

European High-Level Ministerial Conference, 2 February 2022

## Keynote: The meaning of ‘Citizenship, Ethics and Health Data’

### Professor Ilona Kickbusch

Co-Chair, Governing Health Futures 2030.

Chair of the International Advisory Board, Global Health Centre at the Graduate Institute of International and Development Studies.

Thank you to the French Ministry of Solidarity and Health and the European Commission for inviting me to this important meeting introducing European Ethical Principles for Digital Health. You will find many of these principles also reflected in my deliberations.

### This is my starting point:

**A European approach to health data must be grounded in a new understanding of digital health citizenship and a strong set of values and ethical principles, including data solidarity.**

This need for a **value-based and people-centred approach** to governing digital transformations in health is in fact the main conclusion of a *Lancet* and *Financial Times* Commission titled *Governing health futures 2030: Growing up in a digital world* that I have had the privilege to co-chair for the past two years.

At the centre of our analysis is **the need to redistribute power and agency for the benefit of health and wellbeing in the context of digital transformations in health.** [1]

The WHO has also reinforced the need for a new global consensus on health data governance, underpinned by a core set of guiding principles, so as to **secure health data as a global public good**, and to identify good data governance practices for better health, especially for communities left behind. [2] **Here the European Union can and must take a lead for global conversations to move forward.**

The *Lancet* and *Financial Times* Commission proposes a governance model based on the core values of **equity, data solidarity, digital stewardship and trust, accountability, and public participation.** All are based on an understanding of

governance not as exclusively top-down but as **“how communities invent and shape their destiny”**. [3]

Understanding how digital technologies reshape not only health and care services but **social relations and interactions around health** can lead us to develop new forms of digital health citizenship and civil engagement for health. **This is the direction Europe must take.**

### **Why do we need a value-based governance framework for digital health?**

We know that digital technologies and the data they generate through the technology/people interface offer great potential to improve the health of all people around the world, reduce health inequities, close gender gaps and protect the most vulnerable.

Indeed, research indicates that new forms of **digital health citizenship** have emerged which include how citizens and patients:

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

But governments have not yet provided the **trust architecture** to take this development forward safely and at scale. Despite what the technology can enable us to do, social, economic, and political forces often stand in the way of generating community benefits – and also benefits at the global level.

That is why we need to apply a **broader view that situates “digital health” within a whole-of-society perspective and a solidarity-based digital governance framework.**

This means:

- We cannot see “health data” as something separate from the whole digital health ecosystem and the impacts of digital transformations on society overall.
- We cannot see data sharing as separate from global power relations, as experienced during the pandemic.

- We need to factor in how citizens/patients – as the ones who generate most of the data – interact with technology, one another, health professionals and the health and the broader welfare system.
- And we need to factor in that most of the data generated on platforms can now be considered “health data” and are treated as such – as for example our movement profiles become important during a pandemic.

Consequently, in our Governing Health Futures 2030 report we argue that:

- **The focus of policy makers needs to be on digital transformations in health not “digital health”.**
- The various components of the digital ecosystem must be recognised and addressed as **determinants of health** – either improving health or creating harm.
- Citizens must be able to **co-design the ecosystem** and their collective input must generate collective returns.

**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. While there is much focus on the need for “innovation”, policy makers need to be much more concerned about short- and long-term **health and social harms**.

And, during the pandemic, **the political harms** – the dangers to democracy have become ever clearer.

**The economic incentives** in the digital 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. [4] Health as a high-stake domain for investors was significantly reinforced through the pandemic. While there is great hype and excitement around digital health technologies, governments have been slow in establishing governance frameworks as well as their regulatory response.

**That is why we face the dangerous situation now where the democratic and solidarity incentives are less developed. Yet this digital ecosystem (especially**

during a pandemic) 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 they do not control or understand.

The most challenging analysis of this extreme imbalance of “who benefits” is what Shoshana Zuboff has termed “surveillance capitalism”. [5]

“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”. [6]

Obviously, this is contrary to the values I have outlined, and that the EU subscribes to. **We face a set of novel ethical and human rights challenges in an ungoverned space.** Digital health ecosystems are developing without adequate consideration of the unequal distribution of power and resources that affect an individual’s or a community’s:

- Access to;
- Engagement with; and
- Ability to benefit from digital health technologies.

**The absence of strong ethical and human rights-based values and 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**. [7,8]

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.

These gaps show us that ethical perspectives on digital transformations in health need an expansion from bioethics to **socio-technical ethics that assess the broader impact of technologies on health and health care.** [9] Without a

**commitment to solidarity, justice and new forms of digital health citizenship** health could become a favoured entry point in support of new forms of surveillance capitalism, data colonialism, or digital welfare dystopias characterised by control. Following a “massive surveillance surge” during the pandemic we are already witnessing such developments in several countries around the world.

**The European Union must lead here.** As it has stated “The EU’s approach to artificial intelligence centres on excellence and trust, aiming to boost research and industrial capacity and ensure fundamental rights.” This requires value-based framework of ethical principles for governing health futures **that puts public purpose before profits and guides decision makers and other public and private stakeholders how to harness the potential of digital technologies in support of better health and wellbeing for all.**

Our Lancet/FT Commission argues that any approach to shaping health futures through digital transformations should be grounded in five foundational values: **democracy, equity, solidarity, inclusion, and human rights.**

They reflect a Health for All approach and the universal values that are articulated in the 2030 Agenda for Sustainable Development and the high-level political declaration on universal health coverage (UHC)—both of which have been adopted by all EU Member States.

Last month, the UN Secretary General called again for better global governance of technology as part of efforts to rescue the SDGs. He called for an “emergency response” to put humanity at the centre of digital transformations and close the digital divides. [10]

Today, it is not only lack of access to UHC but also lack of connectivity that kills. **Over half the world’s people have no access to UHC and the same number has no access to the internet.** And let us be honest – it is also lack of sharing health knowledge globally that kills, as experienced during the pandemic.

That is why EU policies need to ensure digital transformations in health that **create public value and actively advance social justice**, rather than promoting a siloed and ungoverned adoption of new technologies and “innovations” as they emerge; within Europe and as global responsibilities.

**What do we mean by a solidarity-based approach to health data?**

The Lancet/FT Commission **recommends:**

- **A solidarity-based approach to health data must be considered a defining feature of 21<sup>st</sup> century public health at national and global levels;**
- **Participatory data governance must be a defining feature of 21<sup>st</sup> century digital health citizenship.**

A 21<sup>st</sup> century social contract in health and health care in the European context must include the way we collect and use health and health-related data for the common good – **health solidarity in the 21<sup>st</sup> century is built on the notion of data solidarity.** In consequence it also implies new governance models and new sets of rights and responsibilities for citizens/patients as an expression of digital health citizenship.

I am speaking here about citizenship in its broadest sense where all people are part of a global community with responsibilities to those both within and beyond their own society.

The COVID-19 response has highlighted the risks of some approaches to data collection and management. But the use of privacy-related arguments to promote an individualised understanding of health and health-related data overemphasises the idea of individual data ownership. **It neglects the social and relational nature of (health) data.** It also ignores the heterogeneity of data coming from several different sources.

But there must be a conscious effort to bring together **individual health agendas**—which for digital applications are more focused on aspects such as behavioural monitoring, precision medicine, and disease prediction through genomic approaches—and the **more structural efforts** towards broader population-based impact that have long characterised public health action. The latter have been critical during the pandemic – but many countries lacked the trusted ecosystem within which to act.

Research on the new “digital health citizenship” shows the willingness of people to share information, experiences, and data – but frequently they are not aware if they are doing this on a public or private platform, what role algorithms play in prompting their choices and what happens with the data they share. [11]

The notion of solidarity, as applied to health data and data for health, goes beyond data altruism, it demands **institutionalised solidarity.** [12] It can be a

way of safeguarding non-extractive and trustworthy approaches to data collection, use, and sharing, building a culture of data justice and equity, and ensuring that the value of data is harnessed for public good as indicated by the WHO.

### How does citizenship fit in?

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;
- 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.

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.

**A central characteristic of governance in the 21<sup>st</sup> 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 be prepared for future changes. It also demands frameworks that clarify rights and responsibilities.

**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 European Union 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 ethical principles.

## To conclude...

Let me recap: the massive challenges and opportunities posed by digital transformations in health constitute a powerful call for governance that is grounded in the core Health for All values: **democracy, equity, solidarity, inclusion, and human rights.**

The development of a European approach to digital health offers the opportunity for all EU member states to put Health for All values at the centre of their policies and programmes and to ensure that digital technologies enable health and wellbeing benefits for all. This is of greatest urgency.

European policies that shape digital transformations in health must be built on a participatory understanding of governance as **“how communities invent and shape their destiny”** – the value of citizen’s engagement, solidarity and social justice must be at the forefront of an ethical view of digital transformations in health – as in other areas of society. One of key priorities in implementing the values and ethical principles **must be a strategy to build digital health citizenship – in Europe and globally.**

I invite you all to read our Governing Health Futures report and to consider how our recommendations could be implemented in your contexts. We hope that our report is both a wakeup call and useful roadmap to realise our common ambition for a healthier, fairer future for all.

**Thank you.**

## References:

[1] Kickbusch I, Piselli D, Agrawal A, etc al. [The Lancet and Financial Times Commission on governing health futures 2020: Growing up in a digital world.](#) *Lancet* 2021. Nov 26;398(10312):1727–76.

[2] WHO. [“Health Data as a global public good – a call for Health Data Governance 30 September”](#). Accessed 31 January 2022.

[3] Gardels N. [“Institutions don’t defend themselves”](#). Noema. Published online 7 January 2022.



- [4] London and Partners. [“UK and US drive global growth in healthtech sector”](#). Accessed 31 January 2022.
- [5] Zuboff S. [The Age of Surveillance Capitalism](#). Profile Books; 2019.
- [6] Couldry N, Mejias UA. [The Costs of Connection: How Data Is Colonizing Human Life and Appropriating It for Capitalism](#). Stanford University Press; 2019.
- [7] Kickbusch I. [The dark side of digital health](#). *BMJ* 2019.
- [8] Alston P (Special Rapporteur for Extreme Poverty). [Digital technology, social protection and human rights: Report of the Special Rapporteur on extreme poverty and human rights](#). New York; 2019.
- [9] Shaw JA, Donia J. [The Sociotechnical Ethics of Digital Health: A Critique and Extension of Approaches From Bioethics](#). *Frontiers in Digital Health* 2021, Sep 23.3.
- [10] Guterres A. [“Outlining Priorities for 2022, Secretary-General Underscores Fighting Pandemic, Reforming Global Financial System, Tackling Climate Crisis, Delivering Peace.”](#) Briefing to the UN General Assembly. 21 January 2022.
- [11] Petrakaki D, Hilberg E, Waring J. [The Cultivation of Digital Health Citizenship](#). *Soc Sci Med*. 2021 Feb;270:113675.
- [12] Prainsack B. [Solidarity in Times of Pandemics](#). *Democratic Theory* 7, 2, (2020) 124-133.