and reliable services and referrals and stay in regular contact with health facilities.
- Enable remote communities and people in isolation to seek health advice and diagnoses from health workers.
- Redirect interventions from secondary and tertiary care facilities (such as monitoring and testing services) to people's homes.
- Provide individuals with different sources of health information and tools to manage, monitor and improve their health.
- Accelerate the development of new drugs, diagnostics and vaccines using genetic sequencing and other analytic capacities.
- Increase the efficiency and cost-effectiveness of health systems.

- Increase transparency and accountability and facilitate the participation of young people, women, and marginalised communities in designing health policies and services that affect their lives.
- Improve prediction and surveillance of pandemics and other phenomena that may cause public health emergencies.
- Provide individuals with digital identities (such as a birth certificate) to strengthen civil registration and vital statistic systems and unlock the use of healthcare data.
- Address factors outside the health system (e.g. water and sanitation, education, economic growth, the environment) that affect health and well-being.

Digital technology is already transforming all these areas. However, in a number of countries, particularly least developed countries, externally-funded digital health initiatives are being applied in an ad-hoc manner and are not being sustainably integrated into health systems meaning they come to a stop when donor funding runs out. These risks reducing the overall effectiveness of the health system as staff and resources get deployed from one short-term initiative to another.

#### Digitally-enabled primary health care as the foundation for UHC

A more systematic, locally-driven and people-centred approach to the digital transformation of health systems is needed to achieve UHC. It is widely recognised that comprehensive primary health care (PHC) is an essential foundation for achieving UHC. A well-functioning PHC system can cover most of the a person's health needs throughout their life including prevention, treatment, rehabilitation and palliative care. Despite its importance, PHC is often underfunded, understaffed, and deprioritised.

Investing in PHC is an effective and efficient way to address the main causes and risks of poor health and well-being, as well as building resilience against future health challenges. Expanding quality PHC is a sound economic investment since it reduces total healthcare costs and reduces hospital admissions.

Digital technology and data have a critical role to play in increasing the coverage and effectiveness of PHC and in addressing health system barriers by enhancing access to health information and services; ensuring greater systems integration and effectiveness; and allowing for greater transparency and accountability, and participation of individuals and communities. Digitalisation and use of digital technology is already a key and growing part of most health systems and it is important that expanding PHC and cross-cutting principles such as equity, inclusivity and human rights are prioritised in all aspects of digital transformation. Achieving UHC will require stronger political will and investment in extending quality PHC to all.

## Mitigating the darker sides of digital health

Digital technology, and the data it generates, is not a panacea. It can enhance, but should not replace traditional health service delivery models, nor should it substitute human interaction. To be effective and sustainable, digitalisation and digital health approaches must be fully integrated into the wider health system and aligned to agreed health strategies and priorities.

Digital transformation of health is not currently happening in an inclusive way. Digital health approaches and solutions are rarely driven or informed by those communities – such as young people, women, and marginalised groups – who experience the greatest burden of disease or who are being left behind in the effort to achieve global health goals.

The ubiquitous presence of the internet offers many opportunities for improving health and well-being, including through knowledge sharing, research, and collaboration. However, limited global mechanisms for the governance of data (including health data) collection and use places individuals at risk from self-interested groups willing to and able to collect and use data for commercial gain, political or malicious purposes.

Without stronger governance, clearer regulations, greater transparency and accountability driven by informed citizens, digital technology also has the potential to worsen health and well-being and increase inequities. Improper application of digital technology may stretch already overextended health systems; respond to the needs of the few rather than the many; provide inaccurate or false health information; or allow third party actors to access personal data for commercial or political purposes. Balancing the collection and use of data to advance health goals while preserving security and the patient's right to privacy is an urgent task for policymakers.

Ethical and human rights concerns arising from the inappropriate application of digital technology and data are undermining confidence in the benefits and opportunities such technology offers, and risk slowing progress towards UHC. These risks include:

- <u>Biased and unrepresentative data</u>: The data used to develop Al algorithms and other technologies is rarely representative of all ages, genders, ethnicities, and regions. This further increases the gap between those for whom technology is designed and those whose data is excluded.
- <u>Data extractivism</u>: To close data gaps, those already marginalised and left behind can be locked into perverse ecosystems that extract data without informed consent and without gaining any benefit from the data collected on them.
- <u>Data ownership</u>: Our data, including health data, is constantly being recorded, stored, and shared, but the rules governing who owns that data are unclear. Unresolved questions about the ownership of health data lie at the heart of many concerns about technology and data use. Most individuals, even those with relatively high levels of digital literacy, do not understand who is collecting their data, how it is used and what their rights of ownership are.
- Increased surveillance of individuals: Digital technology has provided states and private companies with new ways of tracking disease outbreaks and surveilling individuals at risk. COVID-19 has demonstrated how digital technology can be used to tackle health emergencies, but concerns remain about what will happen when the pandemic is over. Whilst some invasions of privacy may be accepted in exceptional circumstances, authorities may continue to justify mass surveillance and further encroachments on the right to privacy of individuals in the name of health or security.
- <u>Misuse of data:</u> In addition to concerns about surveillance and lack of privacy, there are concerns that the commercial potential of health data will drive governments and corporations to use it in ways that

undermine or even contradict the right to health. For example, insurance companies may use an individual's health data to justify increased premiums or reduced coverage. To maintain their commercial advantage, technology companies may refuse to share health data that could be used for a wider public good. Marginalised communities and political opposition groups fear that health data may be misused by authoritarian governments to identify them and undermine their human rights.

- <u>Children's health and well-being</u>: The rights of children and adolescents are particularly at risk in the digital environment. Children have no say on how their life is monitored and quantified. They are often unable to understand the implications of sharing data online and are vulnerable to exploitation from digital marketing. Exposure to harmful online content and excessive use of digital tools negatively affects young people's health and well-being.
- <u>Environmental harm:</u> The environmental harm of data storage, digital waste and the energy required to power our digital lives is becoming increasingly well documented. Failure to address the negative environmental consequences of increased technology use will contribute to climate change and ultimately damage the health of future generations.

To ensure the positive and transformative benefits of digital technology and data outweigh any potential risks we need to accelerate access to digitally-enabled PHC whilst also building strong governance frameworks that protect individual rights and promote equity. Putting young people, women and other underrepresented groups in the driving seat will help to guarantee that the digital transformation leads to better health and well-being for all.

# What are we calling for?

**Transform Health's vision** is that UHC will be achieved by 2030 by harnessing digital technology and the use of data so that:

Everyone has access to equitable, affordable, and high-quality primary healthcare.

Everyone is able to make better decisions about their personal health using real-time health information and their own, protected health data.

Health workers are able and empowered to improve efficiency/capacity of health systems, using digital technology and population and health data to take more precise and effective action, to improve service delivery and strengthen overall health systems to ensure better public and individual health outcomes;

Researchers are able to access and use health data for research purposes that will improve public health.

Everyone is aware of and able to exercise their rights to own and access their own data to improve their own health.

To achieve this, we are advocating and campaigning for:

1. Recognition of the fundamental role of digital technologies and data use to transform and expand PHC which is an essential foundation for achieving UHC.

Stronger political will and leadership is essential for creating an effective digital health ecosystem that prioritises PHC and principles such as equity, inclusivity, and human rights. We are calling on more political leaders, technology developers and digital health partners to demonstrate their commitment to harnessing the digital transformation to improve health for all and to ensure that everyone is fully informed about the opportunities and risks associated with digital technologies and data use.

2. A digital health and data governance framework to allow for the full beneficial use of health data, while safeguarding data privacy, ownership, and security.

The way the world governs health data and data for health has never been more pivotal than it is in this digital age. To create an environment where all people and institutions can share, use, and benefit from data, an inclusive and collaboratively developed global framework for governance of health data is needed. We are calling for a global governance framework that realises health data as a global public good whilst protecting individual rights.

3. Increased domestic and international financial commitments/ investments for strengthening digitally-enabled PHC systems and empowered communities to achieve UHC.

With just ten years left to achieve UHC, we are calling on national governments and international donors to increase their investments in equitable, digitally-enabled primary health care, and to increase digital literacy of youth, women, and marginalised groups.

To guide these investments, we are calling on national governments, with the support of partners, to develop and implement national digital health strategies and approaches that prioritise PHC and the needs of communities and reflect core principles such as equity and human rights. All policymakers and technology

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developers engaged in digital health should involve young people, women, and marginalised groups in all stages of the design, implementation and monitoring of digital approaches that may affect their health and wellbeing.

By working in collaboration with others towards these three objectives, Transform Health will contribute towards the achievement of UHC by 2030 and help to ensure that future generations can continue to benefit from the transformative power of digital technology and data in ways that reduce inequities and protect their rights.

## Join us

Transform Health is building a global movement that brings together different communities, organisations and institutions across different sectors who are committed to achieving UHC by 2030 through expanding the use of digital technology and increasing access to data in ways that are equitable, ethical and enabling for all.

Join us and help raise awareness, influence policy making, increase resources in support of health for all in the digital age and ensure no one is left behind.

Organisations interested in supporting the work of Transform Health can do so by becoming a Transform Health partner. Partners can support coalition objectives in many ways including: helping us to implement or amplify our campaigns, joining a working group, or financing Transform Health's activities.

For more information visit: www.transformhealthcoalition.org

Contact us via email: info@transformhealthcoalition.org

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