

ACTIONABLE RECOMMENDATIONS FROM THE
EIT HEALTH THINK TANK ROUND TABLE SERIES

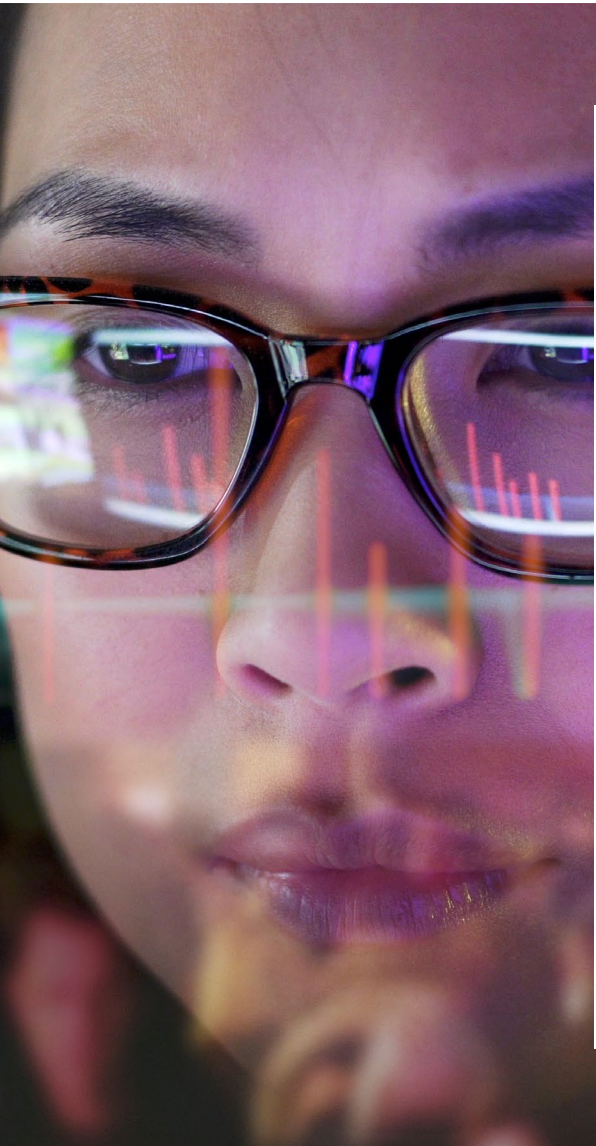
Strengthening data quality, governance, security and interoperability



Health data in many countries often exists in silos which is primarily a reflection of the personal nature of health data and the desire to maintain data privacy and security. As a result, there are often barriers to accessing health datasets to test AI applications, and the process can be slow.

The majority of the Round Table Meetings highlighted the need for greater collaboration between stakeholders involved in AI implementation to help overcome these barriers. Alternatively, it was suggested that a federated learning approach might be of value for testing in some cases.

Data Saves Lives aims to raise awareness amongst citizens and patients.



Case studies:

Successful, secure sharing of health data

[DataFair](#) is supported by Innovation Fund Denmark (Innovationsfonden) and works to collect data and make it commercially available in an ethically responsible way. The aim is to create secure and anonymous access to health data where projects are carried out in collaboration with both public and private actors.

'[Registration at the Source](#)' (Registratie aan de bron) is an initiative in the Netherlands which aims to improve healthcare provision through clear and standardised recording of citizens' care information and facilitating its reuse.

In Denmark, [Tværspor](#) is a research project that gathers data across a wide range of actors to gain insight into inappropriate hospital admissions and readmissions. It has developed a security model that showcases how the project solves the legal requirements under data protection legislation, regulation and health law.

Round Table Participants called for EU guidance on common standards for data management, infrastructure, maintenance, storage, access, anonymisation, governance, and security. At the Round Table in Ireland it was suggested that national bodies could be created within Member States to act as guardians of citizens' health data.

Interoperability of systems and data is also considered key. However, interoperability is recognised as more than just

connectivity, it should set out an agreement for the registration and coding systems to standardise data interpretation.

Round Table participants highlighted several ongoing initiatives that might be beneficial examples in this context, including the European Commission's New [European Interoperability Framework](#) (EIF).

Similarly, it was suggested that global interoperability standards, such as those

developed by [Fast Healthcare Interoperability Resources](#) (FHIR) for passing healthcare data between systems, should be encouraged and implemented.

Uniform standards for data acquisition and usage, resulting from international nomenclatures that have been introduced, such as [LOINC](#) or [Snomed CT](#), were recognised as an important prerequisite for interoperability and networking.

“ In my opinion, the biggest barrier to adoption of AI in healthcare is actually the lack of electronic systems. Many are still paper-based and hospitals that are entirely electronic, are the exception. When you have a paper-based system, it's much harder to analyse the data. This can mean that people in different departments of different hospitals are working in silos. It's much more difficult to collaborate and small projects, even if successful, fail to scale up. ”

Donal Sexton, Adjunct Assistant Professor, Clinical Medicine, Trinity College Dublin, Ireland

[EHAction](#), a joint collaboration programme between EU Member States, is developing its [Interoperability Guide](#) which is currently under consultation with expected delivery in Spring 2021. EHAction supports the [eHealth Network](#), a voluntary network that aims to ensure the progress of digital health and to bridge the gaps between the European Commission's governance strategy and operational implementation.

The Interoperability Guide is intended to assist healthcare providers when planning and procuring standards-based interoperable solutions.

It was suggested that the value of sharing and reuse of health data should be communicated to patients and citizens and data donation should be encouraged. An example of this is the [Data Saves Lives](#) initiative.

Led by the [European Patients' Forum](#) (EPF) and the [European Institute for Innovation through Health Data \(i~HD\)](#), [Data Saves Lives](#) aims to raise awareness amongst citizens and patients of the importance of health data and the benefits of responsible sharing and use.