

Awareness, education and communication: Towards a data-driven culture in healthcare

Challenges and enablers for implementation

Achieving the full potential and benefits of secondary use of health data through the EHDS will require buy-in across all stakeholder groups, from healthcare providers and payers, through the academic research community, pharmaceutical, medical device and digital health industries, all the way to patients and citizens at large. At present, even basic awareness of the upcoming EHDS regulation is reportedly low among key stakeholder groups, including healthcare providers, with most organisations not currently taking any measures to prepare for their future role as data holders. Providing accurate and relevant information to different groups as to what changes are coming, what the benefits are and what will be required of them to comply with the new regulation is thus the first vital step that EU and national policymakers will need to take in the short term.

In the public engagement effort that must be sustained throughout the course of implementation and beyond, healthcare professionals will have to be won over and patients mobilised as credible voices to distil to the wider population the critical importance and life-changing benefits of data-sharing, including for secondary use. Inclusive information and educational strategies should be developed to empower citizens at all levels of digital and data literacy to competently exercise their rights, and support should be extended to help vulnerable groups participate in data-sharing. In the longer term, efforts should be ramped up to develop health literacy and data literacy as part of the education of all EU citizens from an early age.

Citizens' acceptance of secondary use of their health data was seen to vary between countries and to be conditioned on factors such as data privacy and security, perceptions of benefit to the community, and trust in the responsible governance bodies. In some cases, a history of risk-focused discourse around personal data or post-pandemic distrust in scientific and public health authorities will need to be overcome through open dialogue and clear answers to sensitive questions such as the security of data-sharing or ethical issues arising from the use of artificial intelligence. Direct channels of communication between data experts, especially EHDS governance bodies, and citizens will be instrumental to building and preserving public trust as more and more tangible examples of what can be achieved with data become available.

Disclaimer: This text reflects only the point of view of the experts and stakeholders involved in the Think Tank roundtable series and consultation processes held in 2023 based on the European Commission's first legislative proposal

Solutions should aim to

- ▶ **Foster awareness, trust and acceptance of the EHDS across society**
- ▶ **Provide practical answers to facilitate engagement with the EHDS**
- ▶ **Cultivate trust in long-term data-sharing for primary and secondary uses**

At European level

Raise awareness early on the contents of and rationale for the legislation at all levels of healthcare, health policy and civil society.

Develop appropriate communications around the cost effectiveness of high-quality data and proper use by different actors.

Provide clear guidelines for data holders on timelines for data-sharing and reassurance on the security of the data (including security of intellectual property).

Support transparent communication on the generation and use of health data to foster patients' and citizens' role as drivers of EHDS implementation.

At national and regional levels

Develop a national implementation roadmap in consultation with all stakeholders, including the use of public debate.

Develop communication campaigns at national and regional levels to raise awareness of the EHDS among the general public and health professionals.

Educate regional and local decision-makers on the objectives of the EHDS and on their role in implementing the standards required to make it a reality.

Communicate to all stakeholders how data security and patient privacy will be warranted and clearly publicise the penalties for misuse.

Make guideline information and processes transparent and user-friendly, taking into account the variety of stakeholders and different knowledge levels of the communities that need to understand and implement the guidance.

Design inclusive (not only digital) educational resources to empower citizens to make informed decisions about their health data and make competent use of their opt-out rights, leveraging the know-how and reach of multi-stakeholder initiatives (such as Data Saves Lives).

Explore ways to foster inclusion and empower populations with low digital and health literacy to engage in data-sharing through trusted health system actors such as primary care physicians, nurses and pharmacists.

Empower all citizens with digital tools to manage their own health and health data and put in place measures and programmes to address inequities and enhance health and digital literacy.

Emphasise the life-saving potential of data-sharing for citizens, while providing transparency around data collection, storage, use, and the privacy safeguards in place to protect personal data.

Engage with healthcare professionals and involve them in data-sharing platforms early on to demonstrate tangible value and foster trust and active participation in the EHDS.

Patient associations

Mobilise patients as advocates for data-sharing towards the general public.

Work closely with health data authorities to address inequalities and close the health data literacy gap.

Health data access bodies

Warrant clear and timely communication to the public about which datasets are used in practice, for which purposes and with what results.

▶ EXAMPLE

Attitudes towards sharing personal health data in general, especially among citizens, were variable and, as some suggested, correlated with the respective countries' regulatory landscapes for data protection as well as patient involvement in healthcare processes and health data management. In Germany, a discrepancy was described between the public's strong reservations about making data from the healthcare system available for research due to privacy and security concerns, and many people's willingness to share basic health data from wellness apps via social media. Austrian citizens' acceptance of the secondary use provisions of the EHDS was thought to be predicated on the perceived benefits to the community and data protection, while public trust would depend significantly on the choice of EU and national entities responsible for its governance. In Luxembourg, by contrast, the public was reported to have a unique perspective on the importance of data-sharing in a context where cross-border healthcare is relevant for the majority of its 600,000 citizens and 200,000 daily commuters from neighbouring countries. Different stakeholders within the country's limited health ecosystem, which is centred around four large hospitals, also have an intrinsic motivation to engage in data-sharing on a European level. Similarly, the longstanding experience of Sweden's citizens and health system actors with health data being used for secondary purposes has resulted in a high level of acceptance and trust in data-sharing practices. In Ireland, too, findings of a national survey on health information found that participants overwhelmingly trusted and understood the importance of data-sharing for both primary healthcare delivery and secondary research (Health Information and Quality Authority, Department of Health and Health Service Executive, 2021), in spite of this not currently being a reality within the health system.