## HEALTH DATA TALK SERIES:

# Is data solidarity a condition for health data availability for policy making, research, innovation and product development

## WHAT IS DATA SOLIDARITY AND DATA CULTURE?

The role of the individual citizen and of healthcare providers in ensuring that health data becomes available is actually a story of **solidarity**, meaning data produced by people should be available to the people. Health insurance is historically based on the fact that people put money in a box, a cash register, and people can take money from that cash register when they are ill. We have generalised this to our current health insurance, which is based on solidarity, people pay contributions and taxes, which can then be used by everyone when and where necessary.

Actually, the same principles apply for sharing data. The 21st century will be dominated by data solidarity. We all enjoy good healthcare at specific moments in our lives. Good healthcare, scientific research for better health, development of medication, health products and medical technologies, good practices, are based on the usage of shared data and knowledge. This solidarity is important for the patient, for the citizen, and also for the healthcare provider. Their work gains in quality, gains in efficiency, gains in comfort, becomes more interesting if we can create an overall and sustained data solidarity. Data solidarity is building on **open data policy** that is already promoted at EU level but also encompasses the commitment of citizens and society.

For the professionals, solidarity plays an important role because the healthcare provider should register data qualitatively and continuously. The **culture to register high quality data** to make all those electronic health applications useful for the patient, is not yet fully achieved. Also among health care professionals we need a culture of solidarity, where they all contribute to make health data available and to ultimately get a result beneficial to everyone.

Our view is that we should strive to a data-driven health care system, based on a joint collaboration and in full transparency.

## IMPORTANCE

Some people argue that in principle all data obtained with government funds (i.e. tax money) should be available to everyone (of course with all necessary checks to preserve the privacy of healthcare users and healthcare providers in line with the General Data Protection Regulation (GDPR) and European Health Data Space (EHDS)). We all benefit from **evidence-based** medicine, but that also applies to the organization of healthcare, healthcare policy, etc. It should become standard practice that hospitals share figures or that industry shares all non-proprietary data that might be relevant to improve health. Legally it is more and more recognised that data can not be “owned”, and that data holders have **rights and obligations**. Citizens should also share data with respect to their rights and obligations. Collaboration for better healthcare, under the mantra that **availability of health data is a key requirement** to develop good prevention and treatment to ensure healthy lives.

## HOW TO REALISE SOLIDARITY?

Data solidarity should be a guiding principle for **secondary health data use**. It involves recognising data as a societal asset, much like financial and human resources. Just as all citizens contribute to the healthcare system through taxes, so too should data be shared for the **common good**. Data solidarity foregrounds the public value when it benefits people and communities without the risk of invading citizens’ direct privacy.

Moreover, data solidarity democratises innovative Artificial Intelligence (AI) tools in healthcare such as decision support systems and prevents data monopolies that can distort research. Applications based on AI models that are trained by data made available through citizens’ solidarity, should have a clear societal benefit and be easily accessible by healthcare users.

A **strong commitment to transparency and security** should further reinforce this data solidarity. By emphasising trust and involving citizens in the data access process, it should be ensured that health data are used in a manner that aligns with societal values. The EHDS regulation provides clear rules how health data can be accessed, how transparency should be created about the usage goals, and about citizens' rights to clear information and opt out for certain usage goals. These active patient participation and transparency about the data usage empower citizens through linkage with societal benefits of the products developed with health data.

The EHDS also provides a **clear legal framework** essential for efficient health data exchange across borders, by ensuring that health data are standardised and interoperable at the EU level. This legal framework empowers individuals to control their electronic health data and access it more easily. It also secures secondary data use, ensuring that researchers, policymakers and patient organisations can tap into EU health data for scientific research with full respect for a person's privacy.

Furthermore, the EHDS requires Member States to establish **digital health authorities** and **health data access bodies** to implement these provisions. By making health data more accessible at the EU level, the EHDS removes obstacles to data sharing across borders, allowing researchers to conduct transnational studies. These are important for rare diseases where data is limited, and shared data from across the EU would be greatly beneficial to support research in this area.

The interoperability ensured by the EHDS also supports innovative (digital) medical technologies such as AI based applications, enabling researchers to build predictive models and gain insights from real-world data more efficiently.

## KEY MESSAGE

Availability of health data is primordial to the development of better treatment and products, and a reciprocal solidarity mechanism for data sharing would be very beneficial to support health data usage for policy making, research, innovation and product development and evaluation. Empowerment of every citizen that contributes, clear communication and transparency on the usage goals with a return on investment (better and affordable care and treatments) should be a key enabler.

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