



### Governing Health Futures 2030: Key findings and recommendations of the Lancet and Financial Times Commission

The Commission's report, published in October 2021, calls for a radical rethink in approaches to digital transformations in health.

igital technologies and data are changing approaches to health and the design of health systems, but governance models haven't kept up. This has created uneven effects globally, endangered democracy, limited the agency of patients and communities, and compromised trust and human rights.

In 2019, a *Lancet* and Financial Times Commission on Governing health futures 2030: Growing up in a digital world was established to explore how to maximise the benefits and reduce the risks of digital transformations to create better health futures, particularly for children and young people who stand to inherit the governance models designed today.

Nineteen Commissioners from a range of sectors and disciplines were brought together to develop a report. They considered a wide range of governance approaches, ethical guidelines, and institutional responsibilities that must be considered to improve health and wellbeing in an increasingly digital world. The Commission worked closely with Partners to support inclusive dialogues with key stakeholders, with young people and consulted the private sectors through convenings organised by the Financial Times.

The Commission's report, published in October 2021, calls for a radical rethink in approaches to digital transformations in health.



Read the full report on our website www.governinghealthfutures2030.org

### **KEY FINDINGS**

### 01

### A value-based framework for governing health futures

Most countries are yet to adopt an approach based on data solidarity, digital trust, human rights, accountability, and public participation. These are the keys to advancing \universal health coverage, reducing inequities and resolving privacy concerns.

### 02

### Addressing digital determinants of health

A solidarity approach to health data and addressing digital determinants of health are important for maximising the public health value of digital transformations. However these are missing from most governance approaches.

### 03

### Putting young people at the centre

Young people are excited about the benefits digital transformation will have for their health and wellbeing and concerned about the risks. Young people's views and needs are almost never prioritised in policy development or technology development.

## 1

Address the role of digital technologies as determinants of health

2

Build a governance architecture that fosters trust



Govern health data to increase its public value

4

Invest in the enablers of digital transformations for public health

Supported by:









## A new approach to digital health readiness

The Lancet and Financial Times
Commission recommends the use of
ten enablers to fully harness

digital transformations in support of equitable health futures.

Digital health readiness refers to a country's capacity to use digital technologies and data for improving their population's health and wellbeing. Existing tools for measuring digital health readiness are insufficient for assessing whether a country's approach to digital health will support the achievement of universal health coverage (UHC) and maximise the health and wellbeing of young people, now and in the future.

The Lancet and Financial Times Commission on Governing Health Futures 2030 proposes ten enablers for digital health futures readiness that can encourage all actors in a digitally enabled health ecosystemto align their digital transformation efforts with UHC and sustainable development goals.

Ball

Approaches to digital health are Diluciple based are aligned to health goals Human Health & well-being rights-centered in all digital policies approach to digital policies & programmes Do no digital harm to the planet Everyone is able to benefit from digial near transformations **Enablers of digital** Governing for equitable health health readiness Inclusive decision-making health worker & process People-centred Increased digital design health literacy

To fully harness digital transformations in support of equitable health futures, the Commission recommends that policymakers and other stakeholders use the ten enablers as a basis for assessing their digital health readiness, developing digital health strategies, and governing private sector activities in this field.



Read the policy brief on digital readiness and visit www.governinghealthfutures.org.



Editor

Mark Wembridge

Global education editor

Andrew Jack

Production editor

Conor Sullivan

Sub editor

Philip Parrish

Art director

Kostya Penkov

Picture editor

Esan Swan

FT Project Publishing editor

Matthew Vincent

Chief commercial officer

Jon Slade

Account director **Ashley Hamilton** 

Project manager

Andrea Frias-Andrade

Advertising production **Daniel Macklin** 

#### **Contributors**

**ANURAG AGRAWAL** LANCET-FT COMMISSION ON GOVERNING HEALTH FUTURES 2030 CO-CHAIR

FATHAYHA BEGUM FREELANCE
WRITER FARHAN BOKHARI PAKISTAN
CORRESPONDENT DARREN DODD
GLOBAL HEALTH WRITER ADAM

GREEN FREELANCE WRITER BRYAN HARRIS BRAZIL CORRESPONDENT

CAROLINA INGIZZA BRAZIL

CORRESPONDENT **ANDREW JACK**GLOBAL EDUCATION EDITOR

SHALIN JYOTISHI NEW AMERICA FOUNDATION SENIOR ANALYST ILONA KICKBUSCH LANCET-FT

COMMISSION ON GOVERNING HEALTH

FUTURES 2030 CO-CHAIR **DAVE LEE**SAN FRANCISCO CORRESPONDENT

ANGELICA MARI FREELANCE WRITER
SARAH MURRAY FREELANCE WRITER
SARAH NEVILLE GLOBAL HEALTH

EDITOR **ELEANOR OLCOTT** CHINA CORRESPONDENT **BENJAMIN PARKIN** MUMBAI CORRESPONDENT **POOJA** 

RAO QURE.AI CO-FOUNDER HEBA SALEH CAIRO CORRESPONDENT

ANDREW TRISTER BILL & MELINDA
GATES FOUNDATION DEPUTY
DIRECTOR OF DIGITAL HEALTH AND AI
BEN TURNER FREELANCE WRITER

ILLUSTRATIONS SARAH HANSON PHOTO ESSAY ALAN KNOX

**RESPOND** Send us your ideas on how technology can improve healthcare **aihealth@ft.com** 

REPORT The Lancet and FT Commission comprises independent leading experts. Read the peer-reviewed report at: governinghealthfutures2030.org

MORE ONLINE
FT.COM/FUTURE-AI-HEALTHCARE

ALL EDITORIAL CONTENT IN THIS REPORT IS CREATED BY THE FT



#### **OPINION AND FEATURES**

#### 7 Editor's letter

What has the pandemic taught us about governing digital health?

#### 8

#### Overview

Checks and balances lag technological developments

#### 12

#### Asia's Covid response

The advent of tracing apps highlights threats to civil liberties

#### 17

#### Opinion

High-tech tools must be accessible to all, says Andrew Trister

#### 18

#### Brazil's battle for truth

The dire consequences of misinformation on Covid remedies

#### 22

#### The devil in China's data

The rollout of AI technology raises privacy and security concerns

#### 26

#### Data trusts: the debate

This model of stewardship may not serve every community

#### 29 Opinion

Pooja Rao on why businesses must respect the common good on data

#### 30

#### African ventures

How the continent's health-tech start-ups are overcoming hurdles

#### 32

#### Pakistan talks taboos

A social media-based project fills the menstruation information gap

#### 34

#### Big Tech's data scramble

Silicon Valley's help for medics is raising regulatory concerns

#### 38

#### Pictures of health in Mexico

The imaging start-up helping improve access to healthcare

#### 40

#### Made for Kenyan mothers

An AI SMS system aims to turns the tide on maternal mortality

#### 42

#### Seeing past the stigma

The mental health therapy service busting barriers in the Middle East

#### 44

#### **Answering Afghanistan's call**

How telemedicine is addressing the country's healthcare crisis

#### 46

#### Prescriptions for equality

Technology is improving access to services for black people in Brazil

#### 48

#### Photo essay: virtual viewing

The power of telemedicine seen through a camera lens

#### 52

#### Tapping into young minds

The dark side of digital devices for children and how to beat it

#### Opinion

Digital tech design must involve young people, says Shalin Jyotishi

#### 56

#### Heart of the matter

The boon of using AI to spot cardiovascular disease early

#### 58

#### Opinion

Regulating tech is vital, say Ilona Kickbusch and Anurag Agrawal



Read our report on insights into young people's use and opinions of digital health technologies.

Although subjected to a significant digital divide, children and young people are major users of digital technologies but are under-represented—and often overlooked—when it comes to design and decision-making about digital technologies and digital health.

The Lancet and Financial Times Commission on Governing Health Futures 2030 wanted to better understand the expectations, demands, and concerns of young people in relation to the use of digital technologies for improving their health and wellbeing.

The Commission partnered with the UNICEF's Office of **Innovation and U-Report** to conduct a global survey of more than 23,000 young people aged **14-35** from 176 countries.

Inaccurate health information and **privacy** risks are the biggest concerns for young people using digital technologies.

Improving fitness is the most popular health-related objective for **40%** of young technology users.

**50%** of young people think access to health information is the biggest way that digital technologies can help them manage their health and wellbeing

o 🛓

88% of children and youth use digital technologies to support their health and wellbeing.











# Lessons in responsibility

The pandemic has proved the clinical potential of digital health but also shown we still have much to learn about how to govern it, says **Andrew Jack** 

hen the Financial Times forged a partnership with The Lancet in 2019 to convene a commission of global experts on the governance of digital health, the theme was already topical. Then Covid-19 struck.

On a practical level, the pandemic made it more difficult for the commissioners and their secretariat to meet and work, let alone for FT staff to report and coordinate a series of accompanying articles and events to encourage wider debate.

Yet coronavirus accelerated the use of digital health technology and heightened the relevance of the conclusions, which were delivered on schedule last autumn despite the disruptions and pressures.

Technology's effects on health have been profound, bringing many advantages. At a basic level, simple digital tools such as text messaging can provide essential health information in remote areas, while older phones can support telemedicine where inadequate facilities or physical danger impede access, as is the case in countries such as Afghanistan.

Electronic health records can integrate consultations, diagnoses and treatment records to better co-ordinate individual patient care between physicians.

At its most sophisticated, aggregated data offer the potential to connect patients everywhere with a broad range of insights and experts, efficiently and affordably. Artificial intelligence is aiding the scrutiny of vast quantities of information to support "intelligent drug design", interpretation of radiology scans, diagnoses

of symptoms and improved logistics and supplies of medical materials.

The pandemic intensified the applications of digital tools, such as the rapid collection and analysis of infection data, ways to track human movement and the management and analysis of patient records. It helped modelling, patient recruitment for clinical trials, scrutiny of existing and innovative treatments and the unprecedented speed of development of new vaccines.

But many of these applications have been imposed from the top down and unequally distributed, with a suspicion about how personal data are used. If there are concerns about lax safeguards imposed on companies, many governments — authoritarian and democratic alike — have proved still less cautious and more maverick with personal data, with arguably greater consequences.

That has sparked worries about insights collected in the name of public health being used to restrict movement or shared with law enforcement and other agencies. This raises concerns about civil liberties and risks creating a backlash against faith in the state or willingness to comply with measures to curb the pandemic. Examples range from the UK's contact-tracing app, to similar technologies in India, Singapore, Russia and China.

Covid-19 has also drawn a spotlight on broader concerns about inequality in health outcomes. Technology risks increasing these divisions, whether through the "digital divide" in access to affordable internet, or via opaque algorithms using partial data that introduce racial and other biases in their analyses.

There are concerns, too, about the imbalance of new forms of "data colonisation", which perpetuate an imbalance between the providers and beneficiaries of insights into health at the expense of the poor.

Another group struggling to make its voice heard is the younger generation, with so many health policies determined by and targeting the diseases of older people, who typically wield greater power and resources.

Yet it is essential that such "digital natives" are integrated into discussions and the design of future health technology. Partly, that reflects principles of equity and good governance. Practically, it also helps incorporate prevention and wellbeing to complement disease treatment to ensure the broadest benefit.

Alongside this call for intergenerational discussion, the FT-Lancet commission's multiple recommendations include measures to improve investment in digital infrastructure, training to ensure regulators and others are equipped to properly oversee technology for health, and greater "data solidarity" through experimenting with new institutions such as trusts and co-operatives.

The aim is to oversee how individuals' medical information is used responsibly, and to balance legitimate caution over private gain with a desire to ensure it is pooled and shared for the public good — but with adequate safeguards. Data should also be portable, with requirements on interoperability to allow it to be moved easily between different systems.

Further insights and reflections from readers are welcome on the commission's report, along with suggestions on next steps and emerging trends, as well as ways to test and develop the models it has outlined.

Andrew Jack is the FT's global education editor



### Digital checks and balances

The development of healthcare technologies has been accelerated by the pandemic but there are ethical and political hurdles to negotiate if all communities around the world are to benefit

BY ANDREW JACK ILLUSTRATIONS BY SARAH HANSON

ever in the field of human health has so much data been provided by so many with so few safeguards as during the Covid-19 pandemic.

From passively sharing medical records to actively participating in clinical trials, from the uploading of diagnostic test results to the use of mobile phone apps to track individuals' locations, the consumer digital age has been characterised by a surge in tools and insights to tackle infection.

The unprecedented power of technology has helped mitigate the worst effects of the pandemic, not least by enabling people to work and study remotely in ways that would have been unthinkable even a decade ago.

Similarly, it has offered direct benefits for health, with more effective control of transmission, accelerated scientific and medical insights and enhanced vaccine and drug development. Technology platforms have accelerated the shift to online medical consultations, and the data they collect have had far wider benefits.

But much has come through mandatory "test, track and trace" systems, requirements for isolation and proof of vaccination imposed by governments that



restrict movement and enhance surveillance. They have used powers rarely deployed in peacetime by western democracies, while authoritarian regimes have adopted such measures still more aggressively.

The speed of these digital health advances has left checks and balances lagging, fuelling distrust of governments and companies alike. This risks undermining future gains unless health innovations are accompanied by new approaches to "data solidarity" to balance public and private benefits, according to the findings of The Lancet & Financial Times Commission on Governing Health Futures 2030.

Steve Davis, a consultant and author of *Under Currents: Channeling Outrage to Spark Practical Activism*, describes the digital revolution as "net-net one of the most powerful things that will ever happen to human health". He argued

'There are no clear policies on data governance, on digital privacy, on managing disinformation' recently that "there is a huge gap around understanding what is available, the ecosystems are fragile, there [are] no clear policies on data governance, on digital privacy, on managing disinformation".

While many people willingly share their personal data through social networks mined by companies and governments, the pandemic has crystallised specific concerns around health. Medical data is perceived as particularly sensitive, and its forced extraction may create resentment and lead to inconvenience or discrimination.

In the UK, the Information Commissioner's Office (ICO) last year began investigating claims that at least one large Covid-19 testing company had included a notification — buried in extensive terms and conditions — that it could retain its clients' DNA and other genetic information to share with external researchers.

That highlighted worries about the potential commercial exploitation of information derived from government-imposed testing on travellers in the name of public health. Other concerns have emerged over wider sharing of data related to Covid-19 with law enforcement agencies, not always fully assuaged by the regulator. The ICO, for instance, says it has "received assurances that there is no



automatic mass sharing of data from NHS Test and Trace to police forces". It adds that "limited data can be shared under strict controls where police suspect self-isolation rules have been broken".

In Singapore, authorities won initial praise for their prompt action to control the spread of coronavirus with the TraceTogether scheme in 2020. But, last year, new legislation was rushed through to put in additional safeguards over surveillance after officials revealed that data collected for coronavirus control had been used in a criminal investigation.

The collection and use of health data are only set to grow, offering the potential to help disease prevention and treatment significantly. However, it also risks creating ever more divergent outcomes between richer and poorer regions and countries, older and younger

'With the pandemic, health systems, governments and the private sector realise digital solutions are truly a must' people, and those whose data are better or less well integrated into health systems.

At the most basic level, much information is still not systematically collected, digitised or pooled — from details of patients' discussions with doctors in the US, to medical records in poorer countries. Wilfred Njagi, chief executive of Villgro Africa, a Kenya-based investor in healthcare, says medical information from clinics in his country remains "a black hole — and an immense opportunity".

Narrowing this "digital divide" will require substantial investment, though. Hila Azadzoy, managing director of the Global Health Initiative at Ada Health, which is experimenting with artificial intelligence to diagnose illness in Tanzania, Uganda and South Africa, says: "People agree that we need digital solutions. With the pandemic, health systems, governments and the private sector realise it is truly a must, not a nice-to-have."

But many argue there should be tougher reassurances on confidentiality, given periodic data leaks and inappropriate sharing of sensitive information. For instance, Privacy International, an advocacy group, has highlighted the sale to advertisers of information on individuals' mental health collected on apps in France, Germany and the UK.



Greater confidence also requires enhanced safeguards and scrutiny of AI based on imperfect information. In the US, for example, health insurers' poorly constructed algorithms to identify and provide greater support for at-risk patients were found to discriminate against African-Americans.

Darlington Akogo, the founder of an AI-driven radiology diagnosis company in Ghana, is part of an international "Focus Group on Artificial Intelligence for Health" that is seeking to help regulators analyse and verify machine learning. "My optimism has increased, but so has my scepticism," he says. "It's clear we need AI to support healthcare in Africa. These tools have a lot of potential, but they may not be not quite ready. We need more assessments before we put them into wider use."

More rigorous evidence and scrutiny are also necessary to demonstrate the clear clinical and cost effectiveness of much health technology. The evidence base in most such fields, including mental health, remains limited.

Tobias Silberzahn, a partner at consultants McKinsey, argues that one of the problems with digital health initiatives during the pandemic has been the failure to provide sufficient useful insights that are directly relevant to individuals, such as personalised guidance on

treatment on an app tailored to their own risk factors and stage of infection. He suggests future health programmes need to be "fun, convenient and effective", and that there is substantial potential from integrating medical data with broader "wellness" insights, such as sleep, nutrition, stress and movements tracked by wearable devices.

But Pooja Rao, co-founder of Qure.ai, an Indian AI health company, suggests such integration of broader data needs to stress the primacy of individuals as the owners and controllers of their personal health information, with the right to shift it between different health systems. "There is a lack of trust in private actors and government," she says.

That points to the need for new institutions, such as data trusts or co-operatives that supervise any wider sharing of health records, as well as the advent of an approach known as "participatory digital health tools", developed directly with and for users.

As Amandeep Gill, chief executive of the International Digital Health & AI Research Collaborative, says: "We have a data privacy and security paradigm. We need to shift the conversation to a data empowerment paradigm, in which the citizen has more agency on choice around their data."

## Pandemic polemics

Technology that was intended to mitigate the harm from the coronavirus health emergency has generated controversy in some Asian countries over its impact on civil liberties, writes **Benjamin Parkin** 

n the early days of the Covid-19 pandemic, authorities in India used everything from door-to-door surveys to indelible ink hand-stamps to track people suspected of being infected.

In April 2020, however, New Delhi launched a more high-tech solution: Aarogya Setu, a Bluetooth-based tracing app that harvests mobile phone records to identify users' possible exposure to coronavirus.

Meaning "bridge to health" in Sanskrit, Aarogya Setu is one of the world's most widely used contact-tracing apps, downloaded hundreds of millions of times. For many Indians, it remains a feature of everyday life, mandatory for everything from entering airports to visiting some malls.

Those in government say it has played an important role in India's Covid-19 response. But critics — particularly civil society and privacy advocates — counter that the app has done little to bolster the response while harvesting vast quantities of Indians' health and personal data.

India spends about 1 per cent of gross domestic product on public healthcare, compared with 10 per cent in the UK. Technological solutions, such as Aarogya Setu, have therefore been lauded by their proponents as a way of supplementing the country's neglected public health infrastructure.

India — a country of 1.4bn people — has officially recorded 35m Covid-19 infections and 500,000 deaths, though experts believe the true figures are higher, with a brutal wave in 2021 overwhelming both testing capacity and hospitals across the country.

But whether tools such as Aarogya Setu have mitigated the damage is hotly contested.

Using GPS data and Bluetooth to determine whether users have been in contact with a person known or

#### Mass action

The Indian state
has harvested vast
quantities of health
data on the country's
1.4bn people





suspected to be infected with Covid-19, Aarogya Setu alerts at-risk users and feeds information to authorities. Amitabh Kant, head of the government's policy think-tank NITI Aayog, last year hailed Aarogya Setu as India's "curing machine" and "a key tool in our fight against Covid-19".

Senior government officials say that, while some invasion of privacy may be necessary in a health emergency, the app has robust protections. "Transparency, privacy, and security have been the core design principles of the app since its inception," Kant said.

Aarogya Setu was developed in conjunction with private-sector tech executives, and the government has made some of its code open source to allow scrutiny of its inner workings.

However, critics say the app sets a dangerous precedent, labelling it as an example of how authorities and companies have rushed to harvest sensitive personal data without valid safeguards, under the umbrella of supposedly combating Covid-19. Also, it is not fully open source, critics note, with only an outdated version of the user-side code available and not the server code that controls the app.

Apar Gupta, executive director of the Internet Freedom Foundation, a New Delhi-based privacy advocacy group, says there is little evidence that Aarogya Setu has aided the battle against Covid-19. The app has repeatedly failed to detect infected nearby persons and has carried the risk of false negatives and positives, according to the IFF's research into its effectiveness.

As Covid-19 surged in the months after Aarogya Setu was rolled out, the app alone was insufficient to stop the disease spreading, the IFF noted. Its analysts attribute this to a lack of on-the-ground follow-up from health workers.

In 2020, Aarogya Setu had been heavily promoted in authorities' Covid-19 messaging. But, by 2021, it had been sidelined, and critics interpreted this as an indication of the app's limited efficacy.

Rather than help counter Covid-19, Gupta suggests that Aarogya Setu has served to enhance the government's surveillance powers by allowing it to collect enormous quantities of personal and location data on Indian citizens. Authorities show no signs of wanting to relinquish those powers, Gupta adds.

"Extraordinary powers used in times of war, famine or health emergencies have been utilised in the time of Covid," he says. "What is worrying, is that the restrictions on civil liberties are continuing for an indefinite period." Aarogya Setu effectively remains mandatory for many activities, even though, according to Gupta, "there is no stated evidence for [its] effectiveness".

Udbhav Tiwari, a public policy adviser at non-profit internet group Mozilla, says the biggest concern about apps such as Aarogya Setu is the lack of checks and balances on what the Indian government can do with health data, despite a ruling by the Supreme Court in 2017 that Indians held a fundamental right to privacy.

India does not have an overarching law governing the use of data — such as the EU's General Data Protection



Scan analysis in
Assam, India, using
Qure.ai software

**2** The Aarogya Setu tracing app

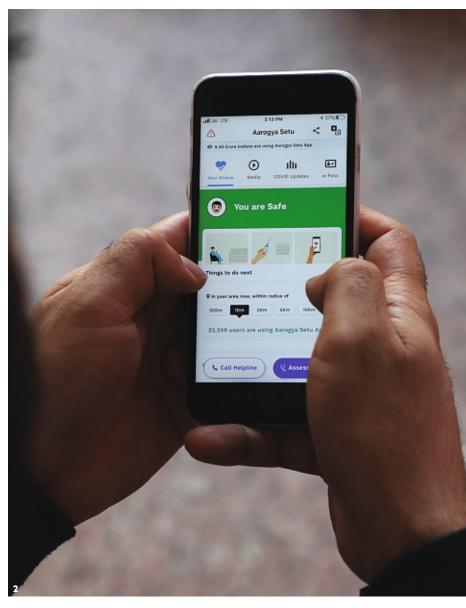
Using the
TraceTogether
app to enter a mall
in Singapore

TraceTogether tokens, which function as an alternative to the phone app



'What is worrying is that the restrictions on civil liberties are continuing for an indefinite period'











#### Access rights

A traveller presents
details from the
Aarogya Setu app
to be allowed into
an Indian airport

Regulation — but a personal data protection bill is waiting to be passed through parliament. Although the draft legislation contains controls on how companies can use sensitive data, it effectively allows government authorities to exempt themselves from curbs on broad grounds such as maintaining public order.

"The case for why [invasive technologies are] justified in a public health emergency can be made, but the framework around the laws and regulations and what can or cannot be done, like a lot of things with privacy in India, is almost non-existent," Tiwari says. "There is no real law that tells you [what] you can and cannot [do] with the data."

India's struggle with contact-tracing apps contrasts with other countries in Asia. In China, for example, authorities have used heavy-handed technological surveillance to control citizens' movement, without the pretence of respecting civil liberties. Singapore's contact-tracing efforts, which include TraceTogether, a Bluetooth-based app, have been praised for their efficacy. Privacy advocates, however, have highlighted concerns about how authorities — including law enforcement agencies — have been able to access data that citizens were promised were collected solely for public-health purposes.

Tiwari says the main difference between India and other Asian countries that have used contact tracing more

'The framework around the laws and regulations, like a lot of things with privacy in India, is almost non-existent' effectively — such as Taiwan and Japan — is in-person follow-up by health workers to test and monitor patients flagged by the technology.

With some exceptions, most Indian states have lacked teams of trained health workers needed to deploy a comparable on-the-ground response, meaning the app on its own has had limited effectiveness.

When it comes to restricting the spread of Covid-19, Tiwari says that comparatively low-tech solutions, such as the requirement to show a negative PCR test when boarding a flight, have proved the most effective.

But technology has been deployed in India's Covid-19 response in other ways, too. Qure.ai, a Mumbai-based start-up that uses artificial intelligence to analyse CAT scans and X-rays, adapted its products to detect and measure Covid-linked pneumonia lung infections.

During last year's wave of Covid-19 in India, when hospital beds were full and resources stretched, Qure.ai also developed chatbots to monitor infected patients quarantining at home. These technologies were used by Indian health authorities, including those in Mumbai, and in other countries such as the UK and Italy.

Prashant Warier, Qure.ai co-founder, praises the Indian authorities, saying they were enthusiastic about bringing tech into their coronavirus response. "We could see how they were eager to adopt new technologies to combat the disease," he says.

Reshma Suresh, Qure.ai's head of business operations, acknowledges, however, that India's privacy "framework is evolving", adding that awareness and transparency need to improve. "If you go to the US, most patients are aware of how and where their data is used," she says. "In India, it would be more difficult."



# Bridge the digital divide

The west's high-tech healthcare innovations must be made more affordable and applicable to communities that will benefit most from them, says **Andrew Trister** 

hile digital transformation has undoubtedly changed the world for the better, the benefits of digital tools in healthcare have not always reached those most in need — a disparity that has been exacerbated by the Covid-19 pandemic.

To improve outcomes and expand access to care, we need more than a new tool or data set. We need a paradigm shift that addresses the systemic problems hindering the power of digital tools to improve access to healthcare in low- and middle-income countries.

Key to this is societal trust, which can be fostered by balancing the power between countries of the northern and southern hemispheres better on issues such as data sharing — and ensuring that products developed in the north are affordable and applicable in the south.

A large gap exists between the research and development of cutting-edge digital tools and the availability of these products in low- and middle-income countries. Although many organisations in rich countries are funded to develop and evaluate the use of digital tools, there are few that use human-centred design to ensure these products benefit poorer nations.

Through partners in India and Nigeria, the Bill & Melinda Gates Foundation is getting involved in education programmes to upskill workers in areas such as data literacy and cloud computing.

The foundation is sponsoring open data challenges, improving access to funding for research and encouraging more private sector investment in digital

health innovation in the global south. Some 97 per cent of newly committed grants through the Foundation's Global Partnerships and Grand Challenges initiatives go directly to researchers in low- and middle-income countries, compared with 49 per cent a few years ago.

It is critical to reach agreement on health data governance and interoperability standards for sharing such data. Promisingly, there has been some early success, with the development of Fast Healthcare Interoperability Resources to define standards for data exchange between different health systems.

The World Health Organization has been working with app developers and tech companies to apply these standards to community health work practice for all member countries. This can help improve health delivery to patients, and, with greater deployment, will be the basis for a more accessible health system.

But data alone will not improve health outcomes in underserved communities. Even if robust data standards were in place today, the flow of data would still go from low- and middle-income countries to high-income countries to perform the necessary machine-learning tasks.

Investment is needed in a different type of digital architecture that supports responsible health data sharing. In many parts of the world, the overwhelming focus has been on health data security rather than ensuring data privacy. But, by building castle-keeps of localised, centralised health data, the opportunity is missed to pool larger volumes of information securely for the public good.

The Lancet & Financial Times Commission on Governing Health Futures 2030 calls for "data institutions" that can act as fiduciaries for individuals' health data. As the global community works towards the goal of making universal, affordable, safe and meaningful connectivity a human right and public good by 2030, a key element will be developing the technical infrastructure to support different layers of data governance and control.

The International Digital Health & AI Research Collaborative (I-Dair) has developed a set of research hubs focused on inclusive data and artificial intelligence research. These hubs will reflect local views on data governance requirements as AI tools are developed.

Efforts to build real-time epidemiology maps with recommendations for public health action will inform this approach. This local-regional strategy can be more effective and efficient than a single monolithic solution.

Using digital tools is the most effective way of reducing barriers to high-quality healthcare access globally. To address this, the global community should focus on the incentives for individuals, health systems and public and private actors to share data and ensure innovative digital health tools can reach everyone.

Virtual care models have already been shown to increase disclosure of HIV infection, potentially by offering discretion around a societal stigma. Treatment for malaria can be more appropriately dispensed over the counter by using a rapid diagnostic test. Reducing the demands these services place on health workers will reduce absenteeism and improve data collection.

With the right tools and governance, there is enormous scope to empower the communities that will benefit most from innovations in digital health.

#### **Andrew Trister**

is deputy director of digital health and artificial intelligence at the Bill & Melinda Gates Foundation





## The battle for truth

Misinformation on Covid remedies, seeded by officials and fuelled via social media, has had dire consequences for public health in Brazil. By **Bryan Harris** and **Carolina Ingizza** 

he darkest moment of Brazil's Covid-19 crisis struck a year ago. Just days after Latin America's largest nation celebrated the start of 2021, a new strain of coronavirus took hold in the Amazonian city of Manaus, triggering a surge in cases that overwhelmed hospitals and cemeteries.

As oxygen supplies ran out, television cameras captured patients gasping for breath and succumbing to asphyxiation. It was as if "they were drowning", President Jair Bolsonaro said at the time.

Although the Brazilian air force was dispatched to deliver oxygen cylinders to the stricken rainforest city, government health officials in Brasília offered an alternative recommendation promoted on social media: patients should take what they called "early treatment" medicines, including anti-parasitic drugs such as chloroquine, hydroxychloroquine and ivermectin. The official recommendation to adopt the drugs, which have no proven effectiveness against Covid-19, was among the most egregious promotions of quack remedies by Brazilian authorities to date — but it was not the first nor the last.

Ever since Covid-19 began to spread, the Bolsonaro administration has promoted the cocktails of medicines — known locally as the "Covid Kit" — as part of a misinformation campaign aimed at downplaying the risks of the pandemic. The rightwing populist leader has twice used speeches at the UN General Assembly to tout the drugs. When Bolsonaro himself contracted Covid-19, he posted videos to millions of followers on social media of him taking chloroquine, which is typically used as an antimalarial. He fired one health minister who refused to promote the drug, while another quit less than a month

into the job. The campaign's results have been clear, health experts say: it caused the death of tens, possibly hundreds, of thousands of Brazilians.

"Brazil is a tragic case. We had misinformation being blatantly spread by our authorities," says Caio Machado, head of the Vero Institute, which tracks misinformation in Brazil. "Bolsonaro was the source of many of the main conspiracy theories that went around. But he brought in all the institutions, he orchestrated the campaigns from the high ranks. It was part of the official narrative. That is why Brazil is one of the worst Covid cases."

More than 600,000 Brazilians have died from Covid-19 — the second-highest number in the world, after the US. Researchers say the bulk of these deaths should not have occurred. In testimony to a congressional inquiry on the government's handling of Covid-19, Pedro Hallal, an epidemiologist from the Federal University of Pelotas, said that as many as 80 per cent of deaths could have been avoided if the government had supported conventional measures, such as social distancing and mask use, and had not propagated quack treatment theories.

"We know many of the 600,000 deaths are mainly due to these kinds of things. It is not just the disease [killing us]," says Luana Araujo, a public health consultant at Albert Einstein hospital in São Paulo, who testified at the congressional inquiry.

Bolsonaro latched on to the Covid Kit at the beginning of the pandemic because he refused to countenance lockdowns, which he said curtailed liberties and would cause hardship for many people. Drugs such as chloroquine would allow the economy to remain open, he claimed.

The message was spread publicly, often in official speeches. But it took root in social media, particularly messaging apps such as Telegram, which critics say do little to regulate misinformation. A multitude of groups sprang up, often with thousands of members, to discuss where to buy "early treatment" drugs and what the side effects were.

Decoupled from science, the issue became a political banner for Bolsonaro's millions of supporters. "You have to remember that Bolsonaro and his camp had really worked to delegitimise the mainstream press in recent years," says David Nemer, a Brazilian assistant professor of media studies at the University of Virginia. "So, when the press reported that these drugs were ineffective, they said it was just the media lying again. They create their own truths. They only believe what comes from channels they trust."

Daniela Braga, a 39-year-old baker from Rio de Janeiro, is one such believer. She says she trusts the drugs because the president vouched for them. She takes ivermectin for three consecutive days every two months because she believes it is a prophylactic. She took chloroquine when she contracted a mild dose of Covid-19. Her mother and stepfather use both drugs as prophylactics. "They go everywhere — they enter supermarkets, malls, everything. And they didn't get contaminated," Braga says.

Public health experts say this mentality is often the real risk of the drugs, not necessarily the side-effects, which in the case of chloroquine can include heart rhythm problems. Having taken the medicines, users feel emboldened to disregard other precautionary measures. "They don't use masks, they go to crowded places — it is even to the point where they don't take the vaccine," says Luiz Henrique Mandetta, who was Brazil's health minister at the beginning of the pandemic but was fired following tensions with Bolsonaro over how to respond to the disease.

Luana Araujo

Anti-vaccine protestors in 2020

President Jair
Bolsonaro holds a
pack of chloroquine
at the inauguration of
a health minister

Luiz Henrique
Mandetta, who
was fired as health
minister over
Covid policy











# 'Covid pinpointed our education problems and showed how easy it is to manipulate a desperate population'

Speaking to local media, Christos Christou, international president of medical aid charity Médecins Sans Frontières, said no other country had demonstrated the same predilection towards quack remedies as Brazil. His message is borne out in research on the impact of misinformation. In a comparative study of 70 countries, Caio Machado found that in Brazil — as well as India — misinformation lingered longer and resonated more in the public debate.

"Brazil and India were way out there — completely separated," he says. "While other countries had peaks with misinformation — things appeared and would move on — in Brazil we kept fighting chloroquine." He adds that it was because "people had a political affiliation to chloroquine".

Araujo says Brazil is fertile ground for misinformation because of decades of neglect of investment in education. "Our education was never a priority for any government," she says. "The Covid crisis only pinpointed how deep our educational problems are and how difficult it is for many people to understand basic concepts. Worse than that, it highlighted how easy it is to manipulate a desperate population.

"Bolsonaro was elected in 2018 as a saviour figure because most people were not satisfied with the previous governments. When you have a figure of power like that, and add it to a population with a low education, along with a global crisis, which naturally generates a lot of questions, that is a very complicated scenario," Araujo says.

Despite the impact of misinformation on the country's Covid-19 response, experts have been heartened by the failure of the anti-vaccination movement in Brazil - widely attributed to the nation's longstanding prowess in not only distributing jabs, but promoting their use through public campaigns. Although Bolsonaro has himself publicly refused to be vaccinated, the number of doses administered in Brazil is the fourth-largest of any country, according to Our World in Data figures. The city of São Paulo says it has vaccinated its entire adult population. "Brazil had a long culture of getting people vaccinated. It is something that society embraced well," says Nemer. "Even those who aligned themselves with the right saw the amount of fake news circulated about [this] and saw there was something wrong here. That helped create some media literacy towards misinformation. [But] I don't think it is enough to change ideology."

Thatyana Borges Machado, a nurse in Manaus, says sometimes the pregnant women she cares for are unvaccinated because they are "afraid that the vaccine will alter their DNA".

"Usually, they don't have much education and have little access to information," she says. "I tell them that they have to be afraid of not taking the vaccine — the baby doesn't choose whether to take it or not, but they can choose to save their own life and the baby's life. In the next appointment, they come back vaccinated."

## The devil in the data

China is setting the pace in deploying Al technologies in healthcare but concerns remain over privacy and security, says **Eleanor Olcott** 

live-stream video of a 76-year-old woman pottering about her kitchen plays on Li Hong's phone. Li is in London, 8,700km from her mother in the Chinese city of Kunming.

Li has narrowed the distance between them by installing cameras in her mother's apartment, where she lives alone. The system has built-in microphones and speakers, enabling the pair to discuss the latest readings from the blood pressure monitor of Li's mother, who has a heart condition. "It's like I am back in China with her. The technology is so convenient," says Li.

China has been quick to deploy a range of new technologies to relieve the burden on hospitals, care systems and families caring for the sick and elderly. But it is in medical artificial intelligence that the country's early adoption of new solutions has been particularly notable, says Eric Topol, a US doctor and author of *Deep Medicine:* How Artificial Intelligence Can Make Healthcare Human Again.

China has shifted faster than the US in medical AI from research to implementation, driven in part by the availability of high-quality data, says Topol. "China has a massive data advantage when it comes to medical AI research," he says, explaining that Chinese researchers can train AI models on data sets covering entire provinces. In contrast, their US counterparts are restricted to working with information from single hospitals — largely operated by private businesses that keep records on internal servers.

AI is widely used in healthcare to help doctors analyse scans and images, improving the speed and accuracy of their diagnoses. Airdoc, a Beijing-based medical AI group, recently became the first company to gain regulatory approval for its retina-scanning software to be deployed in Chinese hospitals. "The eye is a window into the rest of

### Al-powered An Airdoc eye scanner, which has been deployed in hospitals lacking specialist doctors





the body," says He Chao, Airdoc's chief technology officer, noting that changes in the retina, including discolouration, can offer clues about conditions including high blood pressure and diabetes.

"In China, some of the early adoption of medical AI is also driven by need," says Topol. "They don't have enough radiologists and physicians to match up with the population." Airdoc's retina scanners have been deployed in rural hospitals that lack specialist ophthalmologists — China has 44,800 such practitioners to serve its rapidly ageing population of 1.4bn.

The success of companies such as Airdoc has relied on their access to vast amounts of diverse medical data from Chinese patients. This trove of information allows researchers to train algorithms that will eventually perform functions in clinical settings, such as diagnosing diseases from medical images and scans. In the case of myopia (nearsightedness) — which afflicts 53 per cent of children and teenagers in China - Airdoc has developed a machinelearning model that measures the size and shape of the lens in a patient's eye. Implantable collamer lens (ICL) surgery is an increasingly common procedure, in which an artificial lens is implanted between an eye's natural lens and the iris to produce clearer vision. The process is fraught with complexity, however, because of possible post-operative changes in the pupil and iris that could mean the lens does not fit correctly. A British Journal of Ophthalmology article describes how Airdoc's machine-learning model offers 80 per cent-plus accuracy in predicting these changes and selecting the right size of ICL.

"Hospitals are motivated to pursue this digital transformation because China is facing a tough challenge in healthcare," says Sally Ye, a Shanghai-based healthcare analyst at Omdia, a tech consultancy. "The medical infrastructure is insufficient, and AI digitalisation is a way to solve this problem."

Ye says Chinese AI companies have an edge over those elsewhere as China has an abundance of the low-cost labour that is required to annotate medical data and standardise it for machine learning. "China has a big workforce of data scientists, IT engineers and medical professionals that can work on these labour-intensive projects at a relatively low cost," she says. Beijing's policymakers have thrown their support behind medical AI companies that come up with technological innovations to ease the burden on the country's hospital system. Medical and health tech forms a core pillar of the flagship "Healthy China 2030" policy.

Money flowed into medical AI after the policy's publication in 2016, with large internet companies and start-ups battling to be the first to gain regulatory approval and be deployed in Chinese hospitals. In 2020 alone, Chinese start-ups attracted \$1.4bn of financing, compared with \$2.4bn by their US counterparts, and the two nations accounted for 90 per cent of global investment into medical AI start-ups, according to Omdia research.

But the race to get ahead has also encouraged some companies to obtain data through unregulated channels. CN-Healthcare, a Chinese medical media platform and consultancy, reported that, in 2017, third-party data brokers were selling medical records from hospitals to AI companies. "Medical AI companies don't have a strong understanding of data protection," says Deng Yong, associate professor in medical and health law at Beijing University of Chinese Medicine, adding that they have tended to view data compliance as a hindrance.

Sally Ye

Doctors in Wuhan treat a Covid-19 patient in 2020

**3** Chinese start-ups attracted \$1.4bn of financing in 2020

Some of China's adoption of medical Al is driven by lack of doctors









### 'China has a massive data advantage when it comes to medical Al'

Ensuring medical data is both anonymised and secure is expensive, and Deng says there has been a tendency to cut corners. A group of Chinese researchers last year found technical vulnerabilities in how mainland hospitals were processing patient data, which exposed the identities of individuals in a data breach. Hackers have also been on the hunt for poorly secured medical records or data from wearable health devices, which can be sold on to other medical companies or to criminals, who use the information for blackmail or to make false medical claims.

In 2020, Cyble, a US cyber security group, identified a data hack on the Chinese healthcare AI company Huiying, a medical imaging devices manufacturer. Beenu Arora, founder and chief executive of Cyble, says personal health records and Covid-19 test results were taken from the company's servers and advertised for sale on the dark web. Huiying did not respond to a request for comment. Arora says the digitalisation of healthcare, which has accelerated during the pandemic, has increased the intensity of cyber attacks on the medical, healthcare and pharmaceutical industries. "These breaches can lead to patients' histories being used for potential abuse or criminal activities," he says. The vulnerabilities found on Huiying's database are not unique to China. Tech blog The Verge reported in early December that, based on government data, the personal health information of more than 40m people in the US had been exposed in data breaches in 2021.

But, while healthcare organisations in the US must report medical and health data breaches when they affect 500 or more people, the same requirement does not exist in China. Nevertheless, a partner at a law firm in Shanghai says that although data breaches have occurred in China, none has been "very serious", adding that "the overall trend in China is towards building a better privacy protection regime".

At Airdoc, He Chao says the company has the "strictest procedures" and has invested in data protection both by anonymising the medical records that its algorithms are trained on and by inviting external cyber security companies to test vulnerabilities. "These costs are a necessity," says Chao. "Our company relies on data."

These security measures are becoming an industry standard after Beijing introduced the Personal Information Protection Law in November, designed to prevent data hacks and other nefarious uses of sensitive personal information. Much like the EU's General Data Protection Regulation, the PIPL stipulates that an individual's explicit consent must be obtained before their medical health data is collected and places the burden on medical AI companies to ensure that data is secured.

China's AI community is debating how to best secure data privacy, says Jeffrey Ding, a postdoctoral fellow at Stanford University's Center for International Security and Cooperation in the US and author of the ChinAI newsletter. "Federated learning is becoming more popular in China as a privacy tool," says Ding, referring to the practice of spreading data sets across multiple servers to bolster security. "You can never guarantee privacy," says Topol, "but AI is helping us get much better on this issue."







## Models of stewardship

Designed to ensure privacy when health data are shared, data trusts hold great promise, though it is debatable whether they benefit patients in the developing world who provide information for western researchers, says **Sarah Neville** 

hen Julie Parker was invited to join the advisory board of Insight, an organisation that oversees a trove of UK National Health Service eye scans and other images for research, she accepted without hesitation. The retired insurance loss adjuster is living with macular degeneration, which robs sufferers of their central vision. This gave her a special stake in the breakthroughs this data might yield.

Parker's unpaid role points to a new model of data stewardship that is designed to allay privacy concerns. These have heightened in recent years as the role of tech giants in aggregating and profiting from personal data has come under increasing scrutiny.

Parker is part of a team that reviews applications for the eye-scan data set from NHS, academic and industry researchers. The team acts as an intermediary, judging requests against published criteria, including whether each application poses a significant risk to individuals' privacy and if the outcome strikes a "balance between public good, scientific discovery and value generation".

In this way, Insight acts as a "data trust" — and the use of such trusts has been singled out by The Lancet and Financial Times Commission on Governing Health Futures 2030 as a promising model for the future. There are, however, questions about how, and by whom, key decisions on data sharing are made — and whether a model that originated in the wealthy west is appropriate for the developing world.

Insight is one of nine data hubs funded through the UK Health Data Research Alliance (HDR UK), an independent grouping of healthcare and research organisations that is seeking to establish best practice for the ethical use of

Under scrutiny
Questions hang
over how data are
shared in the name of
science and by whom







Fitbit wearers can donate health data for research through Open Humans

> **2** Jack Hardinges

David Seymour

UK health data. David Seymour, executive director, says the positives and the risks around data use have been "brought into sharper focus and amplified" by Covid-19. The pandemic has not only expanded the amount of information available but has also led to quicker and larger-scale sharing of data under the exigencies of the public health emergency.

The chief risk, Seymour suggests, relates to "public perception and understanding... because when decisions are made quickly, perhaps they're not always communicated as transparently and/or the sort of public involvement in those decision-making processes isn't always as strong as it should be".

The data trust model, he says, can be vital to offering a necessary layer of reassurance to the public, "not only about who gets access but under what terms that access is granted". Seymour sees data trusts as connected to a wider approach known as trusted research environments. HDR UK recently defined principles and best practices for these "data safe havens" that provide researchers with a single location to access valuable data sets "similar to a secure reference library".

Parker says she and her colleagues "ask a lot of questions" about each request they receive from research teams. While they have yet to turn down a request outright, a couple have been returned for further information. "We don't reject out of hand, because that's wrong. But we do want to be reassured [that the data will be safe]", she says.

Jack Hardinges, programme lead for data institutions at the Open Data Institute (ODI), a non-profit that advocates an "open, trustworthy data ecosystem", says it is important not to delineate the data trust concept too narrowly. Hardinges, who is responsible for the ODI's work on data stewardship, suggests it has come to be defined in a way that is "specific and niche, in that it's about creating a particular type of trustee relationship and trustees manage data on behalf of a group of individuals".

'There's a risk this conversation about data trusts turns into: "Give us your data and we will solve your problems" He notes that other approaches to data stewardship are also emerging, such as the one espoused by Open Humans, a US-based organisation that allows individuals to donate data from wearables such as Fitbits, or medical records, "and...ensure that it's used for research into a particular condition or cause. It's about bottom-up empowerment of individuals to exert control over data about themselves rather than deferring that control to someone else."

Hardinges adds that for data trusts: "Who is doing the trusteeship around the data is important. We shouldn't inherently trust it just because it's called a data trust."

Such caveats may be even more pertinent in the developing world. Amandeep Gill, one of the moving spirits behind the International Digital Health & AI Research Collaborative (I-Dair) — which is developing a global platform "to enable inclusive, impactful and responsible research into digital health and AI for health" — says the main question is: "How is the thing being governed and on whose behalf?"

In Africa and Asia, there are concerns that data may be handed to western researchers with no clear route for the people who generated the information to benefit. Gill has seen such sensitivities heighten over the past few years. "There's a risk that this whole conversation about data trusts turns into: 'Give us your data and we will solve your problems for you,'" he says. "And there might be a sort of neocolonial tinge to it."

The resulting backlash risks fuelling "a form of data localisation [or] data nationalism", Gill adds. To avoid this, I-Dair is pursuing a "distributed, decentralised approach — almost like confederating data assets".

An example of I-Dair's work involves nationally held data sets covering antimicrobial resistance. Authorities in Singapore and in India, for example, have retained sovereignty over their data but have agreed to share them for research after mutually defining the problem the data are intended to solve and jointly working on an algorithm to analyse them. "The AI that's developed is also done collaboratively, so that you can trust it," Gill says.

Like Hardinges, Gill highlights a model in which citizens come together to generate the data needed for a goal to which they themselves subscribe. A example of this approach in Europe is Midata, based in Switzerland.

Dominik Steiger, a member of Midata's management committee, describes his organisation as "a data trust organised as a co-operative". The idea that citizens or patients should have a say in how their data are used is rooted in the idea that personal data are a resource or an asset. "And that the expectation, or the rights, of people to...decide what happens with their data is something that has to be built into the data ecosystem", Steiger says.

Some 20,000 people have shared their data with Midata, although not all will choose to participate in every project. In one example, people were given an app to record pollen allergy symptoms. "This is citizen science and the data that people generate will belong to them...and then they consent to this being used in an anonymous fashion at an allergy study," Steiger says. He suggests this model can offer a distinctively European approach to data stewardship as an alternative to the behaviour of the US tech giants.

In Europe, he adds, "there is a strong move towards seeking solutions that are more trustworthy, which better represent, or enable participation by, individuals. We have one answer, which fulfils these criteria, and we hope it gives inspiration for such models."



# Respect the common good

Health data belongs to individuals and to society at large. Businesses that seek to extract value from it are taking a short-sighted view, says **Pooja Rao** 

n a medical artificial intelligence business, the quality of your algorithms — and therefore the value of your company — depends on your access to data. In this, the health tech sector is in some ways similar to advertising and internet search businesses: it has quickly learnt that data is immensely valuable.

On the internet, however, most user-generated data is used to train algorithms that encourage consumption, commerce or engagement. Health data is vastly different — it can be used for the global public good, to track epidemics and prevent their spread, discover new drugs and diagnostics, and advance medical research that can help us live healthier, longer lives.

It is imperative, therefore, that our health tech industry embraces this difference.

Data has always been the currency of science: like a form of silver that, when distributed, allows us to evaluate experiments, test hypotheses, discover side-effects and continuously improve the practice of medicine. With the emergence of AI, though, data has become gold.

Some 20 US healthcare systems recently formed a data company called Truveta, raising \$200m to capitalise on the value of their combined patient records. In 2018, pharmaceutical company Roche valued US cancer patient data at almost \$2bn, through its acquisition of Flatiron Health.

Hospitals and diagnostic labs are a rich source of this kind of health data for AI developers. Their databases of images and medical records are fodder for machine-learning algorithms. These healthcare facilities typically seek patient consent for the use of their data via a blanket

"research use" provision that is a condition for using the medical service.

But this wholesale transfer of the value of data from individuals to healthcare providers and then to industry has not escaped the public eye. When it comes to sharing medical records, there is a general environment of mistrust — not only of the private sector but also of public institutions, such as the UK's NHS.

And what of the health data we leak from our wearable devices? Smartphones are used by 6bn people globally — a total that is forecast to exceed 7bn within a couple of years. Body-worn sensors, as well as digital symptom checkers that track heart rate and rhythm, blood oxygen levels, breathing rates and cardiovascular and metabolic status, are not far behind.

In places with underdeveloped and underfunded health systems, this digital version of healthcare could reach people that the traditional physician-centred version has not adequately served. For example, last year, tuberculosis — mainly a disease of lower and middle income countries — became the first medical condition to merit a World Health Organization recommendation that "software programs may be used in place of human readers to interpret X-rays". Digital health looks set to rapidly penetrate densely populated middle-income countries, aided by the wide gap between healthcare demand and supply, unprepared regulators and fast mobile data networks.

We are on the brink of an era in which more health data is generated by individuals through their phones and wearables than by healthcare workers populating electronic medical records in hospital databases.

Imagine you wanted an evidence-based answer to a health question such as, "What is causing my migraines?" or "What side-effects does this new contraceptive pill have in women of my age and ethnicity?" The answer is probably there already, in the streams of data flowing through our health apps and wrist-worn sensors.

We must make this data a common good so that society can benefit from it.

The quantum of open data available for digital health is a good predictor of the number of start-ups, independent developers, research papers and innovative software products that will emerge. Since 2016, publicly funded efforts have made dozens of open radiology data sets available. Five years later, we have 150 US Food and Drug Administration-approved AI radiology products, most developed by start-ups rather than industry incumbents.

Health data is most powerful — and valuable — when aggregated, preferably at scale. Yet individual ownership of health data and consent for its use are inviolable. So, to reconcile these two principles, we need digital health tools that allow individuals to meaningfully and explicitly provide or revoke consent to use personal health data.

We need more experiments with digital health data trusts and co-operatives that are built for user-generated streaming health data. Data unions promise decentralisation, transparency, meaningful revocable consent and a share of the benefits to individuals who contribute data, providing an incentive for more sharing.

With privacy and security regulations, we need data portability mandates that allow control and custody of our health data. Above all, we need those businesses that intend to capitalise on digital health to think longer term — returning a larger share of the value of healthcare data to the individuals who generate it.

#### Pooja Rao

is co-founder and head of research and development at Qure.ai, an artificial intelligence developer for medical images

## A testing process

From raising funds to securing approval for new medical devices, healthcare start-ups in Africa often struggle to make an impact. But a Kenyan pathology business has shown how to overcome such challenges, writes **Adam Green** 

rustrated at the lack of pathologists in Africa's hospitals and the slow turnaround of test results, Kenyan doctor Joshua Kibera believed he had the answer. He envisaged a business that was a cross between a ride-hailing company and a utility, which would connect African hospitals and medical facilities to pathologists and laboratories both locally and internationally.

The problem was that Kibera lacked the funding to get his idea off the ground. But, when he attracted \$50,000 in seed funding from Villgro Africa, a start-up incubator based in Kenya focused on healthcare, his vision became a reality: in 2017 The Pathology Network was born.

Besides the cash, Villgro Africa's advice was vital to The Pathology Network's launch, says Kibera, and encouraged other international investors to put an additional \$175,000 into the business.

"I was clear what problem I was solving, but our business model wasn't well defined," says Kibera. "The Villgro Africa portfolio manager had frequent meetings to help us think through the modelling, the cash flow and so on."

Villgro Africa, whose parent company originated in India 20 years ago, expanded into Africa in 2014 to nurture new health and life sciences companies, with an emphasis on financially viability. The non-profit group raises money from wealthy individuals, family offices and foundations, and distributes grants as seed funding to entrepreneurs and start-ups. Based in the Kenyan capital Nairobi — the heart of the "Silicon Savannah" tech hub — Villgro Africa has funded start-ups in east Africa and across the continent, in Mali, Burkina Faso, Senegal and Cameroon.

"In the global north, if you're a businessperson or masters or PhD student with an innovative idea with







market potential, money finds you," says Rob Beyer, cofounder of Villgro Africa. "In sub-Saharan Africa, that story is incredibly rare."

Backed by donors including the US Agency for International Development and the International Development Research Centre in Canada, Villgro Africa takes an equity stake in some ventures it backs and recycles proceeds from exits into further grants. To date, the incubator has deployed more than \$1.2m to some 40 companies, with an emphasis on healthcare.

"Health and life sciences was an underserved market," Beyer says, describing Villgro Africa's funding as "more like venture building than an accelerator — we give money but we also walk the journey with the companies, sometimes for years".

The Pathology Network gives hospitals a digital account to order tests of samples, which it collects and distributes to a network of laboratories and pathologists in Kenya, other countries in Africa and as far as away as Australia and the US. It can provide results within a fortnight, rather than the months they might otherwise take. In the case of diseases such as cancer — the incidence of which is rising



The Pathology
Network distributes
test samples to a
network of labs

A sample under scrutiny for one of the network's clients

**3** Joshua Kibera in Africa — shaving that timeline could be the difference between life and death.

While Villgro Africa's decision to focus on health is reaping financial rewards for the companies it backs, it requires more patience than fintech or consumer software, for example, because of the extra hurdles and costs of clinical trials, approvals and regulation.

The challenges are tougher in hardware, given the high bar for quality control, supply chain management issues, and Africa's lack of manufacturing capacity. However, for Wambui Nyabero, Villgro Africa's chief technology officer, the prize is worth the effort. "Hardware is the platform that everything else is built on," she says. "If you want to do artificial intelligence or apps, if you don't have the hardware to diagnose and treat, you are

'If you want to do AI or apps, if you don't have the hardware to diagnose and treat, you are missing a big piece' missing a big piece. Even though hardware is difficult, it's worthwhile."

As companies go through the product development process, they acquire experience that will help with future hardware projects. Beyer cites the example of a Ugandan start-up backed by Villgro Africa, called A-lite, which designed, built and tested a neonate vein locator. It allows clinicians to identify barely visible veins in babies non-invasively. "That team now knows the whole process to get a new medical device to market," he says.

African health-tech start-ups could receive a further boost if the continent can put in place a regional regulatory body to approve new medical devices and therapies. In 2019, the African Union adopted a treaty to establish the African Medicines Agency, a body akin to the US Food and Drug Administration, which would authorise medicines on the continent.

Nyabero says the AMA could help start-ups in the long term. "Having something like that across Africa is going to be brilliant because then it means if you get approval in one country, you have approval across the whole of Africa, so now your market just opened up."

## Talking about taboos

Menstruation remains an area of ignorance among many women in Pakistan but a social media-based project is addressing the information gaps, writes **Farhan Bokhari** 

aba Khalid has set herself the goal of breaking some of Islamic Pakistan's long-held taboos with the help of the internet, smartphones and WhatsApp. "Technology offers a sense of comfort," she says of the work of Aurat Raaj, her Pakistani social enterprise. It educates women and adolescent girls about menstruation by means of audio messages sent via the WhatsApp social media platform.

Three years after Khalid, a journalist turned social entrepreneur, launched Aurat Raaj, she believes "there is a change of views coming" among communities in Pakistan's southern Sindh province, where her service operates.

Though still short of meeting its objective of seeing information on menstruation included in Pakistan's school textbooks, Aurat Raaj has come a long way, Khalid says. Rather than treating periods as a matter of shame, she and 30 field workers — so-called menstrual champions — spread their message about periods as a healthcare matter. Aurat Raaj says it has reached at least 50,000 women through urban and rural campaigns, as well as podcasts and gatherings known as period parties.

Internet coverage in the region is patchy, so recorded messages in the native Sindhi language, rather than live content, are sent to the menstrual champions. These cover topics such as instructions on making sanitary pads with locally available cloth and the sanitisation of pads for reuse.

For Shaiwana Nasir, a menstrual champion based in Sukkur, 350km north-east of the port city of Karachi, making inroads into communities is a gradual process. "It's a sensitive subject. People became offended when they were first approached," she says.

The other challenge was the low level of smartphone ownership among women in the roughly 50 villages in



1 Saba Khalid

2 and 3

Menstrual

champions hold
sessions for women

in Sindh province

Sanitary pads made from locally available cloth









### 'Menstruation is a sensitive subject. People became offended when they were first approached'

Nasir's area of responsibility. "We had to first convince village elders that this was an essential service. Once we gained acceptability, we were able to enrol local women in our sessions," she says. Each menstrual champion sets aside a room, typically in their home, where women gather to hear audio messages and participate in group discussions.

Breaking taboos around menstruation in rural Sindh has been difficult, because of the deeply conservative values many residents hold. Similarly, on matters of sex and birth control, the challenge was evident at a clinic in Karachi, where a doctor saw a woman in her mid-twenties who was in her seventh pregnancy in as many years of marriage to a truck driver.

The couple and their six children live in a two-room slum in Lyari, one of Karachi's poorest neighbourhoods, where waterborne infections and other ailments are rife. "I told [the patient] that her life will be in danger [if she has more children], but it's the same reply as I have heard from other patients — the husband doesn't agree," the doctor says.

The challenge of discussing sex-related issues is greatest among Pakistan's uneducated poor — almost one-third of the population lives below the poverty line — but women from middle- and upper-income households also face obstacles in accessing such information. "In many homes, irrespective of their income level, women are under pressure to have more children," the doctor adds. "The ideal of a two-child home is disregarded because families and husbands insist on large families."

Khalid, however, remains optimistic. Although the Covid-19 pandemic forced Aurat Raaj to scale back meetings last year, the platform has since returned to its regular schedule, and the number of menstrual champions is set to rise to 100 in Sindh. Khalid is also hoping to expand Aurat Raaj's services into Punjab province, which is home to some 60 per cent of the country's population, and to send out its messages in local languages such as Punjabi and Pushto.

Aurat Raaj, whose donors include the UN Children's Fund, UN Women, the BMW Foundation and the Vodafone Americas Foundation, is not alone in its push to disseminate information about sexuality in conservative Pakistan. Local non-profit Samaaj ("society") has launched an educational campaign featuring a fictional superhero called Super Sohni, who fights sexual abuse of young girls. Women activists say such developments can have a positive impact in Pakistan, where private television channels and the internet have broadened available content in recent years.

Khalid and her team, however, are focused on addressing the information gaps that prevail across Pakistan for many women. She notes an extreme example in the Kalash Valley, a popular tourist area in Chitral, a district in the north of the country. Menstruating women in that area must leave their homes and relocate to a dedicated house until their period is over. "My aim is to reach out to them [in Kalash] and understand why this practice [of a separate house] prevails before thinking of a solution," Khalid says.

# Sensing the opportunity

As medics strive to make use of the ever expanding volume of information on our health, Silicon Valley is stepping in with tools to help out, though regulation is a concern, says **Dave Lee** 

y one estimate, 30 per cent of the world's total data volume is generated by the healthcare industry, offering detailed insights into who — and how — we are.

And the volume of healthcare data will, according to this research from RBC Capital Markets, grow much faster than the data generated by the manufacturing, finance and entertainment industries.

Making sense of it will therefore be an increasing, but lucrative, challenge. Sensing this opportunity, Big Tech is circling, confident that its Silicon Valley thinking — whether on organising vast amounts of information or harnessing artificial intelligence to fuel new discoveries — will spark a revolution in healthcare.

"Our north star, in some ways, is how we can create tools that give providers a better experience in terms of a more comprehensive understanding of who their patients are," says Peter Clardy, a senior clinical specialist at Google.

Figures from CB Insights, a market intelligence company, show that almost \$7bn was invested in healthcare start-ups by the venture capital arms of Big Tech — Apple, Facebook, Microsoft, Google and Amazon — in the year and a half to mid-2021.

Other venture capital funding for digital health startups reached almost \$40bn globally last year, including a record number of deals. Most of the companies acquired or invested in harness data to create efficiencies in the pharmaceutical sector.

This surge of interest, CB Insights concludes, has been driven by the growing consumerisation of healthcare, thanks to smartphones and wearable technology, an explosion of data, further advances in AI, and a growing

#### Vision of the future

Virtual reality
is among the
technologies making
inroads into
clinical care











realisation that the costs of care, particularly in the US, are spiralling out of control.

The attention from Big Tech coincides with renewed efforts to make healthcare data accessible in ways that were previously off limits, or at least restricted. In March 2020, the US government introduced new federal rules designed to make data sharing easier and more commonplace. The rules were opposed by some hospital association groups and Epic, an electronic health records company, which warned of a risk to patient privacy from third-party apps.

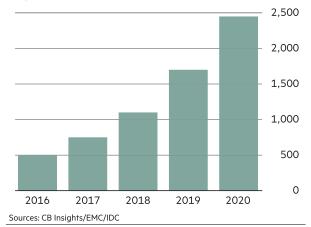
The new rules were welcomed, however, by tech groups and Cerner, another electronic health records provider, which said existing laws that allowed patients to access their data did not work. "Despite the great strides over the past decade of digitising healthcare records, barriers remain in allowing the free flow and exchange of information," Cerner argues. "Consumers should have the right to access the healthcare information their providers have about them and dictate where they want it to go."

The attractions for tech companies are clear: they see data interoperability as core to their strategy of supplying tools for healthcare providers, since it lowers the barriers to running a broad range of apps and services. It has led to wide adoption of a data standard, Fast Healthcare Interoperability Resources, or Fhir, with engineers from leading tech companies taking part in development events that shape how data can become interoperable between health systems.

"These powerful standards have arrived and unlocked the ability to bring together health information in a way that wasn't previously possible," Clardy says. "That, from Google's perspective, has also created opportunities for us to use our experience with organising information and searching across complex information."

#### Big Tech sees an opportunity in health data

Digital information in clinical systems (extabytes)



Other Big Tech groups are pursuing similar initiatives to harness data. Apple has focused on patient monitoring through its devices, such as the Apple Watch. Last June, it added a facility for iPhone users to share health data gathered through the device — such as sleep patterns and exercise — with care networks directly.

Facebook, through its Oculus virtual reality division, is working with hospitals on training, while its social network is being used for research and preventive efforts, by prompting users to undergo routine check-ups.

Microsoft has used its cloud platform, Azure, to host apps that are Fhir-compliant for data entry, cleaning and analysing. Last April, the company announced an agreement to acquire voice tech company Nuance in a deal worth \$16bn, giving it powerful natural language-

The use of electronic health records has triggered debate about privacy

Telemedicine is a growth area for Amazon's cloud computing arm

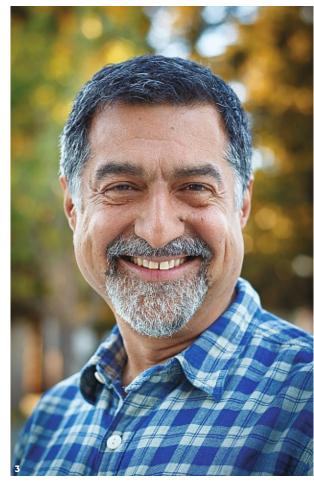
2

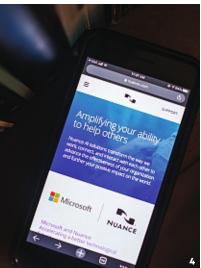
**3** Anil Sethi

4

Microsoft's Nuance
voice tech can
analyse doctors'
discussions of
symptoms







processing capabilities, such as enabling a doctor's discussion of symptoms to be logged and analysed.

Amazon is harnessing its logistics prowess to improve the supply chain, while leaning on its cloud computing division, AWS, to power digital services such as telemedicine. For this, it has used its own workers as a test bed, offering remote care to US employees.

Free-flowing data between these new applications fosters the ability to carry out studies at previously impossible scale and speed. It allows for more accurate predictive care to prevent people becoming ill in the first place and for less guesswork on treatments when they do. It also means breakthrough treatments can be created by AI algorithms and the social determinants of health can be better understood.

Data interoperability could also have profound effects in the developing world, says Steve MacFeely, director of data and analytics at the World Health Organization. Almost all of the world's population has access to mobile broadband, meaning data speeds of 3G or better, according to the International Telecommunication Union. While rural Africa still lags the rest of the world, it is improving, allowing these healthcare data advances to be extended into regions where record keeping has been held back by a lack of technology and connectivity.

"The whole concept of data itself has changed," says MacFeely. "Data were numbers. Now data are visuals,

'Consumers should have the right to access healthcare information and dictate where they want it to go' they're sound, they're text strings. The deluge of data is really a byproduct of the digital revolution. The big challenge is now around interoperability. Of these disparate pieces of data, how do you get them to talk to each other?" The answer, he says, could be to harness the expertise of Big Tech — but this comes with a warning. "There is huge concern now over data colonialism," he says, urging Africa to introduce the equivalent of Europe's General Data Protection Regulation. "The challenge is that if you do it at the country level or a regional level, that still may inhibit the flow of data safely between regions."

Yet, even with increased movement of healthcare data with Fhir and other initiatives, we may still only be scratching the surface, according to a former Apple executive who left his post in 2018 to tackle the issue of "lost" data between health services. Anil Sethi was head of Apple's health efforts but left the company to set up Ciitizen, following the wishes of his younger sister, Tanya, who died of cancer. "We flew Tanya left and right, west coast, east coast, we got her the best treatment," Sethi remembers. "She was seen at 17 facilities by two dozen physicians and oncologists. So there was this fragmented breadcrumb trail that she left behind her."

Ciitizen focuses on pulling together some of the insights captured by doctors but not held by existing electronic health records shared between health services. Often, the best insights on a patient's condition are found in these notes, Sethi says, adding that he finds it frustrating that Big Tech is not making a bigger effort to solve the problem.

The tech giants are "burying heads in the sand and hoping that there's a pot of gold at the end of the rainbow", he says. "One of the costs of that is we lose 16,000 people a day to cancer."

### Pictures of health

Patient outcomes in Mexico are often harmed by slow, outdated diagnostic systems but an imaging start-up is exploiting the potential of the cloud to create efficiencies and improve access to healthcare, writes **Angelica Mari** 

ith various types of cancer running through three generations of his family, 22-year-old tech entrepreneur Julian Rios Cantu was not surprised when his own genome sequencing revealed a predisposition to the disease. Explaining how he came to found Eva, a Mexican health-tech start-up, he says: "Cancer has been a constant in my life. As someone who will eventually face it, my mission is very personal."

Cantu was 16 when he and three friends devised a hightech bra to help women self-diagnose breast cancer. The garment holds biosensors that map and monitor heat in the breast, indicating potentially malignant lumps.

Their business faced barriers to growth, such as the high cost of large-scale production of the bra. So they decided to apply the technology in a clinical setting. By 2020, Eva had built a network of 15 booths in Mexico to perform thermalimaging tests that deliver results in 10 minutes.

But, as in-person medical appointments went online during the Covid-19 pandemic, Cantu and his partners closed the diagnostic booths and switched the start-up's focus to the gap between supply and demand for image-based medical diagnostics. Since August 2021, Eva has set out to improve outcomes for patients and increase efficiency for clinics by digitising radiology processes.

"Running the clinics, we noticed a lack of radiologists: we only have about 7,500 of them [in Mexico] for a population of 120m, and this gets worse outside large cities," Cantu says. He also says that much of the hardware and software clinics use for diagnostics is outdated and expensive.

More than 100 companies, mostly medium-sized clinics, now use Eva's subscription-based picture-archiving and communication system (Pacs) to view, analyse, report



Areas of focus
Julian Rios Cantu says
'dignified' healthcare
should take priority
over data privacy
in Mexico



#### 'As someone who will eventually face cancer, my mission is very personal'

and send results to patients and their doctors via email or WhatsApp. Images are captured by clinics' own equipment, with Pacs sending them to the cloud, along with clinically relevant reports.

The platform enables physicians to reduce paperwork, as radiology reports can be accessed digitally. Images can be enlarged and rotated, allowing for better interpretation and analysis. By digitising the test process, Eva says its services are significantly cheaper than using physical imaging plates.

Radiologists can operate remotely through Eva as service providers, which also cuts turnround times for results. As part of its social impact initiatives, Eva also partners with non-profit organisations, to capture images of patients in remote communities and use the start-up's system for processing and diagnostics. "We can deliver results within 48 hours — users in underserved areas usually have to wait a month or longer," Cantu says.

Backed by investors including Silicon Valley-based accelerator Y Combinator and Latin America-focused venture capital group Kaszek Ventures, Eva has raised more than \$12m in funding since its inception. Currently employing 25 staff, it is targeting expansion into Colombia and elsewhere in Latin America this year.

Despite developments in areas such as telecare and digital diagnostics, access to healthcare in Mexico remains challenging, says Sonia López Álvarez, a doctor and executive director of the Mexican Society for Public Health (SMSP). "We are very far from providing universal care," she says.

López Álvarez highlights a disconnect between healthcare platforms that is hampering progress. "The public and private systems use several platforms that don't talk to each other. That negatively impacts outcomes for patients, since their information is all over the place," she says.

"There needs to be political will to address these issues, and a focus on training more medical practitioners in technologies to improve care. The public also needs to know what [health] tech is out there and how it can be used to help."

Eva plans to harness automation to help radiologists save time, as well as management systems to address issues such as the lack of interoperability, Cantu says.

He says Eva takes data privacy seriously and the company adheres to US standards for sensitive information. "Latin America doesn't require that level of data management sophistication — we do it because we think it's right," he says. "Well-capitalised companies like mine have a responsibility [to comply with] data protection."

Mexico does not have a problem with data protection, Cantu says, but one with accessibility to health services. "People are dying in hospital corridors without proper care, or at home, due to lack of medication," he says. "You cannot [focus on] data privacy when people are not getting dignified healthcare."

For that reason, Cantu suggests that developing countries should be careful about "mimicking" data privacy frameworks in the US and Europe. "What we cannot end up with is regulation that shoots ourselves in the foot in terms of providing better healthcare for people."

### Mothers get the message

Kenya's maternal mortality rate is among the worst in the world but an Al-powered SMS system is aiming to turn the tide — by spotting danger signals in patients' questions about their pregnancy, writes **Ben Turner** 

hich foods are dangerous to eat while pregnant? Why isn't my baby moving? How often should I exercise? Expectant mothers have many questions, but obtaining accurate information can be problematic in countries that lack reliable healthcare.

In Kenya — which has the world's 15th-highest maternal mortality rate — 1m women have registered to exchange pregnancy-related questions with a team of health advisers via a free, artificial intelligence-powered SMS service called Prompts. Run by Jacaranda Health, a non-profit healthcare group, Prompts uses AI to triage messages and ensure that "danger signs", including bleeding and loss of baby movement, receive the fastest responses, such as advice to seek emergency care.

The group uses SMS, rather then internet-based communications, "because it has broad accessibility" in Kenya, says Nick Pearson, Jacaranda co-founder. "Tech-heavy solutions look good, but once they are embedded they might not work so well. While a lot of people have phones with data capability in Kenya, they don't purchase data so often."

Pearson established Jacaranda, which is funded by philanthropic donors and aid agencies, in 2010, initially as a provider of subsidised maternity hospitals in Nairobi, Kenya's capital, before setting up Prompts eight years later.

Expectant mothers can register for Prompts in English or Swahili at hundreds of health centres across 20 of Kenya's 47 counties, primarily in the more populous south-west. Jacaranda's help desk receives 3,000 enquiries a day and aims to respond to all messages within 24 hours, while "clinically urgent" queries are addressed within an hour.



Each incoming message is triaged by an AI system according to keywords such as "bleeding" or "headache". Critical messages are flagged to a senior help desk clinician for an urgent response or phone call. For less pressing queries, the AI prepares a canned response that is vetted by the help desk before it is sent.

"The level of confidence in the AI getting the answer right is around 95 per cent [for critical danger signs], but when it's potentially life-threatening we don't want to take that chance," Pearson says. "That's why we keep the human between the patient and the AI. It's still a human-first system. The AI is serving up a potential canned response. The human agent then checks that it matches the real intent of the question."

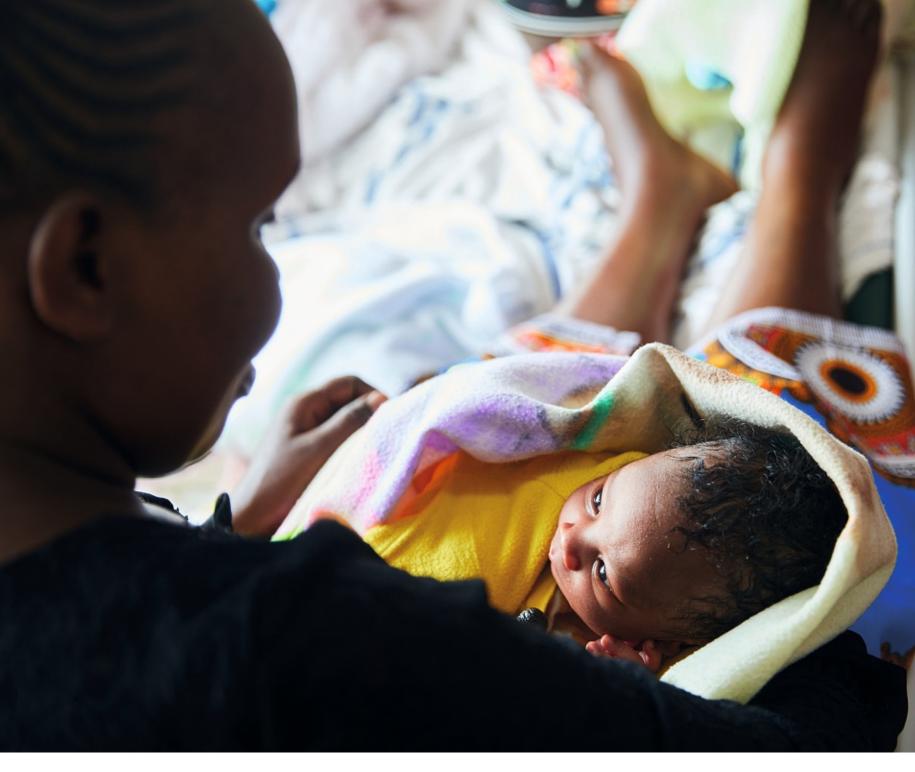
Pearson, a former consultant at social investment fund Acumen, wants Jacaranda to become an integral feature of how Kenyans seek medical care and notes that 85 per cent of women who are flagged with "danger signs" in pregnancy follow the clinicians' advice to attend a hospital.

For new mum Grace Kimenju, 34, who lives near



Nick Pearson, co-founder of Jacaranda Health

Jacaranda's Al-based service is still 'human first'



Nairobi, Prompts helped her with a scare at seven months' pregnant when her baby stopped moving. Rather than scan the internet in a panic for answers, she sent an SMS to Jacaranda. Within minutes, it had urged her to go to hospital immediately. The scare was a false alarm, and last year she gave birth to her baby girl, Angeline.

"If I hadn't interacted with the message, maybe something bad would have happened," says Kimenju, an economic researcher. "The messages pushed me to go and seek care. Before using Jacaranda, I was getting information from the internet or by talking to friends and family. But I think the messages have verified information — it's a reliable source. I know I can ask anything."

'If I hadn't interacted with the message, maybe something bad would have happened' Jacaranda is almost entirely funded by philanthropic groups such as the Bill & Melinda Gates Foundation and the Pfizer Foundation, as well as the US Agency for International Development. This year, Jacaranda expects to receive \$6.5m from such donors, up from \$714,000 in 2018. The organisation aims to reach 1.5m women through Prompts by the end of 2022 and have an active userbase of 800,000.

Alongside Prompts, Jacaranda provides mentoring for state midwives in ante- and postna tal care at 270 health facilities in Kenya. "The two programmes run in parallel to address the two biggest drivers of maternal death — gaps in care and people not accessing care early enough," says Pearson.

However, he admits that making Jacaranda self-sustaining and cutting its reliance on philanthropists remains difficult. "We're exploring funding from local governments, but there is no silver bullet," Pearson says. "One of the challenges with digital health is there is no precedent for incorporating it into the healthcare system."

### Seeing round the stigma

In Egypt, where many can find it difficult to visit a mental health practitioner, an online therapy service has attracted thousands of users and expanded to overcome cultural barriers across the region, writes **Heba Saleh** 

t was a fall from horseback during a tour around the Giza pyramids in 2014 that resulted in easier access to mental health therapy across the Arab world.

According to Mohamed Alaa, the idea for online platform Shezlong was born after his friend Ahmed Abu Elhaz injured a hand in the fall. Told he may lose the use of it, Abu Elhaz lost his job and fell into depression.

After encountering difficulties in obtaining mental health support, Abu Elhaz co-created an online platform to match patients with therapists. He has since left the company, though it continues under the leadership of chief executive Alaa, who says it has filled an important niche in a country where seeking mental health assistance can carry a stigma.

Shezlong now has 120,000 users in 85 countries that it links with 350 therapists. "We mainly serve Arabic speakers, but we want to start expanding to other languages," Alaa says. Users answer a brief online questionnaire and can choose from a list of vetted therapists. Online sessions are held via the Shezlong platform to ensure security and privacy.

"Everyone was against us at the beginning," Alaa says.
"They said there is no such thing as online therapy, but
after coronavirus, therapists who were critical of us
embraced it. We got hundreds of calls from practitioners
saying they were unable to practise at their offices and
needed to go online."

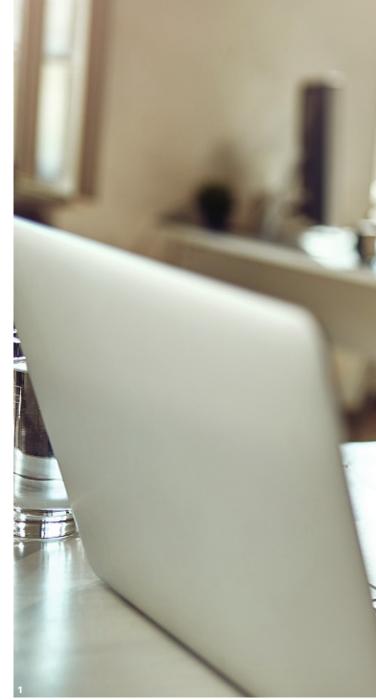
Alaa acknowledges that connecting users to service providers is not "a breakthrough idea". Nonetheless, extending mental health support to people who would not otherwise have access to it, and Shezlong's social media campaigns to raise awareness of the benefits of therapy, are groundbreaking in Egyptian society and other parts of the Arabian region, Alaa says.

1 Women make up 60 per cent of Shezlong's users 2 Mohamed Alaa

Huda Radwan







"Stigma is my main enemy," he explains. "Many people are not aware of the value of therapy and they think, if you need it, you must be crazy or weak. We fight this with social media campaigns."

Women, who are more likely than men to face restrictions on their movements imposed by families in conservative Arab societies, comprise 60 per cent of Shezlong's users and are mostly from Egypt and Saudi Arabia, aged between 20 and 45.

"There are many female university students who have problems, but their parents won't allow them to visit a mental health practitioner," Alaa says. "And there are wives whose husbands won't agree to it. So going online means they just need to close the door of their room and speak in a low voice to a therapist."

Online therapy also enables people living in remote or rural areas to obtain support even when their town or village lacks a mental health practitioner, or if they feel they cannot be seen walking into the office of a therapist.

Huda Radwan, a therapist who specialises in mood and sexual disorders, says she speaks with many clients from rural areas "where communities are close knit and everyone knows each other". The stigma attached to



having mental health problems "is not restricted to the uneducated but extends even to those with university degrees", she says.

Dealing with patients away from an office setting makes it easier to introduce them to online resources to help them understand "they are responsible" for part of their treatment, Radwan says. "What happens is a broadening of the way we interact," she says.

Shezlong has teamed up with Assault Police, an Instagram account set up in 2020 by Nadeen Ashraf, a student and activist, to encourage survivors of sexual assault to seek therapy. "One of the most important questions we get [from victims] is how can I move past what happened to me, how can I find support and psychologically emerge from this period in my life?" Ashraf said in a video launching the account's co-operation with Shezlong.

'Stigma is my main enemy. Many people think if you need therapy you must be crazy or weak' Khaled Ismail, an angel investor who put \$250,000 into Shezlong, encountered the group while sitting on the judging panel in a 2017 television competition for startups, which Shezlong won. The appeal of Shezlong is that it attempts to address a big problem, Ismail says, noting that studies have suggested up to one-quarter of people need some kind of mental health support, including for problems such as anxiety.

"It means that, in Egypt, we are talking about 20m-25m people," he says. "Going to a therapist can be taboo, so there is a real need for the [online] service, as well as a big, potential user base, and the cost is reasonable. These are all factors for success."

Shezlong receives a commission from therapists, and Alaa says the company's annual revenues are in the "hundreds of thousands of dollars", although the group is not yet profitable.

Slowly, the stigma of seeking mental health treatment in Egypt is reducing, Alaa says, thanks to the efforts of awareness campaigns. "We are seeing more people, including actors and artists, speak more openly about mental health, which is helping erode the stigma," he says. "Our message to people is that it's OK not to be OK."

## Doctors you can call on

Prospects for patients in Afghanistan's crumbling healthcare system have vastly improved, thanks to everyday real-time smartphone technology that enables medics to call on the expertise of their peers abroad. By **Fathayha Begum** 

hen the Taliban regained control of
Afghanistan last year, the ensuing
humanitarian crisis sparked fears
both for the millions fleeing the
country and for the health and safety of
those who remained.

The UN estimates 3.5m people have been displaced as a result, while the World Health Organization has warned that Afghanistan's healthcare system — which is beset by shortages of medical supplies and a lack of facilities — is on "the brink of collapse".

But, while some healthcare groups have exited the country, one innovative health tech group is continuing to operate its telemedicine services there despite the deteriorating security and economic outlook. Founded by Waheed Arian, a former child refugee from the Soviet-Afghan conflict and now a doctor in the NHS, telemedicine charity Arian Teleheal provides local doctors with real-time video access to volunteer medical specialists around the world. It aims for a four-hour turnround on detailed emergency investigations and advice.

The service enables doctors, sometimes working in remote regions, to obtain advice via video-chat and instant-messaging tools from a 150-strong pool of volunteer clinicians located in different countries. The system uses everyday technology, such as secure, encrypted social media channels on smartphones.

Piloted in Afghanistan in 2015, Arian Teleheal says it facilitated care for more than 1,000 people between 2016 and 2018, resulting in almost 700 lives being saved. The UK-registered charity receives no government funding and is reliant on public donations.

Telemedicine - remote diagnosis and treatment via

technologies such as video — is a valuable communication tool for doctors on the ground to obtain advice. "Virtual care is even more important [after Afghanistan's regime change]," says Waheed. "It does not replace in-person support, it supplements it, especially in difficult times." He highlights the challenges caused by the civil war and the Covid-19 pandemic, such as intermittent internet coverage.

Waheed hopes the programme can improve health outcomes and promote peace in the war-torn country. "We are all in this not just to solve a singular case. We are all here to reach out to people who are neglected," he says.

Treatment of mental health problems is also possible via Arian Teleheal's telelinks, Waheed says, as it "is an area that doesn't necessarily need a [physical] examination".

Afghanistan has a history of employing the technology: the Roshan telemedicine project was set up in 2007, using the M-Paisa mobile payment system. The Roshan programme came to prominence in 2015 when it provided a virtual link with doctors in Pakistan that led to Afghanistan's first successful operation to separate conjoined twins. The telemedicine technology enabled the twins, Ayesha and Seddiqa, to be treated in Kabul and spared their parents the expense and inconvenience of having to travel far for subsequent check-ups.

Palwasha Anwari, an Afghan-born doctor who left the country in November to study at the London School



'We are all in this not just to solve a singular case. We are all here to reach out to people who are neglected'



of Hygiene & Tropical Medicine, says telemedicine is a useful tool in a country with poor infrastructure and a deteriorating health system. "[Telemedicine] can be a quick win, particularly for diagnostic services and also management of cases", she says, adding that it can offer "help to the experts who are there, particularly [in] trauma or some other surgical cases".

Anwari, who is also a nutrition officer for Afghanistan with the UN Children's Fund, says the country's health system has been strained by the war, with many health workers going unpaid for months. "Primary healthcare, such as child health, immunisations, antenatal care, postnatal care or other essential or basic health services, have all been affected," she says.

Yet telemedicine can only "fill some gaps", says Anwari, noting that both internet access and electricity are subject to outages in Afghanistan. More urgent medical cases "require professional basic health services, while telemedicine can be useful for the treatment of trauma cases and mental health", she adds.

Waheed says the revival of Afghanistan's healthcare system depends on the collaboration of virtual and in-person medical programmes, given the security and infrastructural challenges facing the country. It may be some years before things return to normal, he adds.

"Until then, it is a virtual system that we can fully utilise, and then supplement, with in-person support where needed," he says. ■

### In the loop Waheed Arian on a live telemedicine link from Cambridge university in the UK to an doctor in Afghanistan



or most of his life, Igor Leo Rocha has suffered from folliculitis, a bacterial condition whereby hair grows back into the skin when it is cut, causing painful inflammation. Common among black men, it is often treated mistakenly as acne — and Rocha's case was no exception.

He lives in Salvador, a coastal city in Brazil where the majority of residents are of African descent. Even so, no dermatologist he consulted there was able to properly diagnose and treat the problem.

Rocha, a journalist, says many doctors he saw prescribed "strong medication that made it worse. I then realised my problem was specific to black skin and that I had never been seen by a black doctor."

Meanwhile, Rocha's partner, Arthur Lima, a dentist,

noticed a demand for medical services that met the needs of black patients. "I was asked for suggestions of black dentists for a patient who felt she had been discriminated against by a white dentist," says Lima.

So Lima and Rocha turned to technology and, in 2019, founded the AfroSaúde platform. "We connect black professionals and patients seeking representativeness and diversity in care, as well as non-black patients who might want to use the platform," says Lima.

AfroSaúde has so far enabled 2,000 patients to find and book consultations with nearly 1,000 black professionals in Brazil, including medical practitioners, dentists and therapists. Payment for the consultations is made through the AfroSaúde platform, which takes a commission.

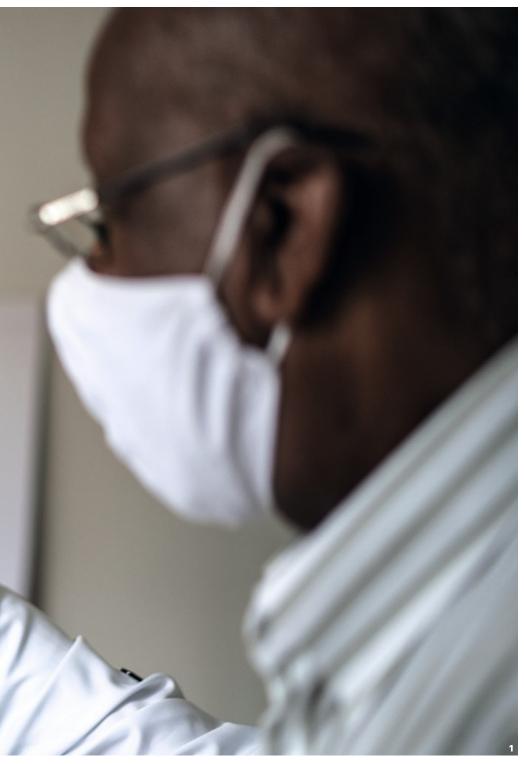
As well as increasing the visibility of black medical

Apps can connect black patients to practitioners with better knowledge of

> **2** The AfroSaúde platform

certain conditions

**3** Igor Leo Rocha, left, and Arthur Lima



# Agendar vina contacts Agendar vina contacts



#### 'Digital innovation aimed at wealthier audiences and led by white male founders leads to a shortsightedness'

professionals, the start-up aims to address other deeprooted problems in the country's healthcare system.

Non-white Brazilians — who make up about half of the country's 210m population — have reported veiled or overt racism during medical consultations, such as the assumption that black people are more resilient to pain, says Lima. Research by the Brazilian ministry of health suggests black Brazilians are less likely than white patients to seek medical advice when ill, because of factors such as fear of discrimination and longer waiting times.

As the Covid-19 pandemic has shifted many healthcare services online via technology such as telemedicine, AfroSaúde has followed suit. "Even though we are now seeing a return of in-person consultations, all appointments booked via our platform are happening online," says Rocha.

To overcome the problem of poor internet coverage in remote regions, AfroSaúde's video consultations — which take place via a browser or app — can be adjusted for low bandwidths.

Government research suggests that three-quarters of Brazilians rely on public healthcare but will still pay for private consultations when their problems cannot be solved in the public system. AfroSaúde is targeting that audience by offering psychotherapy services through its app, as well as content for corporate users — such as videos and newsletters on mental healthcare. An artificial intelligence-enabled chatbot to provide health-related educational content is also on the horizon, says Lima.

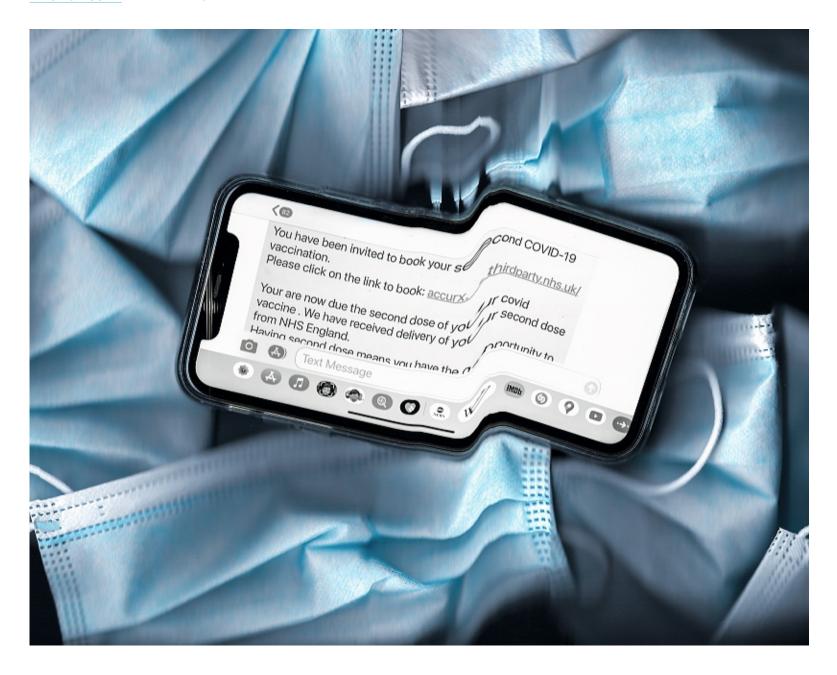
The start-up is engaged in social impact initiatives, as well, he says, including a project to improve access to primary and specialist care in the public healthcare system. The project will entail automating tasks such as medical consultation bookings via a digital platform.

AfroSaúde has received support from a pool of backers, including Google's Black Founders Fund and non-profit group the We Are Family Foundation.

According to Maitê Lourenço, a psychologist and chief executive of BlackRocks Startups, a Brazilian innovation hub focused on tech businesses led by black entrepreneurs, there is a growing demand for racialised healthcare services in Brazil. "[Such services] are crucial because of the specific requirements we have as a consequence of racism in our everyday lives — and digital technology plays an important role in broadening access to care," she says.

But Brazil's technology sector must itself tackle systemic racism to allow more businesses such as AfroSaúde to emerge and thrive, says Lourenço. "Digital innovation in healthcare in Brazil tends to be aimed at wealthier audiences and led by white male founders, who in turn attract more investment.

"This leads to a shortsightedness in business development and innovation, and brings significant challenges to [black-led] disrupters, since they need capital to grow and reach broader audiences." ■



# Virtues of the virtual view

The pandemic has proved the potential of telemedicine, particularly in mental health, where seeing a doctor face to face does not necessarily encourage patients to talk openly

STORY AND PHOTOGRAPHS BY ALAN KNOX

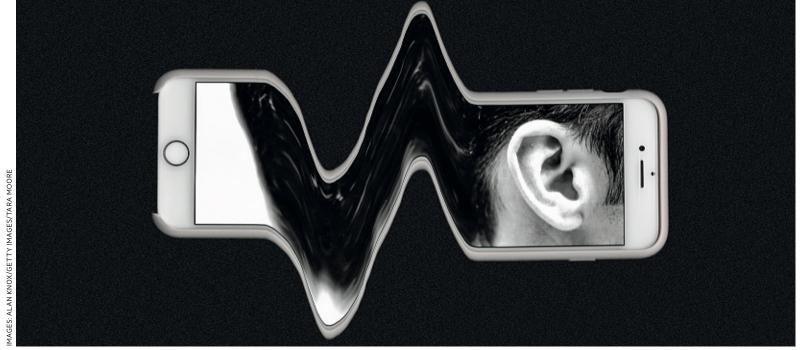
efore the Covid-19 pandemic took hold, accuRx's text messaging software was used in roughly half the UK's general practices. In March 2020, when the NHS switched from in-person appointments to phone or video consultations, that level of usage rose to 98 per cent almost

"Our message volume went through the roof; our SMS bill went through the roof; our support tickets went from 300 to 3,000 a week," says Jacob Haddad, accuRx co-founder. The groundwork his team had done at NHS practices over the years had impressed on him that healthcare is as much a communications industry as a knowledge one. But it took a pandemic for many healthcare providers to reach a similar epiphany, he says.

"Very little of what we built or released was specific to Covid...like being able to reply to a GP, to send a photo without a reply, to send a document to a patient. Something we'd built that was hard to get adopted into the system, suddenly there was this urgent need," he says.

Responding to doctors' requests, accuRx implemented video consultations between patients and general





#### 'Many people do not want to come into a crowded waiting room. They just need a problem dealt with efficiently'

practitioners into its SMS software. Before the pandemic, an average of 50 practices downloaded accuRx's software each week — a figure that rose to roughly 1,200 when Covid-19 hit.

Today, more than 500,000 text messages a day, including vaccination bookings, are sent from NHS practices to patients using accuRx software. Across England, online consultation requests rose from 250,000 a week to more than 550,000 between March 2020 and January 2021.

For David Triska, an advocate of telemedicine, the effect has been to cut waiting times to speak with a GP at the Witley and Milford Medical Partnership in Surrey, where he is a doctor.

"There was always a battle to gain access to your GP. The playing field between doctors and patients feels like it's been levelled," he says.

Similarly, for west London-based GP and accuRx user Sam Shergill, telemedicine has not only allowed doctors to prioritise cases more effectively but has also prompted patients to be more open about conditions that may otherwise have remained unmentioned. "I will always bring in patients if there's some uncertainty," he says.

"If we're doing a review of someone's mental health, yes, you can get a lot by seeing someone face to face, but a lot of patients may engage with you more by having a phone call to review their depression. Patients might feel safer speaking over the phone about these issues."

In the UK, however, the expansion of telemedicine services comes in the face of government pressure to improve patient access to in-person healthcare. In October, NHS England announced a £250m winter access fund — due to run until this March — that GP surgeries could tap into to employ more staff, provided that they pledged to offer in-person consultations to every patient who requested one.

For Alex Kumar, medical director at healthcare marketing agency The Considered and a practising GP in London, the demand to fulfil in-person consultation targets that were set prior to the pandemic is counterproductive. "There is a bridge to be built between patient expectation and the ability to deliver care, and right now that bridge is crucial because it's a crevasse," he says.

According to data from NHS Digital, GP appointments in England totalled 30.3m in November 2021, with 19m (63 per cent) being in-person. This compares with 24m appointments in February 2020, before the coronavirus pandemic took hold, with 19.2m (80 per cent) of those inperson.

"The idea that there is some problem for patients doing [telemedicine] is wrong because many people do not want to come into a crowded waiting room," Triska says. "They just need a problem dealt with efficiently."









# Tapping into young minds

For many children, anxiety and stress are the dark side of using digital devices, but the same technology could also offer ways out of these problems, says **Sarah Murray** 

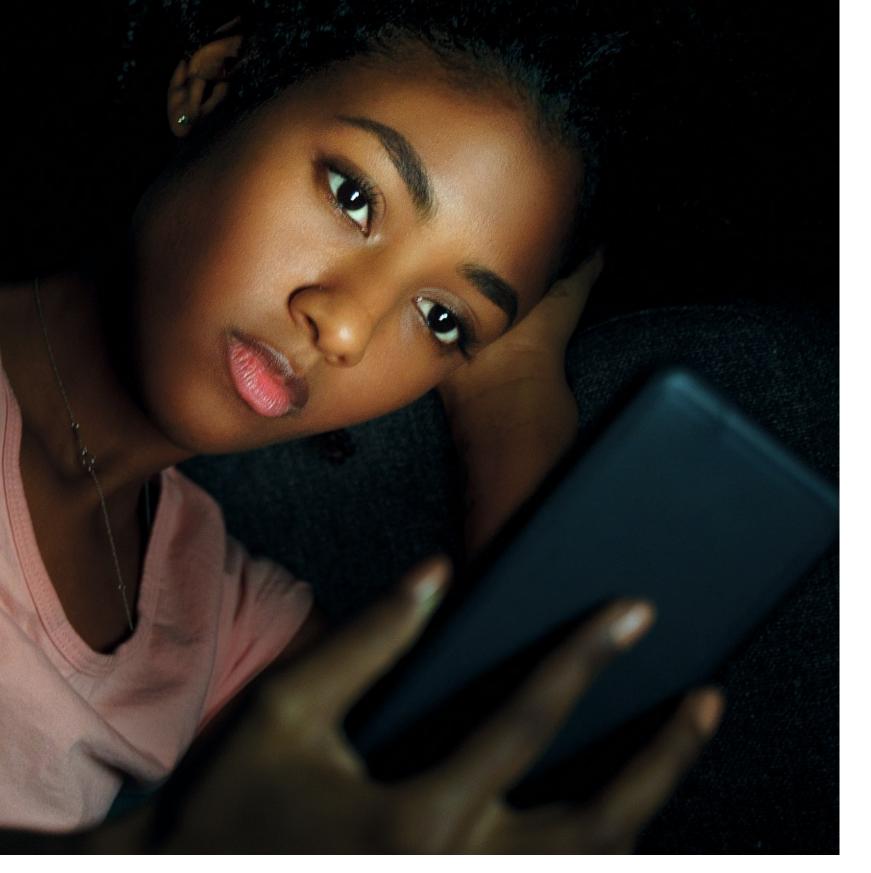


hen Facebook whistleblower Frances
Haugen told the European Parliament
in November that more should be done
to prevent online harm, the welfare of
children was among her concerns.
In highlighting the dangers of
Instagram algorithms, such as posts on healthy foods that
link to others that may encourage eating disorders, Haugen
later told the FT that "kids die as a result of those things".

Time spent on devices such as smartphones has risen during Covid-19 lockdowns, heightening concerns about young people's use of technology, especially the negative impact of screen time on adolescent mental wellbeing. In 2019, a University of Oxford study failed to find a link, noting: "There is still little consensus as to whether and, if so, how digital-screen engagement affects psychological wellbeing."

However, some experts argue that the real risks come not from screen time but the content and types of activities that it encourages. "If you use an iPad to do yoga for 20 minutes, that's very different from scrolling through self-harm images," says Amy Orben, co-author of the Oxford study and a researcher at the University of Cambridge.

Daniel Kardefelt-Winther of the UN Children's Fund agrees. "If you look at specific experiences of children in the digital environment, that's where you can find mental



health impacts," says Kardefelt-Winther, who leads Unicef's Children and Digital Technologies research programme.

Social media exacerbates many of the problems. For young people, comparing themselves with peers or celebrities can contribute to increased stress and low self-esteem. In research by the Royal Society for Public Health (RSPH), young people in the UK said using four of the five most widely used social media platforms worsened their feelings of anxiety. "People only demonstrate their best side on social media," says Merike Sisask, professor of social healthcare at Tallinn University in Estonia. "That can be stressful for children."

To counter this, the RSPH recommends changes to social

media platforms, including pop-up warning messages during heavy social media usage, disclosures indicating when photos of people have been digitally manipulated, and the teaching of safe social media in schools.

Regulators are starting to act. In the UK, the Age Appropriate Design Code prevents companies from tracking children's locations, personalising content or advertising for them and creating behavioural nudges such as default autoplay on videos. But some researchers believe that psychologically damaging online experiences demand a more hybrid approach because they are related to abuse occurring in the physical world.

Cyber bullying is one example. Online, this kind of

Online insecurity
Use of social media
can contribute to
low self-esteem



abuse can be perpetrated more easily. "The online world extends existing crimes or negative experiences," says Kardefelt-Winther, who argues that cyber bullying can be more emotionally harmful than its offline equivalent. "You have no safe space," he says. "You can be in your home on your phone and the bully can reach you."

Instances of cyber aggression have risen as the pandemic has driven learning online. According to US and Israel-based L1ght, which uses artificial intelligence to detect and filter toxic online content away from children, hate between young people in online chats rose 70 per cent during lockdowns.

However, while digital technologies pose mental health risks to young people, they could also offer solutions. Digital phenotyping, for example, is a new technique for tracking online symptoms and behaviours related to mental illnesses in real time. Technology also offers the potential to expand access to mental health services in developing countries and low-income communities.

Nor do digital interventions need to be sophisticated. "People first think it refers to a fancy app that you need a smartphone to download, when often we're talking about low technology, which is having a telephone that connects you to a therapist," says Pamela Collins, professor of psychiatry and behavioural sciences at the University of Washington in Seattle.

"For some of the most neglected communities [in the US], simply getting public transportation to find a mental health provider can take a few hours. That's no different in many countries where you have few providers and they're not distributed evenly across the population."

Collins says technology can help promote adolescent mental health in many ways, "from tele-psychiatry, or training people on a Zoom platform, to digital phenotyping, to people going to a website to have cognitive behavioural therapy". But she adds that poor infrastructure in low-income areas hinders access. "To have a full Zoom session you [need] a data plan and adequate bandwidth," she says.

Designs for digital interventions must take this into account, says Rebecca Braun, who leads the Youth Tech Health Initiative at California-based non-profit ETR. The initiative uses technology to promote young people's health in Africa, Asia, Latin America and the US. "The first step, whether in the Bay Area or Honduras, is to understand





Frances Haugen

2

Online therapy is helpful but poor digital infrastructure may hinder access

Daniel Kardefelt-Winther what's happening in young people's lives — how they use technology, whether they have access to the internet and what's important to them in terms of confidentiality and security," she says. To enhance safety and security, many of the YTH Initiative projects enable users to create avatars for themselves, using any name, a gender-neutral identity and choosing race and ethnicity.

In Estonia, where 10-20 per cent of young people suffer from mental health problems and where the suicide rate for this age group is higher than the EU average, the impact of mobile apps is being evaluated. To test acceptance among young people, four apps — addressing self-harm, depression, suicidal thoughts and sleep patterns — were developed by AppsTerv, an Estonian project that, with funding from Norway, works to increase access to mental health services. "Young people loved these interventions," says Tallinn University's Sisask, who worked on the project. "We got feedback from mental health professionals that they used the apps between face-to-face sessions."

Most apps, however, are developed by private companies, rather than non-profit groups or publicly funded ventures. This is a worry for Rachana Parikh, senior programme officer in the Indian office of Path, a Seattle-based non-profit health group. "In India, they are from foreign startups and largely target English-speaking audiences who can pay for access," she says. "That's not going to address problems for the majority of the country."

Moreover, it is hard to know which digital mental health interventions are effective for young people. A recent review in the US by Columbia University's Columbia Mailman School of Public Health and consultancy Spark Street Advisors found mixed evidence on the effectiveness of therapeutic video games, mobile apps and social networking sites.

In addition, says Nina Schwalbe, adjunct assistant professor of population and family health at Mailman, digital mental health interventions are part of a commercially driven market that is subject to little monitoring or regulation. She cites the example of a child using a chatbot to discuss suicidal feelings. "How does that become a referral? What kind of data is being collected and how does that affect future insurability?" she says. "It's the Wild West out there."

### 'The online world extends existing crimes or negative experiences. You have no safe space'



### Young voices must be heard

It is vital that the design of digital health technologies involves those generations who will be depending on them in the decades ahead, says **Shalin Jyotishi** 

or millennials and the digital natives of Generation Z, the use of technology is second nature. It brings advantages such as fostering interpersonal interconnectedness and expanding access to education and work opportunities.

Yet the widespread adoption of digital technology is also fuelling concerns about its effect on mental health and social development, obesity and attention and memory impairment.

As The Lancet and Financial Times Commission on Governing Health Futures argues, digital tools to support the health of children and young people should be accessible while also being safe and ethical.

It is paramount that young people are given a voice in shaping their digital health future. A new form of intergenerational collaboration that engages them directly should be the standard in the digital world.

A fundamental tenet of such user-centred design is that the users of a given technology or service are the experts, and their views, at least as much as business factors, should inform and influence the development and deployment of digital platforms.

Failure to take this principle into account, particularly in a field as sensitive as health, will result in a consumer backlash directed towards companies and governments. In the US, Democrats and Republicans alike have stepped up their scrutiny of Silicon Valley in response.

One approach is the development, training and use of public interest technology (PIT), a new professional field that adopts best practices in human-centred design,

product development, process re-engineering and data science to solve public problems in an inclusive, iterative manner.

Rather than simply using surveys or focus groups, it engages more actively with the public — including groups that historically have not had a voice — with continuous learning and improvement to produce better outcomes.

Many colleges and universities now offer PIT training, and a book, *Power to the Public* by my colleagues Tara Dawson McGuinness and Hana Schank at the New America Foundation, a think-tank in Washington DC, describes the emerging profession.

Examples include giving youth a say in the design of apprenticeship schemes, and participatory technology assessments. A team led by Mahmud Farooque at Arizona State University's Public Interest Technology programme, for instance, helped gather input for Nasa's Asteroid Initiative. That resulted in the identification of a gap in Nasa's capacity to co-ordinate on planetary defence, which led to the creation of a new office in the agency. Public input also helped inform Nasa's decisions around asteroid diversion and its missions to Mars.

Public interest technology can help avoid the risk of tokenism, where some voices are only included as a box-ticking exercise, rather than being given a formative role. It debunks the myth that non-experts do not bring value to complex or technical topics such as digital health.

Another solution is to give youth a say and harness their expertise when developing digital health standards, even in response to crises. For example, the World Economic Forum, the UN Children's Fund, toy company Lego and the Canadian Institute for Advanced Research, among other organisations, are refining artificial intelligence standards for children, in collaboration with an AI Youth Council.

The project involves drawing up policies that ensure equitable data practices and the safe handling of data on the real-time movements of children that could become a permanent part of their digital footprint — an issue that older generations never encountered. In November, IEEE, a technical professional organisation, published a new standard to address age-appropriate design for children's digital services.

David Walcott, who co-chaired the Covid-19 task force of the World Economic Forum's Global Shapers Community, a network of young people, has argued that youth insights have been valuable in supporting digital health objectives during crises.

At the start of the pandemic, the company Walcott founded, Novamed Health, took advantage of the high levels of digital literacy among young people by working with them. Together, they developed a user-friendly online tool to manage Covid-19 test bookings and results, appointments and test results for Covid-19 for the University Hospital of the West Indies in Kingston, Jamaica.

There is no silver bullet to achieve the goals outlined in The Lancet and Financial Times Commission report. But, by investing in PIT education and elevating the voices of youth when designing digital health policy and governance tools, we can ensure such platforms are truly designed for the people.

#### Shalin Jyotishi

is a fellow in AI and machine learning at the World Economic Forum and a senior policy analyst at the New America Foundation

### To the heart of the matter

The potential of AI to detect early signs of cardiovascular problems could lift a huge financial burden off healthcare systems, especially in developing countries

BY DARREN DODD PHOTOGRAPH BY JONATHAN SELF

ardiovascular disease is the world's biggest killer, responsible for almost 18m deaths a year, according to the World Health Organization. But what if your likelihood of suffering from heart disease could be identified a decade in advance, enabling you to take preventive measures?

That is the promise of new medical imaging developed at the University of Oxford that received EU approval in 2021 and has begun to be used at several hospitals in the UK. The technology, CaRi-Heart, detects normally invisible signs of inflammation around coronary arteries from routine heart scans and uses artificial intelligence to identify the problems that could cause a heart attack.

Charalambos Antoniades, professor of cardiovascular medicine at Oxford, is the imaging expert behind the development, which received early backing from the British Heart Foundation (BHF) and has been spun off into a company, Caristo Diagnostics. "We have developed a method that takes the scans, uses AI to analyse not only the arteries of the heart but also the area around the arteries, and this tells you whether you will have a heart attack in the next eight to 10 years," Antoniades says. This gives the patient time to adopt preventive measures such as taking statins or improving their diet.

Cheerag Shirodaria, Caristo co-founder and chief executive, says the technology — which is cheap, non-invasive and does not requires any special software — could be particularly beneficial for developing countries that are experiencing an "explosion" of heart disease. "What Covid has taught us is that we need to prevent disease," he says. "We've spent far too much money on patients once they've already got an established disease when they're in hospital.

Imaging expertise
Charalambos
Antoniades, left, and
Cheerag Shirodaria of
Caristo Diagnostics



If we spent more on preventing disease...we would save a ton of money in the long run."

But, even when backed by clinical evidence, it can be a challenge to put this kind of technology into practice, says Antoniades. "You're talking about saving costs over the horizon of a decade," he says. "In most countries, decisions are made by employees or politicians who have a short [decision-making] lifespan. That's why prognostic and preventive medical devices are hard to get adopted."

Another development, which Antoniades has written on in the European Heart Journal, is the potential to diagnose heart disease from facial photos, as outlined in a Chinese study. It was already known that features such as male pattern baldness and cholesterol deposits around the eyes are associated with increased heart risk, but AI makes it easier to analyse this data without human intervention. The prospect could be significant for health systems that cannot afford effective screening programmes. Antoniades says it raises concerns about data protection and rising insurance premiums for those identified as at risk from heart problems.



Another imaging advance that has benefited from BHF funding comes from Declan O'Regan, professor of imaging sciences at Imperial College London. He uses AI to build 3D models of the heart from MRI scans to better understand the causes of heart failure. "It's about understanding the heart as a 3D piece of engineering, rather than relying on measures like ejection fraction — the percentage of blood that it pumps out each time. Those measures are crude, approximate and subjective," he says. "They're weak predictors of outcomes. By building a really immersive 3D model, we can get much more useful information."

O'Regan and his colleagues have analysed thousands

'We've spent far too much money on patients [who have] already got an established disease' of scans from the UK Biobank database, helping them build "super-detailed digital maps" of the heart to identify which patients might benefit from earlier, more aggressive treatment. "It may mean also, conversely, being able to reassure some patients that they don't need more aggressive therapy," O'Regan says.

"People have their scan, the computers analyse their beating heart while they're having that scan and, before they've even got out of the scanner, it will have analysed those images and provided the radiologist with a sliding scale of what degree of risk that patient is at and what sort of treatments might benefit them."

Many of these AI technologies could change how care is given, says Julie Hart, director of strategic and industry partnerships at the Oxford Academic Health Science Network, which is helping Caristo secure NHS adoption of its technology. "It's almost a *Star Trek* scenario," she says, "being able to look at people with a scanner and use AI to give a risk stratification or diagnosis…we really are going into the next generation of healthcare delivery." ●



## Time to put tabs on tech

A failure to regulate digital transformations risks undermining progress made in health and wellbeing globally, say **Ilona Kickbusch** and **Anurag Agrawal** 

he Covid-19 pandemic has highlighted the pervasive role of digital technologies in transforming how we understand and address health and wellbeing. It has influenced health behaviours and heightened pressure to adopt digital solutions for improving the health of individuals and populations alike.

Digital tools have helped people access medical consultations remotely via telemedicine, and eased case identification through online symptom reporting. They have supported public health surveillance and decision making via contact-tracing apps, predictive analytics, geospatial modelling of viral spread dynamics and data sharing.

But digital technologies have also fostered the online diffusion of disinformation and misinformation about the pandemic — for example, by contributing to vaccine hesitancy. In addition, they have provided governments with powerful tools to erode democracy and human rights under the guise of public health interventions.

Several countries have been accused of using contact tracing to analyse location and telecommunications data (often with the assistance of private companies) and there are fears that digital health surveillance could reinforce discrimination against minorities and other vulnerable groups or deter them from seeking medical care.

Vast research gaps still exist in understanding digital technologies' long-term effects on health and wellbeing, including the prolonged exposure of children and young people to digital devices and products.

Even beyond the pandemic, digital transformations are redefining the future of health in all areas of our lives. The vast inequities that exist in people's ability to access digital and Big Data-driven tools, and the limited capacity of many groups to protect themselves against potential harms, highlight the importance of governing such transformations using precautionary and value-based approaches.

At the same time, as digital health becomes a point of focus for technology businesses and traditional healthcare companies, there is a danger of reinforcing growing power imbalances. Big Tech market capitalisations surged during the pandemic, while multilateral efforts to regulate and tax the digital economy have been slow and have met resistance.

The Lancet & Financial Times Commission on Governing Health Futures 2030 was launched in 2019 to explore these trends. It seeks to help decision makers improve health while mitigating the risks of deploying digital technologies without respect for key public health values, such as democracy, equity, solidarity, inclusion and human rights.

At the heart of our recommendations is the acknowledgment that digital transformations are an increasingly important determinant of health, both in their own right and as accelerators of other commercial, political and social-environmental factors. We urge a series of coordinated and ambitious responses.

First, governments must expand digital access and literacy to fight inequalities in and across countries. The "digital divide" has widened differences in access to health and education. Universal connectivity and the capacity to improve digital competence are essential to ensure no one is left behind in benefiting from digital transformations.

Second, we need to build public trust in digital technologies through stronger protection of rights threatened by extensive data extraction and digital surveillance. That requires greater public participation in decision-making and design, and in the accountability of governments and the private sector. It needs a greater emphasis on public consultations, the systematic adoption of open data strategies, and the development of oversight and redress mechanisms.

Third, we must build a culture of "data solidarity". We need solutions to empower people to exert greater control on how their health data is used, while facilitating sharing for the public good. For instance, data trusts and cooperatives are being tested to provide independent stewardship of health data. All countries should have such institutions in place to support greater accountability of private companies and increase trust in data sharing.

Fourth, governments should scale up investments in, and build capacity for, digitally driven transformations of their health systems. This will require greater engagement and control by low- and middle-income countries and ways to ensure digital health interventions are cost-effective and tailored to the local context.

Finally, it is vital to place the concerns of children and young people at the centre of digital transformation and involve them in shaping their own health futures. Digital technologies must make health services more responsive to their expectations, including concerns around mental health, sexual and reproductive health, and general fitness.

This focus will test the capacity of governments to ensure digital transformations benefit everyone, since children and young people are among the most vulnerable groups in society.

Our report provides a blueprint for stimulating new research, thinking and practices in the interface between digital transformations and health. There is too much at stake for the future of health and wellbeing to leave digital transformations ungoverned.

Ilona Kickbusch and Anurag Agrawal are co-chairs of The Lancet & Financial Times Commission on Governing Health

Futures 2030

PARTNER CONTENT Imagining health futures through speculative fiction 1 2 STORIES 20 COUNTRIES YOUNG PEOPLE AWARDED FICTION Motivated by a desire to go beyond traditional methods of youth engagement, the Lancet and Financial Times Commission on Governing Health Futures 2030 set out to empower young people to inform and inspire its work about the future of health through expression, vision, fantasy, and imagination. Through a partnership with UNICEF, more than 60 young people from 20 countries worked with awarded speculative fiction writers in virtual

writers' rooms. Together, through collaborative storytelling, they imagined different health futures and the role that digital technologies might play.

An anthology with a foreward by Ken Liu, a multiple Hugo Award-winning American author of science fiction and fantasy, reveals young people's hopes, fears, and imagined solutions for the future. The 12 stories in the anthology illustrate both the potential of digital technologies to improve people's health but also the dystopian futures that could prevail if our use of technologies is not guided by key principles such as equity, solidarity, and human rights.



Read the anthology visit www.governinghealthfutures2030.org







### GHFutures2030 Youth network & engagement

The GHFutures2030 Youth Network was launched in April 2020 by Commission co-chair, Ilona Kickbusch. The youth network was created in response to a call from young people to have a shared platform to co-create and co-lead future research, advocacy, and dissemination of the report. Currently there are **182** members from over **44** countries.



Work with young people across all geographies and disciplines to advocate for greater involvement of young people in the design and implementation of policies and programmes related to health, technology, and data

Support advocacy and dissemination of the Commission's findings and recommendations, driven by shared values of inclusion, democracy, solidarity, equity, and human rights

Amplify youth voices and mentor members of this network to co-create and co-lead future research, advocacy, and dissemination activities related to governing health futures in a digital world.

#### Hold decision makers accountable

for their commitments to health and the equitable and responsible use of technology and data

#### Collaborate with other networks

engaged in policy change to promote and govern health future



Global consultations with youth led to the development of the **Youth Statement and Call for Action** to act as a partnering document to the Commission report.

Three key aspects youth want to see in health governance:

- A human rights-based approach to (digital) health
- Strong and inclusive governance mechanisms
- To foster digital skills, education, and innovation.



Read the youth edition report and Call for action

www.governinghealthfutures.org

Supported by:





Join Us

Blogs by youth | Podcasts featuring youth leaders | discussion and advocacy group on Facebook