Empowering citizens through data interoperability
- data federation applied to consumer-centric healthcare

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Abstract

During the era of open systems, healthcare services and related data are in a constant flux caused by digital transformation. The amount, sources and dimensionality of data grow rapidly, and solutions for data governance, integration and interoperability are urgently needed. At the same time, digital data and information technology–enabled healthcare services are offered as a means to empower citizens. The objective is for active citizens to take better care of their own health. It is possible to support empowerment in many ways, such as with easy-to-use information systems (IS) or personal health records (PHR), or by supporting citizens' participation in health data creation. In this article, we first present the federative approach to data governance with data federation matrixes in order to show how data are made interoperable by combining data from different data storages. Federation matrixes define shared attributes with their technical, information-flow and socio-contextual metadata. We then contemplate how the federative approach can be deployed to citizens' healthcare data empowerment. We propose that data ontologies, e.g., data federation matrixes, are useful in bridging gaps between the social contexts of citizens and healthcare professionals and, by doing so, to promote citizen empowerment. The present article contributes to research on the federative approach to data governance, its deployment to citizens' healthcare empowerment, and to the practice-oriented further development of the federation matrix tools for this and other use cases.

Keywords: patient empowerment, data federation, consumer-centric healthcare, data interoperability, health literacy

Introduction

The availability of the electronic health record (EHR), E-prescriptions and other healthcare data has been the norm in Finland since 2007 [1]. That, along with the continuous increase of (electronic) communication between a citizen and healthcare professionals, facilitates the empowerment of citizens in healthcare [1]. Citizens are encouraged to actively monitor their own health, that is, to proactively make appointments, to coordinate the services of various clinics, e.g., between occupational healthcare and municipal healthcare, and to provide personal data about health and treatments [2]. Despite good intentions, data compilations from multiple databases and providers are often too complex and error-prone for citizens to digest. Hence, citizens seldom perceive that they are true members of their own healthcare teams. The focus so far has been on allowing access to a citizen's own data, "my data", created and maintained by professionals, e.g., entered into

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the Kanta service (www.kanta.fi). In the Kanta service, data flow one-directionally from professionals to citizens. Tools and information systems are bundled together into "personal health records" (PHR). PHR is defined as the compilation of tools that offer a citizen the possibility to look at their health history records [2].

In prior research, we developed a federative approach to data governance [3,4] and related data federation matrix tools [5]. By federative approach, we mean governance, methods and practices that make data interoperable through the shared attributes (=data elements) of information systems (IS) and/or data storages. Interoperability implies that data are linked and made available from their original data sources by using shared attributes. Shared attributes could be stored into a metadata repository together with the metadata descriptions of these attributes. Matrix tools are used at an operational level to establish interoperability between diverse data storages that have different data characteristics such as formats, cardinalities, search keys, granularity, dimensionalities and structure. Ontologically, our approach builds on the proposition that data are contextually defined [6] as opposed to canonically defined. The canonical definition assumes that data have one true value and meaning across all usage contexts and over time [7–11], whereas the contextual definition proposes that the meaning of data depends on their social use context, which may change over time [4,6]. Our approach and matrix tools have been used in manufacturing industries to federate product and customer data. We then applied them to demonstrate how breast cancer data can be made interoperable for the medical expert teams at a university hospital [5]. The purpose of the present article is to extend the use of the federative approach to citizens' healthcare data. We detected a research need here. Citizens appear to request that PHR and other health data should be accessible to them in more organised, functional and flexible ways than today [12]. From this backdrop, we formulated the following research questions for this article:

> **RQ1.** Is the federative approach to data governance able to support the interoperability of citizens' healthcare data?

RQ2. Is the federative approach to data governance able to support the empowerment of citizens in accessing and using personal healthcare data?

RQ3. What benefits can the federative approach to data governance offer to citizens in the use of personal healthcare data?

We answer the three research questions theoretically by combining the findings of the literature review on citizen empowerment and health literacy with the results of the breast cancer case we investigated earlier. We formulated research questions so that it is possible to reason from this evidence whether the federative approach to data governance offers a potential means to empower citizens to access and use their personal healthcare data. The next section depicts the literature review and the breast cancer case. We then report the findings of our study and end the article with a Discussion and conclusions section.

Material and methods

We conducted the breast cancer case study at a Finnish university hospital. In that research, we learned that breast cancer data, similarly to other healthcare, treatment events and patient data, are scattered to dozens of ISs owned and operated by different healthcare organizational units and organizations with limited or no data interoperability. We witnessed situations in which the same patient and breast cancer data were entered repeatedly into ISs instead of transferring once-entered data between ISs. Repeated manual entry of the same data reduced their quality and resulted in data errors and inconsistencies.

The breast cancer research case had two objectives in helping the professionals of the hospital who were handling the information: to detect malignant breast cancers as early as possible and to estimate the effectiveness of various cancer treatments in terms of predicted and realised patient survival rates. We further used and developed the federative approach to data governance [5,13] in order to make patient and cancer data interoperable. In this article, we reason how the

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same approach and tools could be used to create interoperability for the healthcare data of a citizen with the objective of their empowerment.

Related literature

To investigate the relationship between citizen empowerment and data inter¬operability, it is necessary to review prior research on both constructs. However, let us first take a look at the rapid increase in digital data and ISs, sometimes labelled as digital data explosion [13]. Similar to other organizations, the IT environments of health¬care organisations have transformed from closed to open, fuelled by the rapid advancements in technology and systems environments. During the era of closed (IS) systems environments, data were created, used, stored and managed in the internal ISs and data storages of an organisation. They were usually also internally developed. Each major healthcare organisation had its own ISs with known data models, health and patient data records, and data flow process descriptions. ISs served healthcare professionals to execute routine tasks as they were the easiest to automate. A significant part of the data was analogous. During the last 20–30 years, (healthcare) organisations outsourced their internal ISs step by step and started to purchase IS services from healthcare IT service markets. The number of ISs and the volume of digital data increased rapidly or even exploded. All storable data have become digital [5,14]. Today, a major healthcare organization may have hundreds of actively used ISs and data storages. The consequence is that healthcare processes have become IT- and digital data–dependent [1], as the responsibility for data modelling has shifted to external healthcare IT service providers at the same time. In summary, the large number of ISs and data storages, the purchase of ISs from IT markets, the dominance of digital data over analogous data, and IT service provider–controlled data modelling of ISs and their data storages describe the current open (IS) systems (healthcare) environments [4].

The transformation from closed to open systems environments in just 20–30 years has increased the need for data interoperability but has also provided opportuni-

ties for citizens' healthcare empowerment. Another consequence is that the business strategies of organisations, industries and countries have gradually transformed into digital strategies [15,16], where IS capabilities are amalgamated into the business and operative models of organisations, industries and societies. For example, at the citizen level, the availability of PHRs has reached 100% in Finland, and PHRs are widely and actively used with many related IT-enabled healthcare services [1]. At the society level, the National Data Law reflects the influence of digital strategy thinking. The justification text of the Data Law describes that healthcare data has several links both to citizens and to healthcare professionals.

Citizens increasingly create and are the sources of healthcare data. They use wearable devices, sensors, various types of mobile applications and home monitoring devices, for example, to measure blood pressure and blood sugar levels or to monitor an elderly citizen's living environment. Attempts to integrate this data into healthcare professionals' data repositories have been investigated [17–19]. This phenomenon is another trigger to citizens' healthcare empowerment [20].

Citizen empowerment in healthcare

According to Gibson [21], empowerment (in healthcare) is "a social process of recognising, promoting and enhancing people's abilities to meet their own needs, solve their own problems and mobilise the necessary resources in order to feel in control of their own lives." Gibson states that promoting and enhancing the capabilities to meet one's own needs requires that assistance is available from external sources. Nurses and other healthcare professionals may help a citizen to construct the view of their health status, to critically assess the status, and to create a realistic action plan. In the future, an intelligent software might be able to do the same. We follow Gibson's advice in proposing the use of the federative approach to citizens' empowerment in healthcare. In concrete terms, interoperable data need to offer citizens access and the means to understand their own healthcare status. Citizens also

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need to receive sufficient support and social inclusion for empowerment to happen [20].

As an empowerment enabler, technology offers individuals and groups of people tools, knowledge and confidence to make personal choices supported by healthcare professionals [22,23]. The availability of healthcare data may increase citizens' demand for services but may also enhance the willingness to improve personal well-being through healthier lifestyles [24]. The idea of the present article is to investigate whether data interoperability makes a citizen's healthcare "story" easier to understand and to interpret to the citizen. We emphasise empowering processes [25] through which sufficient amounts of data and information are provided to a citizen together with tools supporting their easy interpretation. We excluded other forms of empowerment from our study as they are not digital data–enabled. We assume that citizens are health literate, as reported in [26]. Health literacy means having personal competence to act autonomously based on the data and information received about a person's health and to understand healthcare professionals' statements and instructions [26]. Health literacy and empowerment are, however, two distinct concepts [26].

Citizen-centric healthcare concentrates on patients instead of healthcare procedures and treatments performed by healthcare professionals. As an innovative technology, PHR services may act as the catalyst for citizen-centricity [27]. PHR services compile relevant healthcare information from all possible angles and sources, including sources external to healthcare organisations and hospitals. PHR services vary from commercial to self-kept (by a hospital, hospital district, patient, or some other actor) and from tethered to untethered [28]. We do not classify PHR services, but we contemplate that our data federation matrixes are able to support PHR services as the means of citizen-centric healthcare by linking data.

In prior research, ontologies have been used to promote citizen-centricity. Ontologies offer alternative views to data structures for different users [12] and collect and compile data from non-similar contexts [14].

The federative approach, especially the data matrix tools, benefit from the availability of ontologies.

The federative approach to data governance – data interoperability through shared attributes' metadata

The federative approach emerged from master data management (MDM) research [3]. The rapid increase in digital data meant that there was continuously more data about the same persons, (physical) objects, places and concepts. Already during the closed systems era, data types were classified into transactions, reports, documents, contents and metadata (data about data) [8,9]. Master and reference data were introduced as new data types to describe the IS practice of linking separately stored, maintained and managed customer, product and other master or reference data to transactions and other data types. In addition to data volume explosion, the number of data sources and the dimensionality of data have increased. Video data (devices), sensor and other IoT data (devices) are some of the new data sources. Data temporality, spatiality or reality were seldom considered during the closed systems era. Organisations also need to pay attention to the structuredness and internality of data. We introduced the federative approach to data governance [3] to include the consequences of these developments into the data governance knowledge base with the objective of helping organisations to better govern their data in open systems environments.

In the development of the federative approach, we had to challenge the prior prevailing canonical ontological stance to MDM research [3,4]. After introducing the MDM concept, the customer, product and other MDM data were consolidated and stored from various ISs into an MDM database and/or MDM IS. Master data quality improvements, however, were not achieved. Master data compiled from multiple IS databases proved inconsistent and fragmented with different and/or missing values for similar data attributes, e.g., patient data attributes. The next logical step was to propose the harmonisation and cleansing of data with values of the best available data, that is, the idea of the so-called "golden record" MDM approach, also called the single

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version of truth approach [10,11,29,30 chapter 7]. The proposed action is to identify the golden record values of each MDM record, e.g., patient data records and, through harmonisation and cleansing, to replace all other values with the golden value. Other values are deemed low-quality, erroneous or anomalous. After that, only the MDM data storage with golden values should be used to create and maintain master data as well as to link master data to transactions and other data types. The canonical ontology assumption is that the meaning and interpretation of data are similar across all data usage situations and contexts, currently and over time, in present locations and across locations, as well as in reality and in augmented reality.

We had two reasons to challenge the canonical approach of MDM research. Ontologically, we built the federative approach on the premise that the data's social use context determines its meaning. According to this view, data are an abstract reflection and representation of reality [6,31]. Similar data, e.g., patient data, have different significant meanings in different social data use contexts, at different times and in different locations. For example, the perceived real worlds of healthcare professionals and patients are dissimilar up to the point of differences in vocabulary [12]. Similarly, although the social security identification of a patient has a unique value, the current name and address of a patient could be of interest in one data use context, whereas the name (e.g., maiden name), family ties and address history could be relevant in another. The replacement of multiple values with one true value would destroy valuable data. Secondly, in open systems environments, user organisations do not carry out data modelling of the data storages used by them and are even seldom able to influence the data modelling of the data they use. For example, in one IS, the a patient's name could be 32 characters long, but in the golden record database, it could be 48. A healthcare organisation is most likely unable to change the number of characters to 48 in all relevant ISs due to legal reasons and lack of IS development capabilities. Moreover, software markets are global. Some ISs used in Finnish healthcare organisations are purchased from international software vendors. One of the consequences is

that the data models of international ISs do not include the Finnish social security (person) identification.

In (canonical) MDM research, the issues discussed above have been addressed by dividing master data into global and local master data [10,11,29,30]. When the number of data storages deployed by an organisation grows due to the increase in volume, sources, dimensionality and other characteristics of data, the number of global master data attributes tend to decrease, e.g., to the social security identification as the only global patient data. The (canonical) MDM research has also proposed that the local values of master data could be mapped to golden values [30]. For example, the various representations of patient data in the internal and external data storages used by a healthcare organisation could be mapped to an MDM database. This proposal is actually similar to the federative approach with differences in concepts used. The federative approach proposes that data integration and interoperability are achieved by first identifying the attributes shared between federated data storages and by then describing the metadata (mappings) of the shared attributes. It is possible to create a list of shared attributes together with mapping definitions and to call that an MDM IS [5,14]. In summary, the canonical and federative approaches are not antagonistic but complementary. Data modelling needs to produce a canonical data model in a specific use context. The federative approach is needed to make data interoperable between various canonical use contexts.

The data federation between data storages starts from the identification of shared attributes, e.g., citizen identification. The key question is, what do we need to know about each shared attribute to establish interoperability? We need to know where to find the data, its format, cardinality and other technical metadata properties. Secondly, we need to know how the values of shared attributes are created, entered and maintained in each federated data storage and how data flows. For example, if we want to compile human body temperature data from multiple data storages, we need to know what measurement device and procedure were used in each measurement and who/what device created and entered that data. Should there be data quality issues,

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we are then able to ask the right person or check the condition of a specific context. Finally, we need to know what data values mean in their social use contexts. For example, normal human body temperature varies depending on the time of the day, prior activity and healthcare treatment. Definitions of the technical, information flow and socio-contextual metadata of shared attributes make meaningful federation, integration and interoperability of data storages possible. In [3], we proposed a list of metadata properties that must be defined for data federation and governance. We used that list to develop the federation matrixes, i.e., to make data interoperable in real-world use cases and, by doing so, to probe the federative approach.

As discussed above, the federative approach applies ontologies, which are a means of describing the meaning of data in their real-world contexts [31] as represented in ISs. Although the real world changes constantly, an ontology explains the purpose of data creation, use and storage, as well as the socio-contextual meaning of data in each phase of the data life cycle. We reason that ontologies support patient understanding when healthcare data created and managed by healthcare professionals—reflecting their real world—are given to patients for interpretation and use. We reason that the number of perceived data deficiencies decreases and the feeling of empowerment increases, if and when a patient understands the premises of data creation, processing, storing and usage.

The methodology of creating data interoperability in the breast cancer case and using the case results in the citizen empowerment research

We used the federative approach at a university hospital to help the data specialists of the hospital. We demonstrated how to make the data of breast cancer patients and their treatments interoperable. We used Yin's [32] guidelines on case studies regarding data collection, analysis and reporting the findings, such as the use of interview protocols, alternative sources of evidence and cross-checking analysis results. In theory-building, we followed Eisenhardt's [33] guidelines. The breast cancer study is described in more detail in [5,13]. Here, we revisit the breast cancer study, especially the federation matrixes, to describe and reason how the approach and matrixes could be used to make PHR data [18] interoperable in empowering citizens' healthcare.

In the creation of data federation matrix tools, we used a top-down approach. In the first phase, we identified relevant data storages. In the second phase, we described the shared attributes that made the data interoperable. These attributes, shown in Figure 1, had to be described for each federated data storage, as they are focal in recognising and linking breast cancer events. In the third phase, we described the IS technical, information processing and socio-contextual metadata of each shared attribute, as shown in Figure 2. It is worth mentioning that recorded values of shared attributes did not always exist in the federated data storages but that they had to be reasoned by using logical rules. The TMN code is a good example. The logic of the federation matrixes is to establish data interoperability without "mixing apples and oranges". Finally, we note that the matrix shown in Figure 2 is highly illustrative and conceptual. We excluded all detailed cell descriptions and most matrix rows from. Still, we believe that the conceptual idea of this data federation matrix is understandable.

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	Patient IS	Laboratory IS	Surgical IS	Radiotherapy IS	Pathology IS	Information System N
Social security identification	X	X	X	X	X	X
(Cancer) diagnosis code	X	X	X	X	X	X
Tumor node metastasis (TNM) code	X	X	X	X	X	X
Date of events	X	X	X	X	X	X

Figure 1. Federation matrix to identify shared attributes in the ISs and data storages to be federated.

Personal ID / Diagnosis / TNM code	Patient IS	Laboratory IS	Surgical IS	Radiotherapy IS	Pathology IS	Information System N
IS Technical metadata						
- Description						
- Field name/length etc.						
Information processing metadata						
- Place of initial data entry creation						
- Creator of data entry						
- Responsible for data storage						
Socio-contextual metadata						
- Meaning when saving patient data						
- Meaning for treatments						
- Meaning in diagnosis						
- Meaning for medication						

Figure 2. Federation matrix to define the metadata properties of shared data attributes in federated ISs.

Like its results, the breast cancer research produced enhanced data federation matrixes, improved guidelines to create data interoperability, and evidence of the use value of the federative approach. The research confirmed the importance of describing all three categories of shared metadata attribute characteristics, not just technical and socio-contextual (as advocated, e.g., in 27]. Data quality defects, such as wrong values, are predominantly caused by errors made during data entry and re-entry (informational metadata). Similarly, differ-

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ent data meanings do not necessarily signify data quality defects. Secondly, persons supporting the creation of data interoperability should be familiar with the ontologies of federated data storages, which means that they need to know the various data usage contexts of federated data. As the main finding of the cancer research, we discovered that, in addition to master data interoperability, the federative approach is able to create interoperability between any data sets that have shared attributes.

The data federation matrixes shown in Figures 1 and 2 are simplified from the actual matrixes as the objective here is to illustrate the ideas behind them. Figure 1 describes shared attributes that were needed to create data interoperability between the federated data storages. In the breast cancer case, four attributes were enough. Initially, we identified three shared attributes: social security identification, cancer diagnosis code and TNM code. Social security identification was used to identify a patient. The cancer diagnosis code was used to ensure that the patient had breast cancer. The tumour node metastasis (TNM) code told us the size and extent of the cancer tumour (T), the extent of lymph nodes (N) and the distinct metastasis (M). The TNM code value had to be reasoned from other data attributes since a malignant breast cancer value did not exist prior to a positive confirmation. Later, we added the fourth shared attribute, the date of events. Malignant breast cancer spreads rapidly, and thus, all breast cancer transactions needed to happen within a short period of time. The number of shared attributes could be different in other data interoperability contexts.

We filled the matrixes with one specialist user group at a time. Their expertise was needed to describe information processing and socio-contextual metadata. A similar practice is often used in the design science research (DSR) methodology [34]. In our opinion, this approach also works to create interoperability in PRH data.

Findings – citizen empowerment, ontologies, health literacy and the influence of the data federation on these issues

The findings of the literature review indicate that citizen empowerment through better quality and more complete healthcare data may have several positive outcomes. It improves citizens' perceptions about the quality of healthcare services and processes and encourages them to take better care of themselves. Positive outcomes may then reduce the need for healthcare services and improve the effectiveness of treatments when needed. Availability and easy access to healthcare data are important for citizen empowerment. Both the literature review and the findings of the breast cancer research showed that healthcare data are currently scattered across multiple inconsistent data storages. We reason that the federative approach, with its matrixes, can help, as the purpose is to facilitate the compilation of data from different data storages with the objective of creating data interoperability.

The ability to compile and make data interoperable requires that the content and meaning of federated data is known, that is, the ontologies of data need to be described. The current data ontologies of healthcare ISs have been discovered to be too complex for citizens, healthcare professionals, or even both in understanding the personal health status of a citizen. The gap between real-world situations captured in ISs' data and the ontologies of data presentations is seen as the reason for this phenomenon [12]. In our opinion, the crafting of data representation ontologies based on citizens' health needs is the most promising way forward. Our federation matrixes are ontologies since they describe the meaning of data in federated data storages that "represent the real world and its changes" [31].

One of the key findings in breast cancer research was that there need to be clear objectives to achieve meaningful data interoperability. Specific citizen health needs should be the data federation's starting point. As an example, data related to type II diabetes could be made interoperable with the objective of preventing new type II diabetes cases and to improve the quality of life for those diagnosed with the disease. This requires cooper-

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ation between healthcare professionals, data management specialists, healthcare IS developers and citizens. Citizens need support from healthcare professionals to understand the meaning of data values and from data management and IS development specialists to compile data from various data storages. The use of data federation matrixes facilitates the federation of data from visual sensor data to patient register data and from IoT devices to traditional databases.

Health literacy is connected to citizen empowerment through patient behaviour [26]. We reason that the data federation matrixes contribute to health literacy; they provide citizens with detailed descriptions about data made interoperable with their original meanings in multiple social contexts. In addition, they show how shared attributes are related and how their values are entered and processed. Higher health literacy may then result in improved health behaviour and may further citizen empowerment. For example, a recent study associated higher health literacy with several health advantages among senior Finns [35].

Citizen empowerment through new technologies like sensors, home monitoring, and peer support via the web and blogs may create similar effects. Global data, information and knowledge exchange, and data distribution standards support bi-directional communication [12]. On the other hand, the large and continuously growing number of actors in the ecosystems of new technologies create challenges for data interoperability. The federative approach shows that it is insufficient to describe only the structure and syntactical meaning of healthcare data [27]. Data interoperability also requires that the data processing properties and the socio-contextual meaning of data are described. Data silos need to be opened for data exchange and federation, similar to healthcare processes [19].

Discussion and conclusions

We reviewed citizen empowerment and health literature as well as data federation literature. We described the ontological stance and the data federation matrix tools of the federative approach and showed how they

were used in breast cancer research. We then suggested how the federative approach and the data federation matrixes could be used to make healthcare data interoperable by combining data from multiple data storages and to thus empower citizens. Based on the present theoretical study, we reasoned and proposed that the federative approach and the data federation matrixes are useful tools to create data interoperability for citizens' healthcare data. This is our answer to RQ1. We reasoned that the use of the data federation matrixes enables the establishment of interoperability to data created with new technology tools and to data created over time. We suggest that this improves citizens' health literacy and thus empowers them. That is our response to RQ2. We also proposed that the federative approach and the data federation matrixes support citizen healthcare empowerment.

Clarified and interoperational data from multiple data storages benefit citizens by providing a clearer understanding of their health status. Higher health literacy has a similar effect. Increased opportunities to understand and compare the real worlds of various healthcare professionals and citizens with the potential of improved communication and support form healthcare professionals are the other benefits of the federative approach to citizens in the use of healthcare data. This is our response to RQ3.

The rapid development of (healthcare) IS technology and digital explosion appear to continue in the foreseeable future. The ability to process, manage and govern all the time-growing number of data storages and data volume is needed. At the same time, combining citizen-centric and healthcare-centric perspectives to data processing, management and governance are needed to establish seamless healthcare service processes. Data interoperability is needed to support this. Similar to some other researchers [19,27], we reason that the compiling of (healthcare) data into one data storage, e.g., a data lake, is not enough to make data interoperable, even if technical and capacity limitations could be solved. The federative approach emerged from the criticism of a comparable idea to just bring master data into one (large) master data storage. The federative approach and the data federation matrixes are useful in

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establishing needed links between various (healthcare) data storages, whether they are centralised (data lakes) or distributed (at the premises of healthcare organisations).

We did not collect new empirical data and made propositions about the usefulness of the federative approach based on the literature review and logical reasoning from the breast cancer case we conducted earlier. It is possible to remove this major limitation of our study by conducting an empirical study and by proving or falsifying propositions made here. If this kind of study were conducted, we propose using the federative approach to data governance. We have used the federation matrixes in several cases in different industries in one country. Despite these limitations, our article contributes to research on the federative approach to data governance and to research on citizens' healthcare data usage and empowerment. Our study also offers several venues to the practice-oriented further development of the federation matrix tools. Our advice to practitioners is to use, evaluate and further develop the data federation matrix tools. Our advice to researchers is to continue the theoretical and empirical research on the federative approach.

Conflict of interest statement

Neither of the authors has conflicting interests to declare.

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