



European Commission - Speech [Check Against Delivery]



Keynote Speech by Commissioner Stella Kyriakides at the European Patients Forum 2022 - "Continuing the Conversation on the Digital Transformation of Healthcare"

Brussels, 23 June 2022

Ladies and gentlemen,

Health policy is about people. Health systems must fundamentally be about the patients.

That means that you must also be at the centre of any action on how to improve systems.

As European Commissioner for Health and Food Safety, but especially as a long-time patient advocate, I know very well the power of the arguments brought by patients to these discussions.

The reality, the concreteness, above all the humanity to all the talk about systems and policies.

At the end of the day, all we do in the area of health is about you. Us, as citizens.

So I am very happy to join you today – and to be part of this “conversation on the digital transformation of healthcare.”

The COVID-19 pandemic has triggered a huge acceleration in the uptake of digital tools and has demonstrated the importance and the value of health data.

Perhaps most powerfully of all, COVID-19 has amplified the need for coordinated action and enhanced collaboration on the digitalisation of healthcare at EU level.

But we all know examples of legal, technical and procedural obstacles that make it more difficult for digital health solutions and health data to truly serve the patient benefit.

Our initiative for a European Health Data Space is based on these lessons and is meant to unleash the potential of health data. I want to be clear that, fundamentally, this is about improving health outcomes and making our health systems more efficient, resilient and sustainable.

It is absolutely clear to me that this cannot be done without people at the centre of it all. That is why we want to empower patients to take charge of digital health.

This is exactly what we want to achieve with our proposal to set up the European Health Data Space:

- For patients to have the right to use and access their electronic health data in a format that can be accepted across the EU, for free.
- For patients to be able to share data with a health professional of their choice, even across borders;
- For patients to be in control of their own data, to be able to restrict what part of their medical history is shared with whom, or to correct any errors in their health records;
- And finally, to ensure transparency so patients can see who has accessed their data.

Imagine a child living in Spain gets sick on a school trip in France. Thanks to the European Health Data Space, a local doctor will be able to see the relevant medical history in French and be aware of any allergies, existing medication or other important factors. This way the doctor will be able to carry out the best possible treatment.

Or imagine a woman who has a medical image of her lungs taken in the public hospital where she was brought in by an emergency team. With the European Health Data Space, her regular pulmonologist in another hospital will be able to easily see this medical image.

As you can see, this is a great opportunity to ensure continuity of care, even across borders, and to reduce the number of repetitive, sometimes invasive, procedures that patients have to undergo.

The European Health Data Space will make healthcare easier, more accessible, and more efficient.

Health data also has great potential to benefit society at large -- such as health research or innovation -- when it is used appropriately.

It is absolutely clear to me that trust -- your trust -- is indispensable for the success of the European Health Data Space. Data protection is a crucial pillar of this proposal.

This is your data -- and the highest level of security and full protection of privacy will be ensured.

- access to health data for research and innovation will require permits that clearly spell out the specific purpose;
- access will be possible only to data that do not reveal the identity of individuals in the dataset; and
- the data will be accessed in closed and secure environments, and only anonymised data will be downloadable.

In turn, this will make it easier to develop new treatments and more tailor-made personalised medicine. This will deliver real world, concrete and practical benefits to patients.

With a larger pool of high quality, interoperable data we can also better address the needs of rare disease patients who have been waiting so long for effective treatments to be developed.

The European Health Data Space will support the work under Europe's Beating Cancer Plan. Pooling and sharing knowledge, experience and data helps to develop practical solutions for cancer patients.

We will also boost the development of cancer registries, allowing for more timely and efficient collection of information on various types of cancers.

Such an ambitious proposal will affect patients personally -- in fact, that is why we strove to present it, as a mission priority.

Crucially, this also ensures that you are part of this conversation.

Proper governance will be key. That is why our proposal foresees the creation of a new European Health Data Space Board involving the Member States where key stakeholders, such as patient organisations, can participate.

Finally, I would like to underline the importance of digital literacy and skills for citizens, patients and health professionals.

This is crucial so that the European Health Data Space can benefit everyone. We, in the Commission are ready to provide support to Member States in this and I hope to be able to cooperate with you on it, as well.

And you have a critical role to play in getting patients on board, and ensuring they have the knowledge, information and tools to make it a reality.

Ladies and gentlemen,

I want to finish where I began – with you, the patients.

The Health Data Space places patients and citizens at its centre, empowering them with full control over their data to obtain better healthcare across the EU.

It will be a 'new beginning' for our digital health policy -- making health data work for citizens and science.

It is another pillar in the European Health Union – and a major step in our efforts to build a healthier, more equal, and more resilient society.

Thank you.

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