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Digital transformations: why we must build digital health citizenship

I would like to use this opportunity to reflect on the digital transformation of health. Technologies are now at the very core of health – **last not least because they have entered the very core of our everyday life.** Our health futures are unfolding in an era of substantial technological transformation—not to mention political, economic, social and environmental transformations—and these will and are already affecting all areas of health and wellbeing.

But in my experience – and to our peril - digital health and public health are still - for most people - two distinct communities, fields of study and practise.

Yet there is an **increasing convergence between digital health and public health – some of which we have experienced during the COVID19 pandemic. And – contrary to expectations and promises – this conversion is aggravating existing divisions in health rather than lead us towards a common digital future.**

The Lancet and Financial Times Commission on Governing Health Futures 2030, which I co-chaired, considered the intersection of these two major societal transformations—health and digitalisation. Of course, using new technologies to improve health is not a present-day phenomenon. Medicine has always been driven by scientific breakthroughs and technological innovation. But the very nature of the technology linked to the level of convergence that we are seeing now, and the speed of change, are unprecedented.

The COVID-19 pandemic brought the convergence between digital health and public health to the forefront. It showed us how health, data, and the power of digital connectivity transcend borders but at the same time reinforce established inequalities and discriminations. The pandemic also highlighted the influence of the large, global digital providers and platforms, many of whom were already rapidly entering the health space and gained increasing relevance during the pandemic.

In the Commission's report, we argue that as well as offering new tools through which public health goals can be achieved -, **digital technologies are changing the approaches to and understanding of health and wellbeing, even for those who are currently unconnected.**

Universities must be leaders and integrate the challenges of the digital transformation into curricula, research centres and the priority societal challenges which they want to help resolve through science and evidence – you have such initiatives here at Valencia University, including your digital transformation conferences. Intersectoral work will be essential – new links between biology, computer sciences, social sciences and public health are just one example as are new forms of cooperation between universities and the private sector. Independent actors are critical in this transformation process.

I have grouped my reflections around three questions

- Must we think of the digital transformation as a multi-dimensional determinant of health?**

•Must we widen our understanding of solidarity in health to include data solidarity?

•Must we develop a concept of digital health citizenship?

But before we come to these three questions, I want to address the “mindset” with which we need approach the governance of the digital transformation in health.

The ubiquity and the impact of the digital transformation is becoming so pervasive that it will soon become the dominant prism through which we think about and address all issues. Health and wellbeing will be no exception.

We cannot think of health in the future without thinking digital, which of course is just shorthand for many of the developments underway, including AI as well as genomics. In fact, our Commission suggested that in the future, we won't talk about “digital health” at all since digital technologies and data will just be an integral part of how health is understood and delivered. Paul Sonnier has defined digital health as “the convergence of the digital and genomic revolutions with health, health care, living and society.”

The boundaries of digital transformations of health are being pushed forward at an accelerating pace, often without concern for their effects on health equity and human rights. Regulation and legal frameworks cannot keep up. Indeed the rapid access to real time information and the intensity of the digital debate

create new pressures. Some analysts speak of a “quicksilver domain” which requires constant vigilance and updating. Just think of the recent chatGBT developments.

The economic incentives in this ecosystem are extraordinary. Health is emerging as a key driver of innovation and a business frontier for major technology companies and platforms all around the world. A record \$51.3 billion has been invested in global “health-tech” in 2021, up 280% on 2016 levels. [3] Health as a high-stake domain for investors was significantly reinforced through the pandemic.

The development of digital technologies has also become an issue of highest geopolitical relevance with calls of a “new tech order” being formulated by the present G20 Indian presidency. The goal is to use technologies potential as “a great equalizer” and **combine cross-border flows of technology and investment with development and growth aspirations based on the principle of “data for development”**.

The Lancet/FT commission issued an urgent call to action for health and digital policy makers to ensure that digital transformations **are driven by public purpose** rather than private profit, and support **the missions of public health, universal health coverage and health for all.**

Based on this thinking the Commission proposes a value driven governance model for the digital transformation of health based on the core values of **equity, data solidarity, digital stewardship and trust, accountability, and public participation.**

The mission is to reduce inequities, ensure digital inclusion and improve health and wellbeing.

First reflection: Must we think of the digital transformation as a multidimensional determinant of health?

For increasing numbers of people, a life without digital access is unimaginable. In consequence digital determinants of health are increasingly shaping our health and wellbeing both **directly** (for example, via promoting health information or misinformation, the use of digital health and wellbeing tools such as wearables and the impact of body and beauty norms or mobbing) and **indirectly** through a wide range of social, economic, commercial, and environmental factors. They do this positively and negatively and many policy makers are still fascinated by technological promises and less concerned about short- and long-term **health and social harms**.

2.9 billion people—more than one third of the world's population—are not connected to the internet. They are therefore excluded from digitalised health systems, online sources of health information, and the growing number of health tools that are accessible through mobile phones and other digital devices. A recent report by Oxfam India has provided detailed analysis of this process of exclusion.

At the same time over 50% of the world's population do not have access to Universal Health Coverage. **We find that the same equity principles apply to digital access and UHC: they must be universal, accessible, affordable, interoperable and acceptable.**

But health in a digital age means more than giving medical care through digital means. It means recognising that digital transformations are determinants of health that interact with larger political, societal and economic dynamics, and addressing them accordingly.

The digital divide is now a critical multidimensional determinant of health between and within countries. The capacity to participate in digital life – and by association in digital health - is not universal. It mirrors existing social determinants and is reinforced as algorithmic categorizations deepen divides in society.

- It includes the collection and use of people's data for the purposes of profit or surveillance and unregulated online content and spaces which can put everyone but particularly young people and other vulnerable groups at risk.
- Increasingly we learn of algorithmic tools which create databased information that categorizes individuals in ways that are to their disadvantage, including the role of artificial intelligence and opaque algorithms in decision making.
- Often digital tools and connections are expensive, they can be complicated and demand high levels of digital and health literacy.

In short: there is huge overlap between the communities who are not connected to the internet, who have low levels of literacy and who have least access to quality healthcare.

Collaborative governance models that bring together different sectors – public and private – must also include communities to address these reinforcing equity challenges. Interesting PPP models have been tested in developing countries, for example the Technology-enabled Remote Health care (TeRH) approach in the South Of India.

Data can be a matter of life or death in a health crisis – they also pose a set of ethical and human rights challenges. We saw during COVID-19 how missing data on the ethnic background of those who become critically ill with COVID led to unaddressed disparities in health outcomes. The lack of harmonised data collection standards made cross-country comparison of epidemiological information unnecessarily challenging. Health misinformation is another well-known consequence of poor data governance.

Such concerns about privacy, safety and other rights violations are contributing to a lack of trust among communities, health workers and other groups. This limits the adoption of potentially beneficial innovations as well as the sharing of data and solutions between countries and digital health actors – and leads to lack of evidence based decision making for health.

The Lancet Commission argues that building trust among all stakeholders of the digital health ecosystem is one of the most urgent areas for action as low-trust environments are risk environments for health.

In summary: Digital transformations hold great promise to improve health and wellbeing. But this potential will remain

theoretical and limited to certain privileged pockets of the globe or within countries and regions unless some important steps to address the digital divide and the multidimensional digital determinants of health are taken.

Second reflection: Must we widen our understanding of solidarity in health to include data solidarity?

There is so much that we don't know yet about how digitalisation and the different digital determinants of health impact the health and wellbeing of different population groups, particularly over the longer-term. We need to build our knowledge base by collecting robust and representative data.

But without trust to share data at local, national, regional, and global levels, we will never be able to benefit from the huge volumes of health data that exist to improve health, health care and decision-making. Innovations with the potential to advance public health goals will remain limited.

The World Health Organization has recognised the need for common standards and coordinated approaches to realise the potential of digital health. In its Global Strategy on Digital Health, the WHO identifies **interoperability and health data governance as two of the most pressing areas for future international agreements.**

Hundreds of organisations recently called on the WHO and its member states to start working on a global framework for health data governance that will allow the value of data to be harnessed

for public good whilst protecting individual rights. **Health data governance must have a prominent place in all public health policies whether global or national or regional.** The pandemic treaty that is currently being negotiated is a case in point at the global level, the General Data Protection Regulation and the proposed Artificial Intelligence Act are examples at the European level. For example, the AI ACT would be the first law on AI by a major regulator anywhere.

The law assigns applications of AI to three risk categories. First, applications and systems that create an **unacceptable risk**, such as government-run social scoring of the type used in China, are banned. Second, **high-risk applications**, such as a CV-scanning tool that ranks job applicants, are subject to specific legal requirements. Lastly, applications not explicitly banned or listed as high-risk are largely left unregulated.

In its report and complemented by a recent White Paper, the Lancet and Financial Times Commission has **outlined why solidarity must be one of the core principles on which any approach to health data governance is based.** The premise of solidarity-based data governance (in short: data solidarity) is that benefits and risks of digital practices need to be borne by societies collectively, just as we have established for public health.

Based on public health values data solidarity seeks to increase collective control over data use with the goal of public benefit which includes protection from harm and promotion of communal use and benefit. Three dimensions are critical:

- A solidarity-based approach can ensure that data collection and data use yield high public value as well as preventing harmful data use.
- Data solidarity also entails that people who are harmed by data use have access to support and compensation.
- Finally, data solidarity aims to redirect profits emerging from commercial data towards global health and other public purposes.

Current data governance frameworks have been designed to protect primary data subjects, meaning individuals. In digital societies, however, the risks and benefits of digital practices can affect a much wider range of people – this is very similar to public health. Digital practices are also embedded in stark power asymmetries, both within and across countries. Addressing these challenges and inequalities requires an approach that goes beyond merely giving individuals more control over their own data – just as in public health we understand that individual health rights need to be complemented by public health measures.

The wider ranging impact requires a greater emphasis on collective control, responsibility, and oversight. Inequities in digital societies harm everyone, not only those directly affected by them. Similarly, everyone benefits from good deliberations and rules on what parts of people’s bodies and lives should be exempt from datafication, from the existence of effective mechanisms to support people who have been harmed by data use, or from the fair taxation of commercial activities in digital societies.

As well as expanding the benefits of data, global partnerships and coordinated investments are needed to scale up access to open-source digital public goods that can improve health, especially in low-income contexts. **Digital public goods** are open-source software, open data, open AI models, open standards, and open content that adhere to privacy and other applicable laws and best practices, do no harm by design, and help attain the Sustainable Development Goals (SDGs).

Free and open-source software (FOSS) is an example of digital public good. Since FOSS is licensed to allow it to be shared freely, modified and redistributed, it is available as a digital public good. Another example is the DHIS2 open-source health information system, a global open-source project coordinated by the University of Oslo (UiO). More than 76 countries worldwide use DHIS2 for collecting and analysing health data. 3.2 billion people (40% of the world's population) live in countries where DHIS2 is used. DHIS2 is offered free of charge as a global public good.

Third reflection: Must we develop a concept of digital health citizenship?

The most challenging dimension of the extreme imbalance of “who benefits” from the digital transformation is what Shoshana Zuboff has termed “surveillance capitalism”.

“Surveillance Capitalism” turns the whole human experience into an unlimited resource that is converted into data and consequently into profits. This is also termed “data extraction”

or “data colonialism”.

The digital ecosystem is grounded in its users – it only works if citizens/patients are willing to cooperate and “feed” it with their data, consistently share and interact with one another and maintain it while being steered by algorithms.

Research indicates that new forms of **digital health citizenship** have emerged which include how citizens/patients:

- **Contribute proactively to knowledge generation;**
- **Create communities to deal with health challenges;**
- **Practice data sharing; and**
- **Interact with health services and providers.**

But so far very few governments have worked to strengthen the democratic and solidarity incentives and benefits of the digital health ecosystem. These would need to be based on an understanding of governance not as exclusively top-down but as **“how communities invent and shape their destiny”.**

The digital ecosystem offers new spaces for political participation and civic debate, including on health matters. But equitable health benefits can only be realised when citizens are able to:

- **Critically engage with these ecosystems;**
- **Have access to safe spaces and protect themselves and others from misinformation and abuse; and**

- Make informed choices in respect to their data, such as practice data altruism and data solidarity at different levels.

In all parts of the world, countries are being challenged to make their health systems digital first, to make more and more services available through digital tools and platforms. But aside from the enormity of the challenge to get all people and all health facilities online in the face of weak or non-existent infrastructures, other bottlenecks will need to be addressed for this vision to become reality.

Civic and digital literacy are fundamental enablers of public participation and informed citizenry, which can contribute to advancing social justice and health equity. **In our Lancet/FT report, we highlight the interconnections between digital literacy, health literacy and broader democratic and civic literacy skills**, arguing that none of these skill sets can be expressed effectively without the other in a digital age. We recommend actions to enfranchise communities and advance public participation in health and wellbeing, particularly among young people.

One characteristic of governance in the 21st century is inclusion. Individuals and groups must be able to actively participate in and cocreate the design and implementation of digital health policy and technologies, and to feed back to decision makers, development agencies, and private companies. This includes equity frameworks for technology development and digital spaces, such as decolonial and feminist approaches and building community resilience to future changes. It also

demands frameworks that clarify rights, responsibilities and benefits.

Civic technology models, which broadly refer to the co-creation and use of digital technologies to improve public participation in democratic and decision-making processes, are increasingly seen as enablers of improved public policy and service delivery, including in health. The link to democracy is obvious and the Europe should be at the forefront of these civic-tech developments bringing together the experiences in many EU countries and at the local level to support and bring alive the implementation of the values and principles.

Within all countries there are large gaps in digital, health and civic literacy. Closing these gaps is essential if all people are to be able to take full advantage of digital health transformations and use digital tools and information in ways that will improve their health and wellbeing. Citizens must be able to **co-design the ecosystem** and their collective input must generate collective returns.

The absence of strong ethical and human rights-based principles when designing, implementing, and evaluating digital health solutions risks ignoring or exacerbating existing health inequities and other forms of discrimination, or even creating new ones, as one of the recent human rights special rapporteurs has analysed through a critical view of the **digital welfare state**.

He also draws attention that the values underpinning and shaping the new technologies are unavoidably skewed by the fact that there is **“a diversity crisis in the AI sector across**

gender and race.” Those designing AI systems in general, as well as those focused on the welfare state, are overwhelmingly white, male, well-off, and from the global North. This leads to **algorithmic bias** which has only recently been addressed in legal frameworks, such as the European Union’s General Data Protection Regulation (2018) and the proposed Artificial Intelligence Act.

To redress power imbalances, and to enable all people to engage effectively and safely with digital ecosystems, governments need to enfranchise communities and advance public participation in digital health policy and governance. The Lancet Commission through its own partnerships with youth networks, aims to support a new generation of digital health citizens who are empowered to build the digital health futures they want and need. We hope more organisations will get behind this effort.

Role of Europe

The overarching message of the Governing Health Futures 2030 Commission is that all stakeholders must enact a precautionary, mission-oriented and value-based approach to governance of digital transformations of health. The Health for All values of democracy, equity, solidarity, inclusion and human rights must be upheld at all stages of the digital development and implementation cycle.

The recently developed EU Global Health Strategy has identified the digital transformation as one of the priority areas of global health action. **A European approach to the digital**

transformation must be grounded in a new understanding of digital health citizenship and a strong set of values and ethical principles, including data solidarity.

National policymakers and other digital health actors must work together to ensure these values are prioritised, the benefits of digital transformations are equally distributed within and between countries, and to protect populations from any digital harms.

The opportunities and risks of digital transformations of health are global and require global action. Spain in its presidency of the European Union in the second half of 2023 can help towards moving such an agenda forward.

I believe that if our leaders can view digital transformations through the lenses of UHC and Health for All values, if they can consider digital transformations from the perspectives of today's young people and future generations, then the full health potential of digitalisation can truly be realised.

