



White paper

European Health Data Space in Portugal

April, 2024

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Context

This white paper, prepared by LabToMarket at the request of EIT Health Innostars, presents a comprehensive study on the current status of European Health Data Space (EHDS) implementation in Portugal.

About EIT Health

EIT Health is one of nine Knowledge and Innovation Communities (KICs) of the European Institute of Innovation and Technology (EIT), an EU body. EIT Health is an Institutionalised Partnership under Horizon Europe's Pillar III – Innovative Europe. Established in 2015 to tackle the societal challenges of health, demographic change and well-being within the EU, its mission is to help overcome the well-known EU paradox whereby state-of-the-art education, excellent research and a dynamic industry seldom turn breakthrough ideas into new transformative products and services. Within the EIT Health network, 120 partner organisations and institutions from academia, business, research and healthcare delivery collaborate across disciplines, borders and sectors to reinforce excellence, create knowledge and innovation, and encourage greater investment in innovation that delivers the outcomes that matter to citizens and patients.

About LabToMarket

LabToMarket is a strategic consultancy that drives innovation forward and works as a one-stop-shop that helps start-ups, researchers and clinicians, successfully launch their healthcare innovations into the market. Also, with a vision that promotes a symbiotic relation between healthcare, Innovation, policy-makers and industry, LabToMarket specialises in multi-stakeholder projects, having developed programs for both public and private organisations at national and European levels.

Introduction: Setting the Scene

On May 3rd 2022, the European Commission published a proposal for a regulation to create a European Health Data Space (EHDS). The proposal is the first of nine European sector- and domain-specific data spaces set out by the Commission in its 2020 communication, "A European strategy for data". EHDS focuses on establishing a unified framework for health data across Europe.

The Council agreed on its mandate for negotiations on December 6th 2023. Almost 2 years later, on March 15th 2024, the Council of the EU and the European Parliament reached a provisional agreement which was officially approved on April 24th 2024.

The aim of the EHDS is to make it easier to access and exchange health data across borders, both to support healthcare delivery ("primary use of data") and inform health research and policy-making (re-use of data, also referred to as "secondary use of data").

Objectives

In this landscape, EIT Health Innostars can and should play an active and supportive role in guiding member states toward agile and sustainable integration into the EHDS.

With these objectives in mind, this white paper aims to be an [all-in-one resource for stakeholders](#) in the Portuguese health data ecosystem that everyone can consult to learn what EHDS is, its objectives and its status in Europe and Portugal. Moreover, it aims to outline [actionable steps](#) that national organisations and entities within the health data space in Portugal can take to align with European guidelines and ensure successful integration.

Finally, this study aims to highlight the [pivotal role that EIT Health Innostars](#) can play in driving transformative healthcare initiatives and promoting Portugal's readiness within the EHDS framework.

Methodology

To achieve these goals, the methodology adopted comprised the following steps:

- > [Literature review](#): research on EHDS and the state-of-the-art throughout Europe, as well as the initiatives promoted by EIT Health Innostars.
- > [Expert interviews](#): identification of an expert panel to collect personalised insights into the Portuguese health data ecosystem and benchmark with other member-states. This panel includes four experts representing stakeholders in the health data space within Portugal and one international expert from Estonia:
 1. Representative of a public hospital
 2. Representative of a private hospital
 3. Representative of a governmental entity and specialised in cybersecurity
 4. Profile with expertise in literacy and research in public health
 5. Profile with expertise in implementing EHDS in Estonia, with pan-European experience
- > [Systematic analysis of interviews](#): conduct a comprehensive mapping of the Portuguese landscape to assess the level of preparedness and integration of the Portuguese system within EHDS.
- > [Identification of challenges and recommendations](#): identification of current and future challenges, along with recommendations to overcome and mitigate them and outlining their potential impact.

1 | Background: Understanding the EHDS

Genesis

The European Data Strategy of 2020 established a roadmap for the European single market for data - a common framework for data sharing within the EU. To achieve these policy goals, the EU passed the Data Governance Act and Data Act, which facilitates the development of European Data Spaces across strategic sectors, including the Health sector [1]. In May 2022, Vice-President of the European Commission, Margaritis Schinas and Commissioner for Health and Food Safety, Stella Kyriakides, jointly announced the launch of the European Health Data Space (EHDS) proposal [2].

Objectives and proposals

The EHDS aims to advance how healthcare is provided across the EU, by empowering patients and citizens to control and use their health data. It aims to foster a single market for digital health services and products, and a framework to use health data for research, innovation, policy-making and regulatory activities while ensuring full compliance with the EU's high data protection standards [2]. Figure 1 overviews the EHDS concept, its objectives, scope, means, and expected impact.

The EHDS seeks to provide rules, common standards and practices, infrastructures and a governance framework for both primary use (using personal electronic health data to provide health services to an individual) and secondary use

(using electronic health data for broader needs, such as health research or public policy) of public health data. To that end, EHDS:

- > Strengthens patient control over their data;
- > Establishes rules for electronic health records (EHR) systems to promote reliability, security and interoperability;
- > Sets rules for the secondary use of health data;
- > Establishes mandatory cross-border infrastructures, one for primary use and the other for secondary use.

MyHealth@EU and HealthData@EU are key data intermediary platforms for implementing the EHDS, promoting the sharing of personal and non-personal data generated while using digital devices and related services, including medical equipment and wellness devices [3].

- > For the primary use of data, the regulation calls on Member States to develop electronic health records services at a national level and to allow the exchange of patients' data through the infrastructure MyHealth@EU.
- > For secondary use, the cross-border data exchange in Europe would be done through the infrastructure HealthData@EU and a single data permit.

Stakeholders relations and benefits

The way data can be accessed and used is often defined by the role of the user within the healthcare system. In this way, to better understand the benefits that the EHDS proposed to bring, it is useful to understand the stakeholders involved,

OBJECTIVE			
Effective use of health data			
SCOPE			
Primary Use of health data.		Secondary Re-use of health data.	
MyHealth@EU <ul style="list-style-type: none"> > Empower individuals to control their data. > Standardisation and mandatory certification of EHR systems. > Voluntary labelling of wellness apps. > European Electronic Health Record Exchange Format (EEHRxF). 		HealthData@EU <ul style="list-style-type: none"> > Health data access bodies. > Purposes for use and forbidden use. > Data security. 	
MEANS			
Legal/governance	Quality of data	Infrastructure	Capacity building/digitalization
EXPECTED IMPACT			
<ul style="list-style-type: none"> > Single market for health data > Free movement of people in EU > Data protection > Digital goods and services 		<ul style="list-style-type: none"> > More opportunities for research and innovation > Better policy making 	

Figure 1 - EHDS overview.

their roles and the relations between them.

Figure 2, illustrates the categories of stakeholders that play action within the EHDS: citizens, healthcare professionals, policy-makers and regulators, industry and innovators, and researchers.

Some of these players will have a commercial interest in the data through direct revenue generation or as the holder of a fiduciary duty of care within a public healthcare system, while others will have non-commercial roles in the public sector, but will nonetheless be focussed on generating value from data.

These roles are not static, since a healthcare professional may also be a researcher, and a patient can be an active data provider when data are collected by a personal device or a passive data provider through an interaction with a healthcare professional. Identifying and understanding these relationships is important as it impacts the regulations, policies, and practices that must be considered [4]. Implementing the EHDS is expected to benefit each ecosystem's stakeholders by fostering relationships between them.

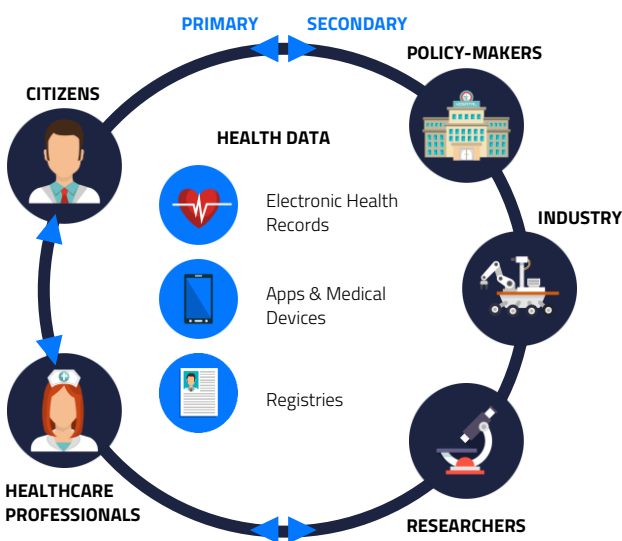


Figure 2 - Relations between stakeholders in EHDS.

2 | Problem Framing: Addressing the Challenges

A key step in building the EHDS is creating a governance framework adapted to the special characteristics of health data and the needs of all players and stakeholders who wish to use health data and benefit from it. However, for the benefits to be fully felt, the European Union depends on the cooperation of all member states so that today's challenges regarding health data management can be tackled.

Table 1 - Challenges and limitations regarding health data management from stakeholders' perspective.

	PROBLEM	LIMITATIONS
INDIVIDUALS	Difficulty accessing and controlling their health data.	<ul style="list-style-type: none"> > Add information and rectify errors > Access and share health data electronically, immediately, for free. > Monitor and restrict access to personal data > Share data with healthcare professionals to support medical decisions > Fewer unnecessary exams
HEALTHCARE PROFESSIONALS	Difficulty accessing health data.	<ul style="list-style-type: none"> > Sharing data between healthcare providers (nationally and cross-borders) > Better treatment and diagnosis supported by more relevant data > Second advice via telemedicine > Savings of hospital expenditure and fewer unnecessary exams > Fewer manual data input
POLICY-MAKERS	Difficulty accessing non-identifiable health data.	<ul style="list-style-type: none"> > Better policy-making supported by more relevant data > More resilient and efficient health systems > Lower costs
INDUSTRY	Barriers to developing and providing digital health services and products.	<ul style="list-style-type: none"> > Greater availability of health data to support new and better medicinal products and medical devices > Access to EU-wide market for EHR systems with same standards
RESEARCHERS	Research and innovation based on limited health data.	<ul style="list-style-type: none"> > Greater availability of health data to support new and better medicinal products and medical devices > Easier access to larger amounts of data, more effectively and less expensively.

Status in the European Union

To overcome these challenges and barriers, since 2021, the EU member states have been connecting to the infrastructures of MyHealth@EU and HealthData@EU.

MyHealth@EU

MyHealth@EU is the eHealth Digital Service Infrastructure (eHDSI) that ensures the continuity of care for European citizens while travelling abroad in the EU. This allows EU countries to exchange health data securely, efficiently and interoperably [5].

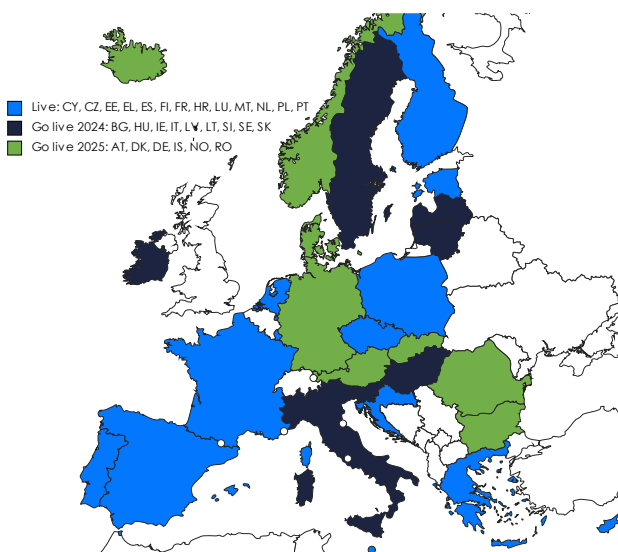
The electronic cross-border health services that are currently being introduced in all EU countries are:

1. **ePrescription and eDispensation**, which allow EU citizens to obtain their medication in a pharmacy located in another EU country, different from their country of residence.
2. **Patient Summaries**, that provides doctors with essential information in their own language concerning the patient (e.g., allergies, medication, previous illness, etc.) when the patient comes from another EU country and there may be a linguistic barrier.

These services are expected to be expanded to include laboratory results, medical images and imaging reports, and hospital discharge reports from 2024 to 2026.

The new electronic cross-border health services are being established progressively in 25 EU countries until the end of 2025 [6]. According to the 24th eHealth Network Meeting in June 2023, 11 Member States were currently connected to MyHealth@EU and providing these services [7]. Figure 3 illustrates the play status of MyHealth@EU. Up to date, on the Europa webpage [5], 13 countries are already reported as having launched one or both of these services.

Figure 3 - Play status of MyHealth@EU among the Member States.



HealthData@EU

HealthData@EU is a 2-year project, launched in October 2022, to build a pilot version of the EHDS infrastructure for the secondary use of health data to serve research, innovation, policy-making and regulatory purposes. The project brings together 17 partners from different member states that will collaborate closely with the European Commission [8].

- > The pilot will design, develop, deploy and operate a network of nodes (representing different data brokers, holders and data consumers) supported by central services that will be provided jointly by the Member States and the European Commission.
- > Currently, the pilot involves 8 nodes: Germany, Denmark, Finland, France, Belgium, Norway, Croatia and European Research Infrastructure.
- > Post-pilot, the aim is to expand this infrastructure to all EU Member States, enhancing collaboration and data integration across the EU [9].
- > In this context, the QUANTUM project, funded by Horizon Europe, is ongoing. It aims to develop a data quality and utility label for HealthData@EU, providing member states with a standardized tool for labeling health data sets. This action involves a consortium of several countries, including Portugal [10].

To illustrate the feasibility and potential of reusing data from several countries, the project will run 5 use cases that encompass a wide range of research and policy [11].

Recent developments

In December 2023, the European Council approved the mandate for negotiations with the European Parliament on an EHDS legislative proposal [12]. After almost 2 years of conversations, on March 15th 2024, the Council and the Parliament reached a provisional agreement on a new law that will allow patients to access their health data wherever they are in the EU, while also providing scientific research for important reasons of public interest with a wealth of secure data that will greatly benefit the development of health policies [13]. Under this proposal and agreement:

- > **MyHealth@EU** infrastructure, will be expanded with the mandatory establishment of a digital health authority

Table 2 - Availability of MyHealth@EU services between EU member states [14].

ePRESCRIPTION / eDISPENSATION	PATIENT SUMMARY
<ul style="list-style-type: none"> > ePrescriptions of Portuguese citizens can be retrieved in pharmacies in: Estonia, Finland, Croatia, Spain, Poland. > Pharmacies of Portugal can dispense ePrescriptions presented by citizens from: Finland, Croatia, Estonia, Spain. <p>41 member pharmacies in Portugal</p>	<ul style="list-style-type: none"> > Health data of citizens from Portugal can be consulted by doctors from: Malta, Croatia, Luxembourg, France, Czech Republic, Spain, Estonia, the Netherlands. > Doctors from Portugal can access health data of citizens coming from: Malta, Croatia, Czech Republic, Spain, Estonia, Luxembourg. <p>37 member hospitals in Portugal</p>

to ensure the conformity of EHR systems before being placed on the market [12]. Thus, citizens' access to electronic health data will be easier, ensuring quality, security and privacy while sharing information [13].

- > **HealthData@EU** infrastructure will be set up to support cross-border access to secondary use of health data [15]. At national level, it will be required to set up health data access bodies (HDABs) that will review requests for access to data and issue data permits. Also, to reduce the administrative burden, member states may establish trusted data holders that can securely process requests for access to health data (and that communicate with the HDABs) [13].

Currently, the level of digitalisation of health data in the EU varies from one member state to another, making it more difficult to share data across member-state borders. The proposed regulation requires all electronic health record (EHR) systems to comply with the specifications of the European electronic health record exchange format (EEHRxF), ensuring that they are interoperable at EU level [13], [15].

More recently, on April 24th 2024, the European Parliament finally approved the creation of EHDS [16], confirming that:

- > Citizens will have access across the EU to an EHR containing prescriptions, imagery and lab tests.
- > Anonymised health data will be shared for research e.g., into rare diseases.
- > Strong privacy guarantees will govern how sensitive data is shared and for what purposes.

Current state in Portugal

Over the last two years, the Portuguese entity of Shared

Services of the Ministry of Health (SPMS) has taken part in meetings, analysing and discussing the proposals between member states to guarantee citizens' rights regarding their health data [17].

MyHealth@EU

Portugal has adopted an electronic health data sharing structure for several years, under the MyHealth@EU, allowing for the cross-border exchange of both ePrescription / eDispensation and Patient Summary [5]. As shared by Jéssica Domingues, a Cybersecurity Expert from SPMS, *“this infrastructure is already aligned with the best reference practices of information security and cybersecurity, as well as EU regulations and guidelines.”*

Also, regarding the primary use of data, *“it recently became possible for any private laboratory operating under an agreement with the NHS to share structured laboratory test results with primary health care units”.*

HealthData@EU

Portugal is not part of the HealthData@EU pilot consortium [8]. However, in line with the European project but at a national level, SPMS is coordinating the HealthData@PT project [18]:

- > A 4-year project (2023 - 2027) co-funded by the EU that aims to implement the national infrastructure, network and fundamental services needed to guarantee secure access and secondary use of health data.
- > The creation of this national body will be crucial to guarantee Portugal's future integration into cross-border infrastructures for sharing health data for secondary use, such as HealthData@EU.

- > HealthData@PT will “leverage and prompt the expansion of the data lake solutions being currently implemented in Portugal, which among other services, comprise a massive repository of health data transversal to the NHS”, according to Jéssica Domigues.
- > On the data quality enhancement, advances in HealthData@PT outcomes will be driven by the ongoing efforts in the QUANTUM project, in which SPMS takes part [10].

Addressing the challenges in Portugal

In addition to the frameworks promoted at the European level for adoption by all member states, each country's specific circumstances significantly impact its readiness to implement the EHDS.

In order to thoroughly assess Portugal's readiness across various dimensions - such as infrastructure, hospital information systems and literacy levels among citizens and healthcare professionals - five key stakeholders were interviewed.

The collected insights provide a more comprehensive view of Portugal's current status, its readiness and some ongoing initiatives aligned with the EHDS objectives:

- > The **national EHR system** and the **high digitization and digitalisation level in healthcare** make Portugal one of the most prepared countries to integrate EHDS. Furthermore, there is a national initiative that comprises the regulation of a universal EHR with information from public and private hospitals.
- > SPMS is implementing a **health data lake** and a portal for managing data access applications. Just like some hospitals, as ULS Coimbra, that is creating a data lake that aligns with key measures, incorporating PROMs, PREMs, varied patient conditions and telemonitoring for chronic diseases.

“These initiatives underscore our commitment to a VBH [Value Based Healthcare] model, focused on ensuring our IT infrastructure and data management systems are compliant with EHDS standards and optimised for future scalability and interoperability.

— Alexandre Lourenço
CEO at ULS Coimbra

- > Despite the **strong innovation ecosystem** – great innovators, disruptive startups, and incredible human capital full of scientific quality and creative minds – the general **literacy in health and data management** is not very high among the most important stakeholders.
- > Regarding **financial incentives and guidelines** for EHDS implementation, there seems to be no equality between the support given to public and private organisations. Public hospitals have been receiving incentives from government and EU funding streams, while private hospitals do not report any contact with the organising entities.

“We have a great ecosystem, with great innovators, very disruptive startups, and an incredible human capital (...). The blend is perfect to generate an amazing country-size lab for new approaches to healthcare.

— Sofia Couto da Rocha
Chief Transformation Officer at Lusíadas Saúde

With a focus on addressing the challenges more frequently reported, the status of Portugal can be grouped into four main areas, each encapsulating specific issues:

- > **Literacy & public awareness:** low health, digital, and data management literacy among the general population, alongside inadequate training of healthcare professionals in collaborative data usage processes and lack of trust in accessing patient data.
- > **Infrastructure:** need for a robust infrastructure for secondary data sharing, which is critical for ensuring data protection, privacy, and efficient health information exchange across various healthcare settings.
- > **Data management:** issues with interoperability, system integration, and the secure data flow among information systems. Additional concerns include ensuring privacy, obtaining proper consent, and establishing robust encryption mechanisms to protect citizens' identities.
- > **Stakeholder engagement & leadership:** need for more effective stakeholder engagement and role-orientation. Challenges also include difficulties in aligning national health policies with EHDS specifications and the necessity for a long-term vision aligning with human resource availability and sustainable financing.

3 | Solution Overview: Charting the Path Forward

The previous section identified the current and potential future challenges and obstacles related to integrating the Portuguese system with the EHDS. The next step is exploring possible solutions to overcome or mitigate these challenges effectively. Viewing limitations as opportunities for improvement paves the way for a more streamlined and successful integration into the EHDS.

This section proposes potential solutions/recommendations to address the challenges identified and outlined in the previous section.

Overcoming challenges

The actions presented are grouped by areas of operation, similar to the previous section structure. Additionally, each recommendation is accompanied by an assessment of its potential impact, providing valuable insights into its effectiveness. Finally, each area also includes possible partners that could play an active role in implementing each solution.

It is important to mention that the recommendations listed below are the outcome of a multi-stakeholder perspective, resulting from unique insights into the challenges of various sectors of the national health data ecosystem.

Literacy & public awareness

Recommendations:

- > Launch targeted awareness campaigns tailored to various sociodemographic groups of citizens about health data and its management.
- > Establish informational contact points/educators for citizens and also healthcare staff, where they can clarify their doubts or concerns regarding health data management (e.g., pharmacies, local health centres).

Impact:

- > Greater awareness and health, digital and data management literacy among general population.
- > Boost in understanding, trust and proactive engagement with EHDS by citizens and healthcare professionals.

Potential partners:

Government organisations such as the SPMS, DGS, ACSS and CNCS will have a very important role in disseminating information to citizens and health professionals. The curation and elaboration of content, as well as the strategic definition of the targets for each campaign, could be a joint effort by these entities in collaboration with universities that develop research in the area of public health and health data security and with policy-makers, supporting with fact-checking.



Building trust through communication and training can contribute to a more seamless integration of EHDS into healthcare practices.

— Sónia Dias

Dean at National School of Public Health (ENSP NOVA)

Infrastructure

Recommendations:

- > Digitise all healthcare processes, even the most basic ones (e.g., admin protocols).
- > Architect data systems that support secure and efficient data management tools (e.g., middleware).

Impact:

- > Streamlined healthcare operations that allow real-time access to health data.
- > Secure and efficient handling of sensitive data.

Potential partners:

Government organisations such as SPMS in collaboration with CNCS, have (and have had) a crucial role in creating a robust infrastructure that allows health data to be stored, used, and shared safely and effectively. In addition, IT experts from industry, academia and hospitals should be involved in the architecture process to guarantee a solution based on a wide range of expertise and capable of responding to the needs of all stakeholders who hold data.

Data management

Recommendations:

- > Develop a national interoperability platform that sets technical and semantic data-sharing standards.
- > Draw inspiration from sectors like banking, energy and education to implement secure data-sharing mechanisms for secondary purposes.

Impact:

- > Streamlined healthcare operations that allow real-time access to health data.
- > Robust architecture that enables seamless and safe use of health data.

Potential partners:

In addition to government organisations, such as SPMS and CNCS, it is crucial to involve IT experts from various sectors - public and private hospitals, to guarantee an appropriate response to the multiple information systems; from other industries where healthcare can get inspiration; from academia, who are aware of the most effective solutions and standards. It is also important to involve policy-makers, guaranteeing legislative alignment concerning data protection and sharing.

“ *The banking, energy and education sectors can act as references in implementing data sharing mechanisms and repositories for secondary treatment.*

— **Jéssica Domingues**
Head of Cybersecurity Unit at SPMS

Stakeholder engagement & leadership

Recommendations:

- > Create a multi-stakeholder committee to set roles in overseeing EHDS alignment strategies.
- > Harmonize national health policies with EHDS requirements.

Impact:

- > Foster a multi-perspective and comprehensive national healthcare ecosystem.
- > Streamline EHDS integration into the national healthcare system, making legal frameworks enablers of progress rather than barriers.

Potential partners:

National and european bodies such as SPMS and EIT Health should work together to promote communication between all stakeholders. Policy-makers should also be involved in the process, ensuring alignment between Portugal's legislation and EHDS.

EHDS action toolkit: a guide for stakeholders

Table 3 summarizes each area's recommendations, projected impacts, and potential partners that can carry out the implementation.

However, the purpose of this study extends beyond mere documentation – the goal is to empower all participants within the national ecosystem to actively engage with these recommendations and implement them within their organisations.

To promote this, a resource that works as a guide for stakeholders – easy to download and share - was developed. The “EHDS action toolkit” includes additional recommendations besides the ones previously presented.

Table 3 - Target recommendations and impact to address national challenges.

	RECOMMENDATION	IMPACT
Literacy & public awareness	> Launch targeted awareness campaigns and training on both general public and healthcare professionals.	> Knowledge increase
	> Establish informational contact points/educators for citizens and also healthcare staff.	> Trust
Potential partners: SPMS, ACSS, CNCS, DGS, academia, policy-makers.		
Infrastructure	> Digitise all healthcare processes, even more basic ones (e.g., admin protocols).	> Set the foundation
		> Traceability
Potential partners: SPMS, ACSS, CNCS, IT experts from hospitals, industry and academia.		
Data management	> Develop a national interoperability platform for data sharing standards and frameworks.	> Proactive defense
		> Accountability
Potential partners: SPMS, CNCS, IT experts from hospitals, academia and other industries, policy-makers.		
Stakeholder engagement and leadership	> Create a multi-stakeholder committee to oversee EHDS alignment strategies.	> Multi-perspective ecosystem
	> Harmonize national health policies with EHDS requirements.	> Streamline the integration of EHDS into the healthcare system
Potential partners: EIT Health Innostars, SPMS, ACSS, policy-markers.		

In turn, the recommendations are grouped by stakeholder/player, so that each reader can quickly know and bring actionable solutions to their organisations.

Feel free to access this guide and see how you can be involved. Use it to drive positive change and foster improvement and collaboration across the healthcare landscape.



EHDS Action Toolkit

https://bit.ly/ehds_pt

4 | Call to Action: Mobilising for Change

Sections 2 and 3 provided a better insight into the challenges faced in implementing the EHDS in Portugal and possible recommendations that could turn these barriers into opportunities driving the successful implementation of EHDS within the country.

In particular, as an European organisation dedicated to the health innovation sector, EIT Health can play a proactive role in this regard. Considering an effort/impact ratio, there are two critical areas where EIT Health's involvement can make a significant difference:

1. Creation of a national committee

With a diverse network, EIT Health is ideally positioned as the connector and coordinator to bring together a multi-stakeholder workgroup in Portugal. EIT Health could be crucial in identifying national stakeholders for inclusion in a newly formed committee. This agency would oversee and ensure the alignment of national strategies with the EHDS. The main objective would be to clearly define the roles and responsibilities of each entity and stakeholder, thereby establishing a robust leadership structure that facilitates effective implementation and oversight of EHDS initiatives across Portugal.

2. Driving a literacy program

EIT Health is well-positioned to spearhead the development of a literacy program tailored to specific segments, including citizens and healthcare professionals. This initiative would enhance collaboration and build trust in adhering to EHDS standards, both by those who provide and use the data. By leveraging its European network, EIT Health could actively map key stakeholders and co-design the program content, drawing upon best practices at a European level. This strategic approach would facilitate widespread understanding and effective implementation of EHDS across Portugal.

“Public awareness and collaboration are essential for the successful implementation of EHDS.”

— Ain Aaviksoo

eHealth expert from Estonia

Conclusion

The EHDS represents a transformative initiative to streamline access to health data across borders for healthcare delivery and research. However, both at the EU level and in Portugal, numerous challenges must be addressed to fully integrate within this framework.

This white paper has comprehensively analysed the EHDS landscape in Portugal, synthesizing key findings and providing actionable insights to address challenges and enhance readiness. Through this collaborative effort, stakeholders can better understand their role in aligning with EHDS guidelines.

Outputs

As key outputs of this white paper:

- > [Strategic and specific recommendations](#) for the areas within the national health data space.
- > [“EHDS toolkit: a guide for stakeholders”](#), featuring concrete recommendations tailored to different stakeholders or players.
- > [A potential role for EIT Health Innostars](#) in driving the implementation of these measures.

Statement of EIT Health Innostars

“It is clear from the study that Portugal has a series of conditions and ongoing programmes that position it as a developed country in terms of health data management. However, processes still need to be improved, such as the collaboration between stakeholders and the alignment of national health policies with EHDS goals.

Thus, with our extensive network of partners and expertise in fostering innovation, we are uniquely positioned to catalyse collaboration among Portuguese healthcare stakeholders, leveraging EHDS to its fullest potential.

In light of the pressing need for enhanced collaboration and commitment across the European healthcare landscape, EIT Health stands out as [the optimal, neutral platform for industry, hospitals and governmental agencies](#) to collaborate effectively, forging a cohesive task force dedicated to implementing the EHDS framework in Portugal.

Additionally, considering our European expertise in spreading information across several sectors, we believe that we can promote more [tangible initiatives, such as health and digital literacy training for patients and healthcare professionals](#) to ensure the engagement of all citizens towards the EHDS initiative in Portugal.”

— **Marta Passadouro**

Ecosystem Lead of Portugal at EIT Health Innostars

“The European Commission has [recognised EIT Health's capabilities and entrusted us with the pivotal role of spearheading the implementation of the EHDS](#) across all territories. This acknowledgment underscores our commitment to advancing cross-border healthcare and maximising the impact of EHDS on research, innovation, and, ultimately, improving healthcare outcomes for citizens across Europe.”

— **Ferenc Pongracz**

Deputy Managing Director at EIT Health Innostars

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Feel free to access this guide and see how you can be involved.
Use it to drive positive change and foster improvement and
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