



# Health Data Semantics: Exploring Requirements for Sustainable Health Systems

Mate Bestek<sup>1,2</sup>  and Erik Grönvall<sup>1</sup> 

<sup>1</sup> IT University of Copenhagen, Copenhagen, Denmark  
{mbes,erig}@itu.dk

<sup>2</sup> 3fs d.o.o., Kranj, Slovenia  
mate.bestek@3fs.cloud

<http://www.itu.dk>, <http://3fs.cloud>

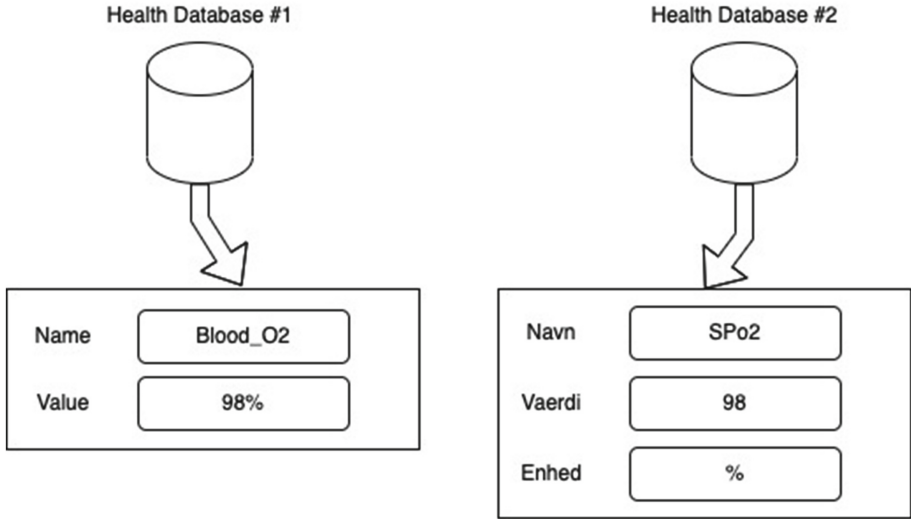
**Abstract.** Health data cannot easily move from one healthcare provider to another, let alone between different countries. There is a de facto lack of health data interoperability in many healthcare systems preventing mobility and sharing of health data. Hitherto the literature has mainly considered technical aspects and challenges related to interoperability, but this paper will foremost explore semantic aspects. Using two cases of exploring data interoperability and the democratisation of health data as a backdrop, this paper presents existing challenges preventing sustainable health systems by focusing on semantic aspects of data interoperability in healthcare. A key finding is that data interoperability is possible and standardised data semantics are key resources to support data access within or across systems, for example between countries. The democratisation of health data, allowing different health systems to interact with each other, requires management of the shared semantic resources and the governance structures defining them. Domain experts, like medical doctors, can play an important role in co-designing and managing such shared, semantic resources.

**Keywords:** Health Data Semantics · Semantic interoperability · Democratisation · Co-Design · Human-Data Interaction

## 1 Introduction

It is not hard to imagine a healthcare scenario in which a person becomes involved in an accident while travelling abroad. Let us take a person named Mark who travels to Denmark. It is not his first time there, but this time Mark gets hit by a car and loses consciousness due to a blow to his head. Mark is brought unconscious to the hospital where a physician orders a magnetic resonance scan to understand if there are internal injuries to the brain. But what if Mark has had previous accidents and has a metal plate implanted in his head? The treating

physician does not know Mark, nor does he have access to his medical record. In such situations and any other situation where medical decisions need to be made, access to information from existing medical records is fundamental. One could not even get a medication dispensed abroad due to issues of differing dosages, compounds, and packaging of medications used in different countries - in spite of many project initiatives funded by the EU, e.g. epSOS, MyHealth@EU, that have greatly influenced our previous work [1,2]. At this point, one could say that such cross-border scenarios do not happen often. But the Covid pandemic forced us to lift priority for such scenarios. The European countries, for example, were collectively able to quickly implement a standard in the form of a Covid passport that enabled travel between countries. However, as we explain in Sect. 4, no health data has been transferred between countries with the European implementation of the so-called Covid passports. But to help Mark transfer his electronic medical record to Denmark, we need to transfer medical data and solve much more complex underlying issues. As we will also learn in this paper, these underlying issues are also preventing health data flow within countries or even between neighbouring hospital wards (naturally depending on how each country and region manage their health systems). The above-mentioned issues are categorised on different levels of interoperability, for example technical, semantic, organisational, and legal. These levels of interoperability all play a role in establishing the capability of data exchange in which data is understood in the same way by all parties irrelevant of location or language used [15]. Interoperability problems are difficult to solve due to the complexity of health systems and the large number of stakeholders involved at different levels and with different roles. As a result, health data are scattered across health systems leading to health data being an underused resource that cannot flow where needed since manual health data transfer between systems is expensive, highly labour intensive, and prone to semantic inaccuracy [38]. Figure 1 shows an example of semantic inaccuracy on the blood oxygen level data stored in two different databases. What we see in the example from Fig. 1 and from literature (e.g. [38]), is that health data are defined in different ways which are usually not compatible without additional data work. One solution to reduce the need for such additional data work is to define and store data in the same way in both databases. That is, to establish shared semantic resources as standardised definitions of health data to ensure a standardised interpretation and understanding of data, regardless of where, when and by whom the data is used [2]. Such shared semantic resources are at the core of solving data interoperability. However, such approaches heavily influence how information systems are designed and developed in the first place and thus impose constraints on e.g. EHR system providers. But in order to reduce the semantic difference between data coming from different systems in a highly complex domain such as healthcare without compromising on the completeness of individual patient's health data, we have pursued such solutions. To define how to store data, OpenEHR is an existing architecture that supports semantic work - the creation of shared semantic resources in healthcare [22]. OpenEHR is a blueprint for how to set up a technical infrastructure for storing and managing



**Fig. 1.** We see differing structures and semantics for a data structure that captures a simple measurement of blood oxygen levels in the blood. The database on the left only uses two data fields to store the measurement while the one on the right uses three data fields. In addition, the names of the fields differ due to the different languages used.

electronic health records [2]. OpenEHR “consists of open specifications, clinical models and software that can be used to create standards and develop information and interoperability solutions for healthcare” – [26]. Previous research provides insights on how to sustainably establish semantic work by promoting the process of democratisation of health data semantic resources [1, 2] or sharing of health data semantics [40]. Democratisation in the context of data has been defined by Samarasinghe et al. as “*an ongoing process of enabling digital data access to both technical and non-technical users to understand, find, access, use, interact and share appropriate data...*” - [33]. Influenced by this data democratisation definition by Samarasinghe et al., we can define health data semantics democratisation as an ongoing process of enabling access and sharing of health data semantics. The democratisation of health data semantics can be seen as an alternative approach to the currently prevailing lock-in-based business strategy. In lock-in-based business strategy software companies hide the semantic resources that define the data in their systems. The end goal of such behaviour is to force the dependency of end users on the companies for the firms to ensure themselves long-term business engagements [1]. We do understand, however, that protecting intellectual property rights might be one of the factors influencing the need for such business models. Using two case studies from Slovenia, this paper focuses on understanding semantic work as a prerequisite for achieving democratised or shared semantic resources. These semantic resources enable a shared understanding of data that can then flow where needed. That is, shared

semantic resources enable data interoperability and data flow not only within complex health systems environments with many different stakeholders with different roles in specific countries or regions but also between health systems of different countries. In this paper, we try to point out the need to recognise semantic work as a crucial prerequisite of shared health data semantic resources which can support more sustainable health systems in the future. In this paper, we point to existing very important legal mechanisms that the EU is currently rolling out that could help achieve that goal. The rest of the paper continues as follows: in Sect. 2 we introduce important concepts that we use in the paper; in Sect. 3 we describe how our data was obtained which we describe in Sect. 4. In Sect. 5 we analyse and explore the empirical data and what we can learn from it. Finally, we wrap up the paper with a discussion and contributions in Sect. 6.

## 2 Related Work

Due to the importance of understanding semantic work we try to align with existing research work to inform our understanding of semantic work. This includes aligning with work on co-design that can provide methods used as part of semantic work. In addition, it includes aligning with research on human-data interaction where interesting insights can help position the importance of semantic work. After bringing forward these two sources of inspiration for our research, we shortly review the existing state of standardisation and legislation activities in the EU to support our discussion on how to establish a more long-term sustainable and scalable semantic work. This first includes the Covid-19 passport activities that have resulted in an implementation of a standardised solution across the EU member states. This work is important as it provides evidence of the successful tackling of interoperability problems between countries. However, as it lacks focus on semantic resources and semantic work, we also provide here a short overview of some of the relevant EU legislation that has lately been adopted or is still in the process of being adopted, as such legal frameworks may help with achieving a sustainable and scalable semantic work in the future.

### 2.1 Co-design and Participatory Design in Health Care

Co-design and Participatory Design (PD) are often treated as synonyms and described as an approach to design together with end-users and other stakeholders [12, 13, 34]. With its roots in work on knowledge development, and early projects like Utopia, Participatory Design (PD) first emerged as an effort to include workers in the design of workplace computer systems and later matured into an approach to design with different stakeholders [10, 36]. The healthcare sector has from early PD projects to more contemporary co-design projects been the context of multiple collaborative design projects [3, 23, 39]. Relevant to this paper, PD and co-design have been used to design collaborative health systems that support different professional and informal carers in their collaboration [5, 6]. These papers have for example highlighted the importance of different stakeholders collaborating, also across organisational boundaries, to support a

positive care trajectory. PD has for example been used to involve people with dementia and their carers [37], and co-design has been used to promote knowledge creation among stakeholders [27]. Recent work by Grönvall et al. has looked into how social workers can design training materials for their clients on a collaborative platform disregarding which care organisation or municipality they are employed in [24]. To sum up, the collaborative design process is not new in healthcare and has been used to improve learning, foreground knowledge within cross-organisational communities and develop care systems and technologies.

## 2.2 Human-Data Interaction

In recent years an increased focus on Human-Data Interaction has emerged as a complement to the broader field of Human-Computer Interaction [19, 29, 41]. Human Data interaction emphasises how people work with, and generate, data rather than the interactions people do with interfaces inserted between them and the data sources. Within a large part of the healthcare sector data (both individual patient health data and Big data) is seen as an enabler for effective and quality care, and Electronic Healthcare Records (EHR) are used in many parts of the world [7]. Within healthcare, HDI has been used to explore how we can for example make better use of data [11] allowing for example healthcare professionals to engage in data-work [4]. Bossen et al. describe how data is not always readily available and may have to be combined, analysed, and contextualised to be valuable; they define data work as “any human activity related to creating, collecting, managing, curating, analysing, interpreting, and communicating data” [7]. Work related to HDI outside of the healthcare domain has also explored how experts in non-IT domains can turn data into objects of design and explore how to use data in new and innovative ways [34]. Seidelin et al. discuss for example scenarios where it is useful to explore HDI from a multi-stakeholder and multi-organisational perspective [35]. Seidelin et al. also recognise that in such scenarios it can be fruitful to involve data users in the design of how data is stored, used and analysed and they identify co-design as a way to meaningfully involve the different actors [34].

## 2.3 EU Digital Covid-19 Certificate as a Cross-Border Standard Implementation

During the Covid-19 crisis, a transnational need emerged to allow Covid-tests (e.g. Antigen and PSR) performed by a health institution in one country to be valid and verifiable in other countries. In response to that need, the European Union developed a digital documentation standard for Covid-tests and vaccine certificates valid across the European Union. Key features of the certificate are according to the European Union [14], that it works for both in digital and/or paper format, it is based on a QR code, it is free of charge and available in both the national and English language. It’s also secure and valid in all EC countries. The functionality is built around the above-mentioned QR code that can be scanned at for example airports, shopping centres, restaurants, and bars.

The Covid passport app (and its paper-based alternative) is an interesting solution in terms of interoperability and trans-national mobility of health data and certificates that prove that a person has received a Covid-19 vaccine or been tested negative no matter where in the EU (or world if they accept the standard) the verification is performed. The generated QR code contains the signature of the local health provider in a specific country that has issued the certificate. Based on an EC-wide common format and an EC-level gateway the Covid passport validity can be verified without sending an individual's actual health data between countries.

The above example is interesting as it enables a cross-national validation of medical data. However, it does not work in the case of medical records where actual health data has to be moved or accessible from different nations or between providers. A health record is also far more complex and contains far more data that could hardly fit into a QR code. In addition, this case is important for this paper because it shows that a cross-national solution is possible in the EU. This means that existing legal frameworks and technical infrastructure can be used to achieve such goals. However, the crucial aspect of this case that is important for this paper is the complete lack of focus on health data which is never actually carried abroad. For this, there is no need to handle semantic resources which greatly simplified the overall design and implementation.

## 2.4 Standardisation and the European Union Health Data Spaces Regulation

The European Union (EU) Strategy on standardisation “*aims to strengthen the EU's global competitiveness, to enable a resilient, green and digital economy and to enshrine democratic values in technology applications*” - [16]. The strategy only recognises standards that are developed by a recognised European Standards Organisation (CEN, CENELEC, or ETSI) upon request from the European Commission. Then, once accepted, such standards become part of EU law and are provided to manufacturers across the European Single Market. Initiatives like the HSBoosterEU project have been initiated to offer standardisation services to existing projects funded by the EU to pursue the implementation of the EU standardisation strategy in practice. However, the strategy and the HSBoosterEU project represent initiatives that mostly fall under legislative and policy matters, and through standards also technical aspects of health data sharing (e.g. epSOS project [28]), but do not address the more complex health data semantics. A step in that direction can be seen in the latest European Health Data Spaces regulation [18].

The European Union has presented the Health Data Spaces Regulation proposal to better use health data. The proposal (1) supports individuals to take control of their health data, (2) supports the use of health data for better health-care delivery, better research, innovation and policy making, and (3) enables the EU to make full use of the potential offered by a safe and secure exchange, use and reuse of health data [18]. The European Health Data Space is a health-specific ecosystem comprised of rules, common standards and practices, infrastructures

and a governance framework with the goal, among others, to foster a genuine single market for electronic health record systems. Since trust is a fundamental enabler for the success of the European Health Data Spaces, it will provide a trustworthy setting for secure access to, and processing of, a wide range of health data. To achieve that, the European Health Data Spaces Regulation build on the General Data Protection Regulation (GDPR) [31], the Data Governance Act [32], draft Data Act [17], and the Network and Information Systems Directive [20].

### 3 Methods and Materials

This article is based on empirical work involving OpenEHR and different health-care projects. In particular, we use data from a workgroup (WG) in Slovenia that tried to consolidate semantics across several national e-health projects which involved key stakeholders such as doctors and the government. The data includes primarily documents and communication exchanges which have been made anonymous. For this paper, inductive thematic analysis was used, as the themes identified are strongly related to the data itself and do not come from a theoretical framework [8]. We convey the themes in the following section in the form of two case studies that represent empirical data in this paper. These two case studies can be seen as the contrast to the already introduced case of the Covid-19 passports in Sect. 2 where we learned that in reality no health data was exchanged between EU countries. We have chosen the Covid-19 passport as a contrasting case because it is a public and well-known example of a standardised solution that enables sharing of health data, albeit only implicitly utilizing digital signatures, across national borders and health systems. With this contrast, we try to point to the importance of semantic work as was done within the WG. We see such semantic work as the basis for achieving shared or democratised semantic resources.

## 4 Empirical Data: Two Case Studies of Semantic Work

We will now outline two real-life cases to help us in our work. The two examples come from the exploration of health data interoperability through the development of semantic resources by the aforementioned National e-Health Programme Working Group (WG). We contrast these two cases with the aforementioned example of the Covid-19 passport where the certificate allows, for example, a tourist from one European country to visit another using a Covid test certificate issued at home.

### 4.1 Scenario 1: The Asthma Questionnaire

The work group of the national e-Health programme (WG) worked on different types of semantic resources during its existence. The WG worked on a specific sub-project of the national e-Health programme that focused on creating

national datasets for the primary level of the health system so that the Ministry of Health could better track the health status of the population.

Clinically validated questionnaires are one of the most important semantic resources in healthcare. These are used as medical tools which are often developed by pharmaceutical companies which raises ownership issues and issues with intellectual property if misused. The WG encountered such questionnaires, like the asthma health status questionnaire, that is used to assess patient asthma status. Since the WG worked on a specific project that included a limited number of use cases on the national level, the asthma questionnaire could not just be used as part of the national semantic resource set. To be able to do that, a legal agreement had to be established with the owner of the intellectual property over the questionnaire, being a large international pharmaceutical company. One of the participants of the WG - a medical doctor - offered to obtain permission from the pharmaceutical company that would allow the use of the questionnaire in the national project. The permission was obtained in a form of a contract that defined the rules of use for the questionnaire at hand.

We consider this case important for this paper because it depicts specific semantic work. It points out a specific semantic resource - the asthma questionnaire - that has specific requirements to be governed properly as a shared semantic resource. We can also learn that the direct involvement of e.g. the Ministry of Health was not needed or required in our case, even if it dealt with the national governance of semantic resources that are under the protection of intellectual property legislation. At the same time, this case shows how members of the WG were able to find a solution non the less. However, the solution can be seen to only be partial and could not scale to include potential future use cases or projects. Future projects could perhaps not be approved by the pharmaceutical company which could also pose payment of high fees for the rights of use.

## 4.2 Scenario 2: Doctor-Created Data Structures

The WG engaged with several other semantic resources including clinical concepts like blood pressure, blood glucose and disease diagnosis. Each such clinical concept was discussed in terms of what additional data is needed to fully capture the context within which a measurement is made or a data point captured. This was done by discussing a set of support data for each clinical concept to achieve a sound structural definition of the concept. In addition, each support data element could include values from existing medical terminologies. Therefore, the WG semantic work resulted in defining precise data structures and mappings to different terminologies for the clinical concepts that were important for the project at hand. At this point, it is important to stress that the members of the WG, by referencing the OpenEHR approach, were able to obtain existing data structures and mappings to terminologies for several of the clinical concepts they worked on. The global OpenEHR community works on such concept definitions that can be freely used. However, despite the convenience of being able to learn from and even reuse some of the existing concept definitions, the semantic work also included making changes to existing concept definitions or

even creating new ones. In some cases, this also included work on reducing the complexity of some data sets and clinical concept definitions. An example of such simplification was a rather complex survey-like questionnaire. The reasoning for the simplification was that simpler semantic resources could be reused to design different more complex semantic resources. In this case, some common elements of the complex questionnaire could become reused in different questionnaires. In addition, simpler semantic resources could also offer a superior user experience for the end users when implemented in technical systems. Another example of doctors working on semantic resources can be seen in their collaboration on a single code from the International Classification of Diseases (ICD). It turned out that different doctors used different codes to identify smokers and non-smokers. One doctor pointed out that he uses the ICD code F17.1 to identify a smoker and Z000 to identify a non-smoker. But the doctor was eager to define a better set of codes if that would be needed. We consider this case important because it introduces additional aspects of the semantic work done by the members of the WG. It depicts how the WG jointly worked on finding consensus on several clinical concepts definitions that included work on data structures, like the overly complex survey-like questionnaire, and mappings to different terminologies, like the codes for identifying smokers and non-smokers. Such work is the essence of semantic work but is currently not recognised by health systems as a permanent activity and a need. This means that in spite of the fact this WG existed and worked on data structures and terminologies, they stopped their work immediately after preparing their results. These results - the semantic resources - were then used to develop a technical information system but unfortunately, the semantic resources have not become part of a national governance initiative of semantic resources that could ensure these semantic resources would be used, reused or improved in future project initiatives.

## 5 Analysis and Results

We have learned about a successfully implemented and interoperable cross-border Covid-19 certificate solution enabling people to travel between countries based on their vaccination status. However, this implementation did not require any health data from a person's medical record to travel across borders. The EC Covid-19 passport implementation was based on a digital signature that had to be verified and it was then implicit what your vaccination status was. To enable electronic medical records to be transferred between health systems, even between countries, something that would have been useful for Mark from the beginning of the paper, is a much more complicated task. Even if we do not consider complex technological and data security challenges, the very practice of using health data originating in health systems other than your own can be difficult. It requires collaborative work on health data structures and their semantics - what we call semantics work - is not only considered in local contexts but also international health data exchange. Our two empirical cases show that medical doctors can collaborate on defining data structures, vocabularies and their

harmonisation. Looking at such semantic work through the lens of human-data interaction and the work of [34], it is beneficial to have multiple stakeholders involved in such activities in the early stages of healthcare system design, where it is defined how data is stored in the first place. Seidelin et al. [34] point out that the active involvement of data users can be of great importance in designing the data structures that will later store the data. Our two empirical cases can thus be seen as instances of co-design that resulted in health data structures and a shared understanding of the meaning of different health data. In our two empirical cases, the co-design process utilised the methodology of OpenEHR to arrive at the designed objects - the health data semantic resources.

Unfortunately, semantic work - despite being crucial for achieving health data semantics democratisation and consequently trustworthy health data interoperability, is usually not long-lived. Such work is mainly temporary and does not scale on a national or international level and therefore often remains on the level of a small-scale project. More importantly, semantic work is often not recognised as a part of the health system as no legislation supports or requires this work to happen. As has been explored in [1,2], it would be desired to have such data interaction work in the early design stages of technical information systems development and it needs to become an ongoing activity of health systems because such work is a needed prerequisite for achieving trustworthy and interoperable health data exchange. As we have learned, human data interaction work benefits from having multiple stakeholders participate in the co-design of data structures. In Europe, the European Commission is one such needed stakeholder that is of crucial importance. We have also learned from our empirical cases that focusing only on semantics is not enough as even in semantic work there are e.g. legal questions to be addressed. Having a European Commission as a stakeholder dealing with such legal issues would gravely impact the implementability, sustainability and scalability of semantic work. As we have learned in Sect. 2, Europe has prepared strategies and legal grounds that support future health data exchange between countries. These strategies and legal frames can help support the collaborative design of health data structures and health data semantics - semantic work - in a more sustainable and scalable way. We observe a link between the semantic work as a need of health systems and existing EU strategies and legislation that have great potential for addressing that need.

In particular, the EU Standardisation Strategy is a mechanism through which new standards can be introduced to all the EU member states' health systems. This means that standardised health data structures and semantics could be adopted through this process and new requirements for the health systems could be created. In addition to establishing a legal and standards framework, the mechanism could also be used for the ongoing creation and dissemination of new semantic resources. In this way, a sustainable work practice for the governance of semantic resources could be achieved.

In addition, the Health Data Spaces Regulation is a legal framework that supports achieving health data democratisation. This means that standards and procedures could be established that would support implementation. In addition,

the regulation brings forward data altruism - data voluntarily made available by individuals or companies for the common good. An interesting avenue for the future would be to consider semantics altruism, a term very similar to shared semantic resources. This idea could perhaps be supported in the Data Governance Act, by potentially introducing governance of data semantics resources and the Data Act where interoperability standards are the focus.

## 6 Discussion and Contributions

We learned in Sect. 2 that successful implementations of cross-border solutions in the field of healthcare are already possible. An example of such a successful implementation is the EC Covid-19 passport implementation from which we learn that technical, organisational and legal interoperability problems can be addressed in a rather straightforward way following a top-down definition of a standard solution. The crucial challenge lies in the semantic interoperability issues. To solve these issues means establishing shared semantic resources. A joint effort is needed for defining and implementing shared semantic resources in all the technical systems as blueprints of how to store data [38]. This is different to what existing standards like the HL7 FHIR [9, 21, 25] ensure as their primary focus is on integrating technical systems [30]. However, the Covid-19 passport implementation has been designed in a clever way that completely avoids transferring any health data, and therefore there has not been any need to conduct semantic work as a collaborative design effort between stakeholders and across the EU member states. While the current implementation has successfully enabled people to travel between countries through trust about their vaccination status, it is not the approach needed to solve Mark's problem (from Sect. 1) of transferring electronic medical records between countries. Such implementation is highly dependent on establishing shared semantic resources that define the data elements found in typical medical records. Democratising health data semantics requires software engineers and medical professionals to collaborate on the initial design of semantic resources that define how data is to be stored in the technical information systems and co-create the semantic resources. In this paper, we want to put forward semantic work that we observed in our empirical cases as presented in Sect. 4. Such semantic work involved medical doctors and engineers and should be seen as a need in health systems and addressed accordingly. It will be challenging to get a real impact from the semantic work done by for example the work group in our empirical cases if the results are not considered in a wider context, being regional, national or international (e.g. at the EU level). Referring back to the problem of differing approaches to defining semantic resources - it can be solved by democratising health data semantic resources and the supporting semantics work not only on a local level as in our empirical cases but, more importantly, on an international or EU level. The existing EU standardisation and legislation structures can help achieve that. With this, the important work done by medical doctors as briefly presented in our two empirical cases, should not only be recognised as important but should be recognized

as a need of health systems. By recognising semantic work as a need we point to a future in which such work can be made sustainable and scalable, also at an international level like across the EU member states, based on utilising existing standardisation, legal approaches and frameworks.

Our goal in this paper is to bring attention to the semantic work that is already being done in the health systems as exemplified in our two empirical cases but is not sufficiently recognised as a crucial work practice and a need in health systems. We argue that the role of semantic work in healthcare must be further understood if we are to achieve not only democratised health data semantics but also interoperable health data and more broadly, more sustainable health systems. Working with international legislation, like the EU healthcare legislation, is one way to put attention to semantic work in healthcare systems. By doing so, we envision a reality for achieving the participation of the European Commission as a crucial stakeholder in the co-design semantic work efforts, but more importantly, we point to a way to achieve a sustainable semantic work practice that would not only exist during specific projects but would become a cross-cutting ongoing semantic work practice as a solution to the problem of democratisation of health data semantics. Perhaps our last pointer towards such a reality can be seen in referencing the HSBoosterEU project that has been set up in a cross-cutting way, spanning projects, to support standardisation. One can imagine a similar endeavour focused on health data semantic resources.

In this paper, we point out the need for doctors to participate in semantic work to define shared/democratised semantic resources. Such semantic work is currently not recognised as a need and is therefore not supported in the current health system. There is tension between how doctors work and what the health system recognises as work. To help ease this tension we call for better recognition of the semantic work done by the doctors that include very fine-grained work on data structures and terminologies that is the essence of achieving shared semantic resources and with this democratised health data. Due to the important latest legislative work at the EU level, such semantic work could potentially become a reality in the near future.

**Acknowledgements.** None to declare.

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