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Are EU member states ready for the European Health Data Space? Lessons learnt on the secondary use of health data from the TEHDAS Joint Action

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Abstract

The proposal for a regulation on the European Health Data Space (EHDS) contains provisions that would significantly change health data management systems in European member states (MS). This article presents results of a country mapping exercise conducted during the Joint Action 'Towards the European Health Data Space' (TEHDAS) in 2022. It presents the state-of-play of health data management systems in 12 MS and their preparedness to comply with the EHDS provisions. The country mapping exercise consisted of virtual or face-to-face semi-structured interviews to a selection of key stakeholders of the health information systems. A semi-quantitative analysis of the reports was conducted and is presented here, focusing on key aspects related to the user journey through the EHDS. This article reveals a heterogenous picture in countries' readiness to comply with the EHDS provisions. There is a need to improve digitalization and quality of health data at source across most countries. Less than half of the countries visited have or are developing a national datasets catalogue. Although the process to access health data varies, researchers can analyse health data in secure processing environments in all countries visited. Most of the countries use a unique personal identifier for health to facilitate data linkage. The study concluded that the current landscape is heterogeneous, and no member state is fully ready yet to comply with the future regulation. However, there is general political will and ongoing efforts to align health data management systems with the provisions in the EHDS legislative proposal.

Introduction

The COVID-19 pandemic reinstated public health in the European Union's (EU) political agenda and highlighted the need for a resilient and coordinated European Health Union [1, 2]. Effective responses to public health emergencies need to be evidence-based and resulting from collaborative efforts across EU member states (MS). The prerequisite for evidence-based solutions is to have access to evidence and, in this case, health-related data. Additionally, collaborative efforts require a structured network of EU MS [1, 2]. Although healthcare is mostly an MS competence, public health has been a shared competence between the EU and MS since the 1990s [2, 3]. Moreover, the EU digital COVID-19 certificate [4] is an example of MS recognizing the importance of a coordinated response at EU level and requesting support from the European Commission (EC).

The longer-term response for a more resilient and coordinated European Health Union started with the State of the Union address from the President of the EC, Ursula von der Leyen, on 16 September 2020, announcing a new legislative proposal to create a European Health Data Space (EHDS). This address followed a mission letter to Commissioner Stella Kyriakides stating the mission to 'work on the creation of a European health data space to promote health-data exchange' [5]. The EHDS also follows the European data strategy adopted in February 2020, in which the EC stressed the importance of creating nine European data spaces [6].

In May 2022, the EC published a proposal for a regulation on the EHDS. It aims to ensure that citizens have access and control over their health data and to facilitate reuse of health data for research, innovation, and policymaking [7]. The proposal is organized in two parts; the EHDS for primary use and chapter IV on secondary use of electronic health data. Primary use refers to the use of health data for healthcare purposes and continuity of care, using the MyHealth@EU infrastructure. Secondary use refers to the reuse of electronic health data for any purpose other than the one they were initially collected for, through the HealthData@EU infrastructure [8].

To support the drafting of the legislative proposal and the subsequent negotiations with co-legislators, the EC performed an impact assessment [7] and funded the Joint Action 'Towards the European Health Data Space' (TEHDAS) to identify needs and views of MS on secondary use of health data, through research studies [9]. One of these was the country mapping exercise presented in this article.

The objectives of this exercise were:

(1) To map the state-of-play of the national health data management systems in relation to the secondary use of health data.
(2) To provide MS an opportunity to voice their needs and expectations on the reuse of health data and how the EHDS regulation could respond to them.

This study was conducted from December 2021 to December 2022, in the form of country visits in which national stakeholders working with, or exchanging, health data were interviewed (virtually or face-to-face).

This article presents the methodology and results, providing an overview of the current state-of-play of the health data management system in 12 EU MS, and their needs and expectations regarding the EHDS legislative proposal for secondary use. The semi-quantitative analysis of the results focuses on the following overarching themes:

digitalization of health records, findability, accessibility, interoperability and identification of health records, secure processing environments (SPEs) for analysis, and, finally, needs and expectations from the EHDS.

Methods

Expression of interest

A call for expression of interest was launched among the TEHDAS partners. 12 countries volunteered for the country mapping exercise. These countries covered all four regions of Europe as defined by the United Nations geoscheme, ensuring comprehensive continental coverage (see Fig. 1) [10].

Preparation of the TEHDAS mapping tool

A tool was developed to guide the semi-structured interviews. The tool includes guiding questions regarding the health data management system on the following topics: Data collection, data storage, data infrastructure, data access procedures, metadata, capacity building, technical, financial, and human resources needs, and needs and expectations from the EHDS. To develop this tool, several health information system assessment tools were examined, such as the WHO Regional Office for Europe's 'Support tool to strengthen health information systems', the 'HIS Stages of Continuous Improvement Toolkit', the 'Health Information Systems Interoperability Maturity Toolkit', and the 'Joined Up Data Maturity Assessment' [11–15]. The TEHDAS tool is available in the Supplementary files.

Five-step process of a country visit

The methodology for the country visits consisted of five steps:

(1) **Selection of key stakeholders**
With the help of a country contact person, stakeholders were identified to be interviewed. The aim was to select a broad range from healthcare providers, researchers, biobanks, private companies to regulators, insurance companies, and standardization agencies, to provide a clear picture of the health data management system. The number of stakeholders interviewed varied between MS depending on the availability of stakeholders to be interviewed and differences in the health information system structure (Fig. 1).
(2) **Preparatory desk review**
Prior to the country visit, the interviewers reviewed relevant documents and results from previous reports, such as the Health Systems in Transition reports [16] and OECD reports [17].
(3) **Semi-structured interviews**
Due to the COVID-19 pandemic, half of the country visits took place online. Every semi-structured interview started with a short presentation of the scope of the visit and an explanation that the interview was not recorded, the interviewee would not be identified in outputs, nor would any personal information be collected or shared. The interviewers then led the discussion using the TEHDAS tool.
(4) **Multi-stakeholder meeting**
At the end of the interviews, all stakeholders were invited to a 1-h meeting where initial findings for the country were presented. This meeting was an initial cross-check to cover any gaps and avoid misinterpretations.

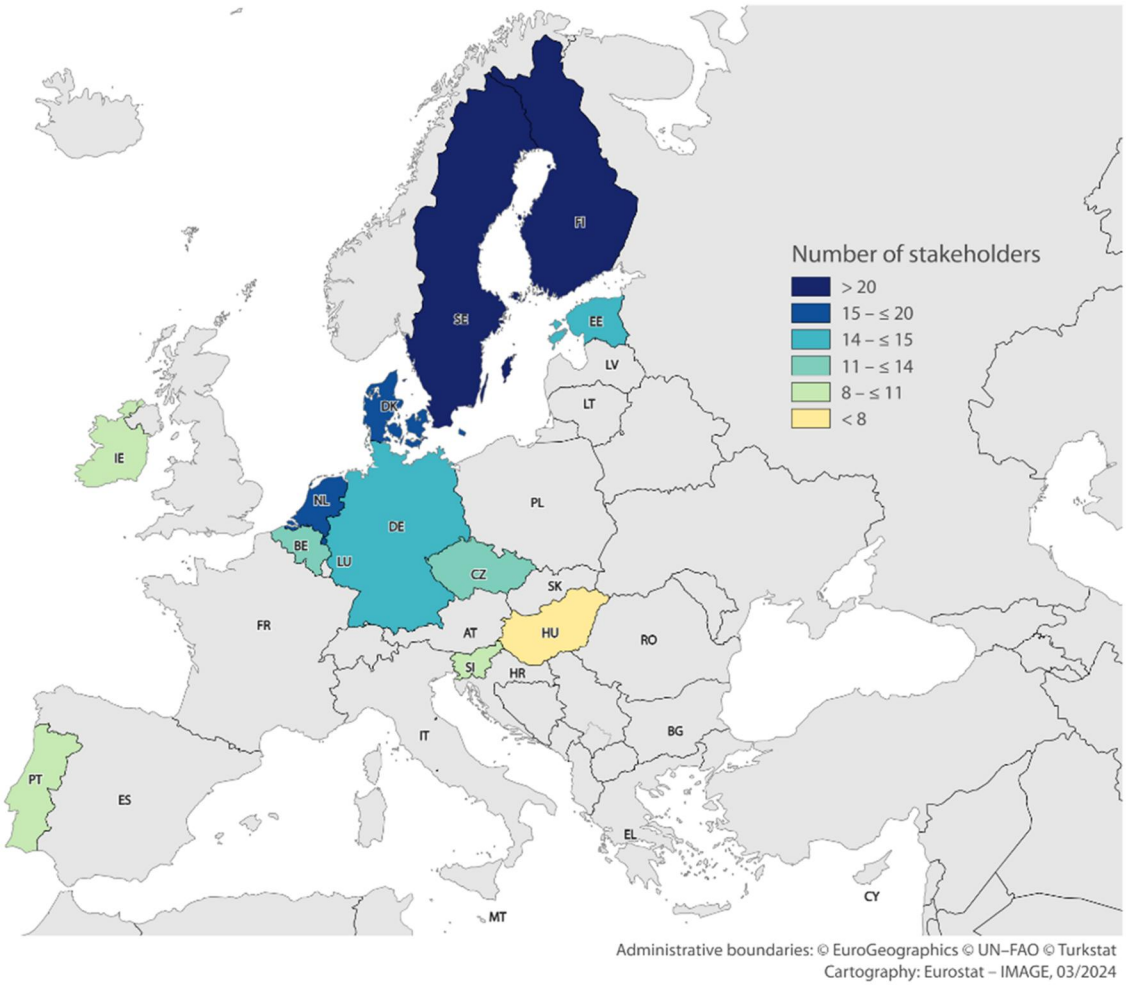

Figure 1. Representation of the countries visited and the number of stakeholders interviewed per MS.

(5) **Results dissemination**
A detailed confidential report and a shorter publicly available country factsheet were produced for each country. The reports included a detailed overview of the current situation, organized in line with the themes in the TEHDAS tool. Both the detailed report and the factsheet were sent to the country contact person, and all stakeholders were interviewed for approval before dissemination.

Data analysis

The findings presented below are a result of a semi-quantitative analysis of the 12 detailed reports that were drafted after the interviews but not published. All reports were reviewed, focusing on specific themes to identify alignment of the 12 MS with the provisions in the legislative proposal for the EHDS. The themes were selected to cover the main steps of the user journey through the EHDS and the essential provisions that MS need to comply with for the user journey to succeed [18]. In addition, as the objective was to support the drafting and negotiations, TEHDAS was also tasked to explore the challenges stakeholders are facing, their views and expectations for the EHDS, and the political preparedness for the EHDS. It is important to note that these findings represent a snapshot at a specific point in time and are based on the input from the stakeholders interviewed in the respective countries [11].

To create the colour-coded maps presenting aspects about the health data management system of the different MS, the Eurostat IMAGE programme was used [19].

Results

Each thematic subsection below briefly presents the relevant provision as mentioned in the EHDS legislative proposal [7], contextual background information, and the relevant findings from the country visits.

Digitalization of health records

The cornerstone for reuse of health data through the HealthData@EU infrastructure is storage and sharing of health data in an electronic format [7]. Therefore, we analysed the information from the country mapping exercise to visualize the state-of-play regarding digitalization of health records in different sectors.

Figure 2 shows the estimated level of digitalization in health records of the countries mapped by sector; whether it is private or public healthcare, in hospitals or in general practitioners. In most MS, health data from public hospitals and general practitioners was generally digitized. More specifically, reimbursement data from these sources is the type of health data the most often already digitized. However, 3 out of 12 countries had significant use of paper-based health records (for storage or sharing): Ireland, the Czech Republic, and Germany. In the Czech Republic, most healthcare providers have digital systems for storing health data but due to legislation and lack of interoperability, sharing of health data between healthcare providers usually takes place in paper format or through PDF reports.

Structure and interoperability between health records

Having digitalized data does not ensure that the data is structured and interoperable yet. Therefore, the mapping exercise explored the use of internationally recognized standards to structure electronic health records, organize datasets, exchange data, and structure descriptive metadata records. Stakeholders reported the use of both nationally developed and internationally recognized standards. Figure 3 shows the number of countries reporting the use of each internationally recognized standard. The most used standards for semantic interoperability were ICD-10 and SNOMED-CT. For data exchange, the most used standard was HL7 FHIR. Stakeholders often reported the need to use a combination of standards since no classification covers the needs of every health-related field. This was noted especially at metadata level, where many organizations developed dedicated standards to describe datasets due to the lack of a health-specific standard for dataset description. Supplementary Table S2 presents a list compiled by the authors of internationally recognized standards for health data and the purposes for which they can be used.

Findability of health data

About 58% of countries visited have decentralized organization of electronic health records (EHRs), with health-related data stored in various locations, registries, healthcare providers, and stakeholder organizations. The remaining 42% have centralized organization and infrastructure, with a copy of every health record stored centrally.

To ensure the reuse of health data, researchers and policy-makers need to be able to find the datasets needed for their study. Under chapter IV of the legislative proposal, Art. 55 and 58 state that health data holders must provide descriptive metadata records in a standardized way to make their datasets discoverable. These metadata records will then need to be centralized into a national datasets catalogue. They should be interoperable with each other to improve findability, including from the central European datasets catalogue.

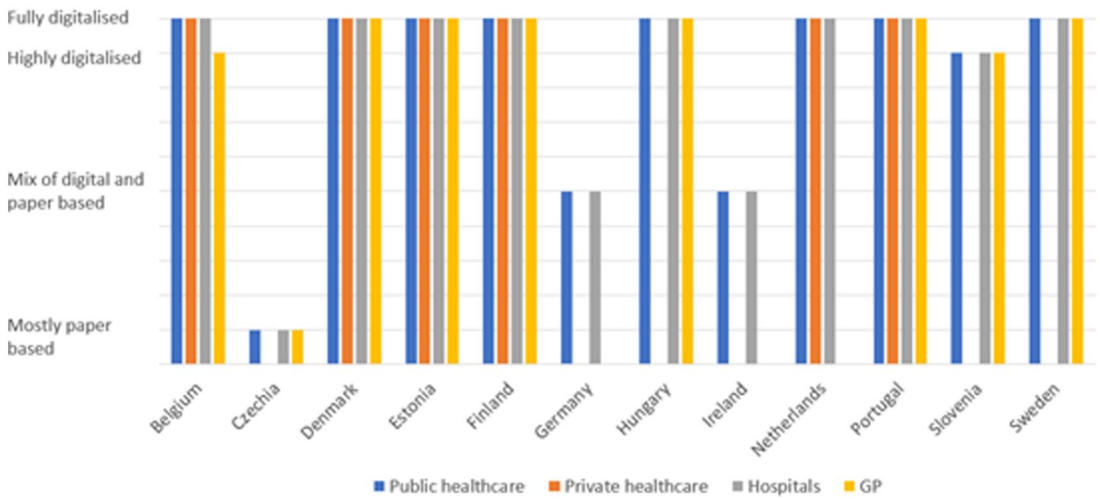

Figure 2. Approximate digitalization of health record sharing per sector: public or private healthcare, hospitals, and general practitioners' data. The absence of a bar indicates unavailability of data for that sector.

During the interviews, we asked about the state-of-play towards a national datasets catalogue. The map in Fig. 4a shows the countries that already have a functional national datasets catalogue, the ones currently developing one, and the countries that do not yet have a common datasets catalogue. Nearly half of countries (41.6%) either have a functional national datasets catalogue or are currently developing one. In the countries that reported not to have a national datasets catalogue, most have several metadata catalogues for different organizations.

Health data access procedure

After finding a dataset, a researcher requests access to the data needed. The country mapping exercise revealed that data access procedures vary between and within countries, as do the time and fees to receive access to data. There is a lack of transparency in data access procedures, lack of clarity on fees, and inconsistency in the time to access data. Not all MS have a central location where a researcher can request access to health data. The EHDS legislation aims to improve transparency and standardize health data access requests, procedures, fees, and time. Art. 45 and 46 provide the specifications for the data access procedure [7].

The common steps in the data access procedure in most MS visited are:

(1) Data requestor must be affiliated to a stakeholder organization.
(2) Request approvals from ethical committees.
(3) Submit a research project proposal with a detailed protocol stating the purpose for accessing health-related data, data granularity needed, anonymization status, need of linkage with other datasets, and planned analysis.
(4) Examination by data permit authority, data controller, and in some cases, Data Protection Officers.
(5) Access to data is granted or refused.
(6) Access is provided to aggregated, anonymized, or pseudonymized data. In very few MS and cases researchers get access to identifiable data.
(7) Access to data is provided in SPE, physical or remote. If there is no SPE then data are sent to the user.

The time from the submission of an application to access data can vary from 2 to 18 months. Fees are most often requested for the data controller to cover the work needed to prepare the dataset. In some MS there are no fees for public or academic researchers. Generally, fees depend on the affiliation of the data requestor and the organization providing the data. Finally, access requirements might differ between national and international researchers, and between public and private sector data requests, depending on the MS.

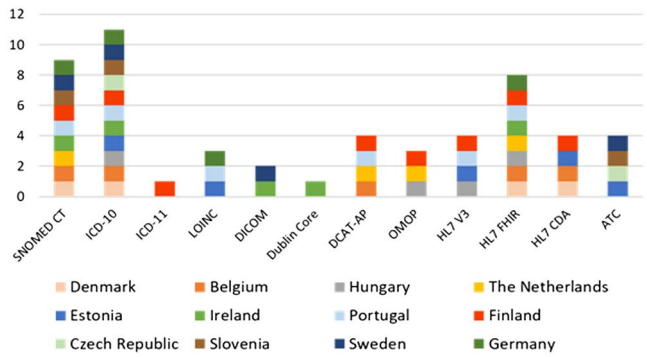

Figure 3. Standards in use as reported by stakeholders interviewed.

Consent and opt-out

The EC's legislative proposal for the EHDS did not include the need for consent for secondary use of health data, nor the possibility for citizens to opt out from the reuse of their health data [7]. However, the right for citizens to opt out from the reuse of their health data became mandatory in negotiations with the Council of the EU and the European Parliament, to achieve political agreement between the co-legislators [20–22]. During the mapping exercise, it was reported that in some MS, national legislation specifies the need for citizens' consent for the reuse of their health data, and in others legislation allows citizens to opt out from the reuse of their health data. Some MS require consent only for the reuse of specific data types (e.g. biobanks and genomic datasets). Several stakeholders in countries

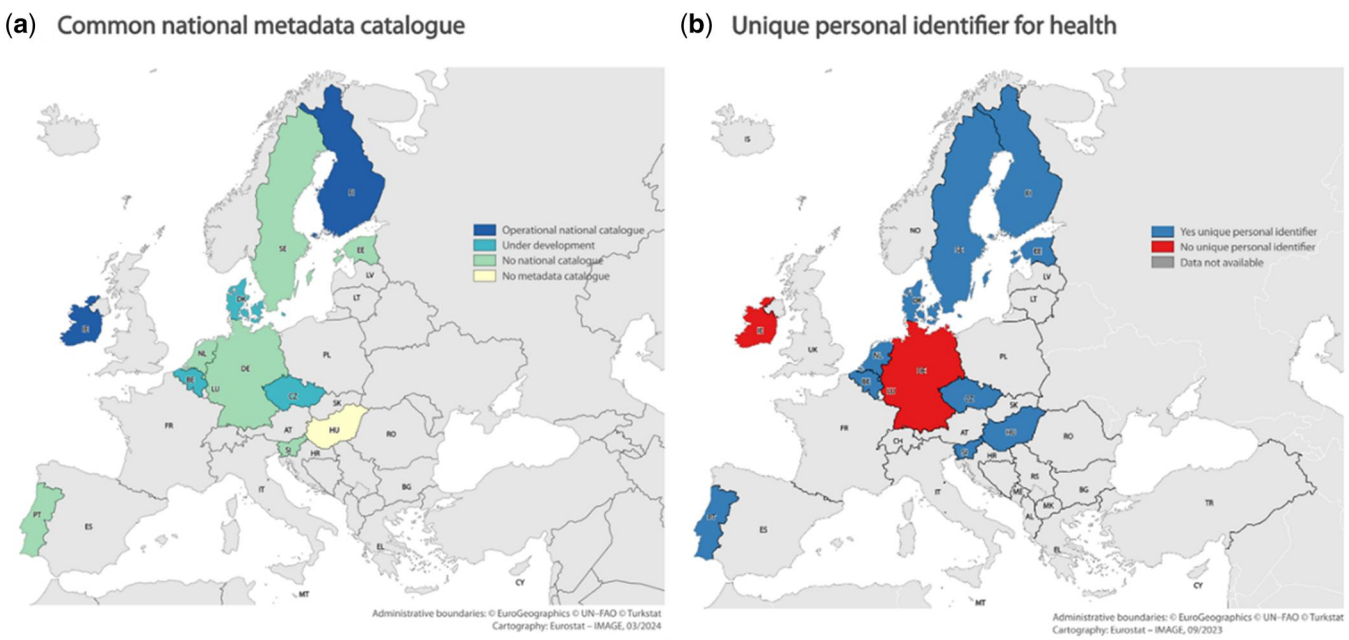

Figure 4. (a) Map demonstrating countries' status regarding a common national metadata catalogue: operational national datasets catalogue in place, national metadata catalogue currently in development, no national metadata catalogue but several metadata catalogues across organizations, or no existing datasets catalogues reported. (b) Map demonstrating the use of a unique personal identifier or not.

requesting consent highlighted the challenges and noted that they are moving towards an opt-out mechanism.

At the time of the visits, 50% of the MS did not request consent for secondary use of health data and did not have an opt-out mechanism as they consider health data to be a public good and the reuse to be in the public interest (Denmark, Hungary, Ireland, Portugal, Slovenia, Finland). Estonia and Sweden require consent only for the reuse of biobank samples and genomic data. In Belgium and the Netherlands consent and opt-out exist in several cases but not across every organization. Finally, Germany and the Czech Republic request consent for any reuse of identifiable or pseudonymized health data.

Unique personal identifier and data linkage

Data linkage allows researchers to use data from different sources and link them at individual level for better analysis and interpretation. The most common way to link data is by using a unique personal identifier. Linkage is followed by pseudonymization to protect data privacy. Stakeholders noted that, pseudonymization occurs either at a trusted third party or within the data holder organization. Figure 4b shows that 83% of the MS visited use a unique personal identifier for health-related data. Stakeholders reported that even in MS with a unique personal identifier (e.g. Netherlands, Hungary), legal and interoperability issues make individual-level linkage challenging.

Data analysis in SPEs

According to Art. 50 of the legislative proposal, health data will be made available for analysis within an SPE [7]. All MS visited have either physical or remote SPEs, or both. Most SPEs are hosted in statistical offices, and a fee is requested to use them. At the time of the country visit, Finland, for example, had eight functional SPEs, which were set up for different purposes (e.g. genomic data, registry data).

Challenges and needs

In accordance with the second objective of this mapping exercise, stakeholders were asked to elaborate on challenges and needs regarding the secondary use of health data.

A common challenge reported is the lack of a centralized and common national datasets catalogue where researchers can find metadata on available health data, and request access to reuse them, in a single place. Some stakeholders mentioned the lack of transparency in data access permit decisions.

Regarding the needs raised, most stakeholders reported that different interpretations of the General Data Protection Regulation (GDPR) resulted in different national legal frameworks. Stakeholders called for a harmonized legal framework for secondary use of health data in Europe.

Finally, we noticed a recurrent call for improved health data literacy. There was a proposal to support capacity-building activities with the creation of a Health Data Academy.

Expectations and concerns about the EHDS

Stakeholders expect the EHDS to facilitate the reuse of a plethora of European health data, benefiting patients, researchers, and policymakers. Moreover, they expect it to enhance interoperability across administrative levels, organizations, and stakeholders.

However, concerns were raised regarding centralized decision-making on health data, emphasizing the importance of maintaining national competence for granting permits for accessing health data. They also voiced concern about data protection and privacy in the EHDS, highlighting the need for safeguards.

Finally, stakeholders noted that the timelines are ambitious, and that additional human and financial resources are required to implement the provisions of the legislative proposal.

Political preparedness

Throughout this country mapping exercise, the political and technical preparedness to join and implement the EHDS legislative proposal has been the guiding principle. Despite some concerns, there is political willingness to join the EHDS for secondary use in all 12 MS visited, recognizing the value that this legislation will bring.

The existence of a national entity that will have the role of national contact point in the EHDS for secondary use was explored as a factor of political preparedness. At the time of the visits, some MS (e.g. Denmark, Belgium, Finland, Portugal), had established or were establishing a national health data authority to take the role of national contact point for the HealthData@EU infrastructure.

Discussion

This article analyses the preparedness of 12 EU MS to comply with the provisions of the EHDS legislative proposal and future EHDS regulation. This article adds to existing research and knowledge on countries' efforts to facilitate the secondary use of health data, including literature in which countries were studied that were not included in this sample [23–26].

Based on the results at the time of the country mapping exercise, we can conclude that no MS was fully ready to comply with the future EHDS regulation, with different levels of preparedness and efforts underway to comply with the different provisions of the regulation. While health data management systems are heterogeneous, most of the MS visited during the TEHDAS country mapping exercise were making progress towards alignment with the provisions of the legislative proposal.

As highlighted by some stakeholders, it is important to improve the quality of health data at source to enable health data reuse. Although in most MS health data from public healthcare providers are digitized, countries have started prioritizing the structuring of electronic health data using internationally recognized standards.

Regarding findability of datasets in Europe, there is room for improvement. Few MS visited have a functional common datasets catalogue describing health-related datasets. It is important to support MS in developing common standardized metadata catalogues.

Despite some common key steps in health data access procedures, our results reveal variation in the specific requirements, conditions, fees and timing across and within MS. For example, the requirement for citizen consent or the possibility for them to opt out of secondary use varied. Each MS visited had at least one operational physical or remote SPE for analysing sensitive health-related datasets, a step towards preparedness for the EHDS.

This country mapping exercise was also an opportunity for stakeholders to express challenges they face in reusing health data for research or policymaking and the expectations they have for the EHDS. Stakeholders hoped that most of the challenges would be alleviated with the adoption and implementation of the EHDS regulation. For example, the development of a common EU datasets catalogue aims to improve the findability of health-related datasets for data users. A harmonized process for requesting access to health data and the possibility to fill in a common data access application form requesting multiple datasets should improve the user journey. Regarding MS expectations from the EHDS legislation, it was recognized as an important initiative that can provide a clear legal framework for secondary use of health data in Europe.

Public health research, monitoring, and development of diagnostic tools and treatments should benefit from the implementation of the EHDS regulation. The future EHDS regulation should facilitate the reuse of a plethora of health-related datasets to answer complex

public health questions and support evidence-based policymaking in a secure, harmonized, and structured way across Europe.

This study had some limitations to consider. Findings were based on information received from the stakeholders interviewed. In countries where fewer organizations were interviewed, there may be gaps in the representation of the situation. Furthermore, this study is a snapshot of the health data management systems at the time of investigation in 2022. Due to ongoing developments, we advise performing such a study periodically. Due to time constraints, more countries from southern Europe were not visited, and this area might be under-represented. It is recommended that this exercise should continue to cover all 27 EU MS. Finally, at the time of drafting of this article the EHDS legislation had been provisionally agreed by the co-legislators. The articles mentioned in the text might change by the time the legislative text has entered into force and is published in the *Official Journal of the European Union*.

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Supplementary data

Supplementary data are available at *EURPUB* online.

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Data availability

The data underlying this article cannot be shared publicly as agreed with the stakeholders interviewed. However, the data are available on request if required. Factsheets summarizing the findings from each visit can be found on the TEHDAS website and on Zenodo (10.5281/zenodo.8329552).

Information on prior or duplicate publication or submission elsewhere of any part of this work

The country visits presented in this paper were performed during the TEHDAS Joint Action. To fulfil the obligations of the project, a short factsheet was developed for each country. These factsheets were presented in a project deliverable entitled 'Country factsheets: Mapping health data management systems through country visits: Development, needs and expectations of the EHDS', which has been uploaded to the TEHDAS website and to Zenodo (10.5281/zenodo.8329552). Conversely, the current paper presents a semi-quantitative analysis and comparison of the 12 detailed reports that resulted from the TEHDAS country visits, focusing on key aspects in relation to the EHDS legislative proposal.

Key points

- This study reveals the current state-of-play of the health data management system of 12 EU MS focusing on the digitalization of their health data, the use of internationally recognized standards, the findability and accessibility of health datasets, and their analysis.
- Although it seems that the landscape is heterogeneous, MS face many similar challenges. No MS is fully ready yet to comply with the future regulation and there are different efforts underway to comply with the provisions of the EHDS.
- Most MS highlighted their efforts to align with the provisions of the legislative proposal for the EHDS.
- After analysing the current needs and challenges mentioned by stakeholders, it seems that the legislative proposal for the EHDS addresses most of them.
- Although there is a general political will to join the EHDS, stakeholders mentioned that the current timeline is too ambitious and that there is a need for more human and financial resources to implement the provisions mentioned in the legislative proposal.

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