

The missing link in the EU's plan on digital health: citizens' empowerment and endorsement

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On 25 April, the European Commission presented its long-overdue communication on the digital transformation of health and care. The proposals are the Commission's latest attempt to shape the European Digital Single Market (DSM).

The communication announces measures to make it possible for citizens to access and share health data safely. It puts forward actions to pool data across Europe to boost research and spur the development of personalised medicine. It also presents new ways to promote the scaling up of digitally-enabled person-centred care models.

The ambitious action plan demonstrates the European Union's (EU) commitment to reap the benefits of digital innovation in healthcare. Nevertheless, a comprehensive approach that encompasses all the dimensions of how people can embrace this transformation is lacking. Moving forward, the effective delivery of digital innovation in healthcare will hinge on the willingness of the EU and national governments to commit to such an approach. The upcoming negotiations on the next Multiannual Financial Framework (MFF) will be very telling in that regard.

The Commission's plan to enable the transformation

In line with the DSM strategy, the communication identifies action areas to ensure the secure and free movement of health data in the digital single market. At present, most EU citizens have limited, if any, electronic access to their health data. The lack of data interoperability and common standards is hindering the exchange between different healthcare institutions, both within and across countries.

To overcome these technical hurdles, the Commission wants to encourage member states to cooperate and exchange best practices on interoperability at national level. It also aims to develop and promote a European electronic health record (EEHR) exchange format that complies with the General Data Protection Regulation (GDPR).

The Commission intends to set up a mechanism of voluntary cooperation between national authorities to connect existing initiatives that pool genomic and other health-related information. This will promote medical research and personalised medicine, thanks to the ability to analyse larger health datasets at the EU level.

Lastly, the communication puts forward measures to facilitate the scaling-up of digitally-enabled person-centred care models. To achieve that, the Commission will support the exchange of best practices, provide technical assistance, and encourage national authorities to create favourable market conditions for technology suppliers.

Transition to digitally-enabled health services: what is missing?

The Commission's plan addresses the major technical and market-related barriers to digital innovation in healthcare. It fails, however, to take into account a critical precondition for a swift deployment of digital health solutions: citizens' ability and willingness to engage in the transition. In fact, the success of the digital transformation will hinge on the empowerment of and endorsement by healthcare professionals, patients, and caregivers. Education and trust are key in this respect.

- **Education** is of utmost importance to enable people to engage in the digital transformation. The health workforce needs to be equipped with digital skills and develop interdisciplinary approaches to patient care. Similarly, it is essential to improve citizens' and patients' health and digital literacy, targeting, in particular, the older segments of the population and the less educated. This empowerment will enable equal access to health services and make it possible for people to engage actively. The communication says little about how to improve digital skills. In this area, the Commission should encourage and support member states in adapting medical education to the digital revolution age, and in developing education programmes for patients and citizens.
- **Trust** is also a key enabler, as citizens must be assured that their health data is adequately protected. The communication does not suggest concrete measures to raise awareness among citizens and ensure a full understanding of the legislative framework that will protect health data privacy. The Commission should thus support EU-level communication campaigns to explain to citizens how their health data privacy will be protected. Similar actions should target the business sector and the organisations processing health data to clarify what their obligations are.

Delivering on the objectives: the next MFF and the comprehensive approach to digital transformation

To fully reap the benefits of digital innovation, it is essential to develop a comprehensive approach that takes into account the secure and free movement of health data, the development of digital infrastructures, and the need for education and trust. Concrete actions to promote digital literacy, fit-for-purpose medical training and confidence in the digital transformation must be proposed and funded, both at the EU and the national level. This transformation will require political commitment, stakeholder engagement, capacity building, and, not least, sustained investments. In short, it calls for a bold political and financial commitment.

EU funding has proven to bring a concrete added value to national actions trying to harness digital innovation in healthcare.ⁱ The Commission proposal plans to support member states and advance the digitalisation of healthcare. The creation of a Digital Europe Programme in its recent budget proposal for 2021-2027 echoes this ambition.

If European health systems are to become fit for the future, the EU and national governments must work together to define this comprehensive approach. As a starting point, there is a need to acknowledge that, without citizens' empowerment and endorsement, technological progress is pointless and is likely to lead to inequalities in access to health services. Secondly, member states will need to back the Commission's digital health agenda and follow through during the upcoming EU budget negotiations by funding the required actions appropriately. The financial gap caused by Brexit, the resulting burden sharing among the member states, and other significant issues such as border management and security will undoubtedly dominate the discussion. Nevertheless, national governments and EU policymakers should not miss this opportunity to live up to the expectations of European citizens calling for more decisive action in health at the EU level.

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ⁱ As an example, the Connecting Europe Facility programme supports existing cross-border exchange of patient summaries and ePrescriptions. Also, EU-funded pilot projects successfully applied digital solutions to integrated health and care services.