SECTION 2

Capacity and skills

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

Challenges and enablers for implementation

Establishing and maintaining infrastructure for the collection, storage, protection, sharing and secondary use of electronic health data requires specific human resources and skills that are not always readily available.

Most EU Member States are generally in the early stages of their journey towards nationwide health data interoperability and accessibility; however, Europe's regions have in various instances benefited from their smaller scale to implement platforms for standardised collection, aggregated storage, and secondary use of their residents' health data. The technical characteristics and lived experiences of these different initiatives can, and should serve to identify best practices and solutions for implementing the EHDS at national and European levels.

The picture that emerged from the discussions in this field is one of heterogeneous progress in digitalisation not just between, but also within health systems' different areas of healthcare provision. A challenge common to all countries involved in the roundtable series is that the electronic data that is available in various organisations and systems lacks the interoperability necessary to easily transfer, aggregate and process it for secondary purposes. Healthcare institutions in particular lack the capacity, personnel and specialised skills to standardise, extract and transfer data from often disparate information systems, and will be challenged to build these up in a context of chronic staff shortages and resource constraints. More generally, the skills gap that Europe will have to contend with as it moves forward in the implementation process ranges from the technical qualifications of various kinds of data specialists, through legal and data protection expertise, all the way to interdisciplinary profiles capable of interfacing between the fields of medicine, nursing, IT, cybersecurity, data science, ethics and social science. Health data access bodies will have an essential advisory and supportive role to play with data holders and data users alike, and should plan their capacity-building and skills acquisition accordingly. However, significant long-term investments will equally be necessary to develop an appropriate educational offering capable of enabling competent interaction with the EHDS and creating a sustainable pipeline of talent for its operation in the future. Various successful examples of regional, national and European data-sharing, upskilling and reskilling initiatives (e.g. partnerships under European Pact for Skills) were highlighted as possible templates or building blocks for the design of a functioning EHDS infrastructure, while the pharmaceutical, medical device and digital health industries could contribute with their expertise and financial capabilities to its implementation.

Solutions should aim to

- **Build a effective EHDS infrastructure**
- **Support capacity-building of Member States and data holders**
- **Enable data users to interact competently with the EHDS**
- **Bridge the skills gaps across society**

Key actors, findings and solutions for implementation

At a European Union level

Draw on the experience and expertise from fields like epidemiology, genetics and radiology regarding proper use of large datasets and design an integration path for the data already available in these specialities.

Support universities and leverage available training offers and reskilling initiatives at EU and national level, including existing career change and professional development pathways within health systems, to develop and source the technical skillsets needed.

Invest and build capacity to reduce the digital divide and related barriers that limit equitable access to digital infrastructures and participation within and between Member States.

Develop educational materials and programmes to strengthen health data literacy among patients and citizens.

At national and regional levels

Accelerate the rollout of interoperable EHRs where necessary, promoting the adoption of minimal EHR requirements to enable a smooth connection with national health data access bodies and aligning technical language changes in new and existing systems across the EU.

Ensure modernisation of data infrastructures in healthcare to improve interoperability and connectivity between health institutions and with health data access bodies.

Enable collaboration between the digital/IT industry and EHDS stakeholders to accelerate necessary upgrades to data infrastructure.

Health data access bodies[1]

Enable and support informational technology / open source providers to develop transnational IT infrastructure and tools for the EHDS including information portals and user-friendly access request interfaces.

Build capacity to support data holders with data cataloguing, extraction and handling, data counselling/advice on data quality and accessibility, including good practice sharing between countries and regions.

Develop information material on the possibilities for secondary use, including scenario-based data access guidance for users and ethics committees, as well as supporting documentation and training for data permit applications.

Build capacity to assess complex data requests and the security and privacy risks they pose.

Establish a support function to guide data users through the application and use process.

In addition to the public health data catalogue, develop a public catalogue of secondary use projects to enable cross-border synergies and collaborations at scale.

Health institutions

Build the right capacity for data gathering in healthcare workflows, automating primary data collection and improvement processes as much as possible with technological solutions.

Upskill current staff and develop career pathways promoting skills acquisition and development for data management and data science.

Cooperate with health professional organisations, associations and medical scientific societies and form coalitions to develop capacity and skills for the EHDS and lead change in professional communities.

Higher education providers

Develop micro-credential courses to train data holders in the health domain on the requirements of the EHDS, the local/regional implementation choices, health data access bodies and the procedures and technical frameworks implemented in each Member State.

Train researchers in the same stringent data security principles as healthcare professionals.

Integrate training in digital health and digital literacy, including a solid understanding of the EHDS and health data, in medical schools and other faculties concerned by the changes: e.g. public health, engineering, pharmacy, health sciences.

Develop education on new business models related to data spaces in general, and health data spaces more specifically.

Develop curricula to train specialised new profiles such as health data scientists, healthcare data specialists, health data managers, etc.

Develop upskilling and reskilling offers beyond universities, for example in the form of continuous professional development courses

Digital health and medical devices industry

Develop health information tools around the principle of entering data only once, with more user-friendly interfaces that allow a holistic view of the patient and user-friendly access for patients.

Support the creation of data storage and processing environments with strong cybersecurity.

1. According to the European Commission EHDS first regulation proposal, the health data access bodies are set up by the EU Member States to provide access to electronic health data to third parties for secondary use in secure way, either as a new organisation or part of an existing organisation, building on the Data Governance Act.

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