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Could private companies share their data to public organizations: a scoping review

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Abstract

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Introduction: In the age of big data and artificial intelligence, data has become even more important asset to health care sector than before. To be able to utilize these technologies and get better research and innovation results, organizations need to widen their own datasets by sharing data with other parties. The purpose of this thesis was to find out, could private companies share their data to public organizations for health care research purposes and if yes, what would be the motivation and obstacles for that.

Method: Sources that were used in this scoping review were taken searched in PubMed, CINAHL Complete (Ebsco) and ProQuest Central databases. These databases were selected to find relevant sources on health care sector. Key words for searches were selected by using PIO model and with a pilot search. From actual first search, articles were selected based on titles. Next phase consisted of abstract review and the remaining sources were analysed on full-text level.

Results: Nine articles were selected to final analysis. Sources were analysed to find out what kind of motivation factors or obstacles private companies have faced when discussing about sharing their own data with public sector for health care research purposes. Eight articles discussed on data sharing either from public organizations or individuals' point of view. As a summary it can be said that individuals feel comfortable to share their data with public sector, but the same didn't apply to private sector. A few studies also showed that public sector has been sharing their data to private companies and that has caused discussion on the justification of the data sharing.

Conclusion: Research questions could not be answered directly based on the sources found in this systematic review. At the moment, researchers focus seems to be on individuals and public organizations motives for data sharing.

Keywords: data sharing, health care research, motivation, obstacles, private companies

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1 Introduction

Data is having a new of role in a globalized environment where fast developing technology such as big data and artificial intelligence (AI) plays big role. Data and especially data sharing enables new innovations, better information for decision making and in health care sector that should also mean more personalized care in future. A lot of research has already been done for finding out, what benefits the new data processing models and practices can bring to health care sector. But the growing complexity of systems, stakeholders, and ecosystems, unsuccessful data sharing initiatives, cybersecurity incidents and evolving regulations have increased lack of clarity and trust be the public. Because of this, data sharing is becoming in increasingly controversial subject and there are a lot of discussion and concerns about how and why health care data are shared. (Loundsbury et al. 2021, p. 2).

In Finland, On December 2022, Finland's Ministry of Social Affairs and Health published National strategic objectives for healthcare and social welfare for 2023–2026. Among other objectives data management, digitalization and research were raised to focus areas. (Sosiaali- ja terveysministeriö, 2022). One part of achieving the set objectives, both public – and private organizations needs to have access to large amount of data and to get better results, they should be able to share data between organizations. Without this, it will not be possible to develop health care organizations and social services in an efficient way and to ensure that all legal requirements for the right of health care will be met.

The subject for this thesis came from National Institute of Health and Welfare (THL) that started a program, which aim was to find out how THL can use health related data and AI for preventive health care purposes. The program is named Palvelujärjestelmän ulkopuolella kertyvä tieto hyvinvoinnin ja terveyden edistämisen johtamisen käyttöön (PUHTI) and its aim is to develop and make a

pilot of a method for collecting, analysing, and enriching data from sources outside THL's own "data warehouses". (THL, 2023). THL has a lot of own data, but the target of this program is to get the data also from private sector like private companies and non-profit organizations. When the program was in a preparing phase, there was a lot of discussion on how THL could get the data from private sector on a longer run, while there is no legal obligations for private organizations to disclose data even for research purposes. In addition, data protection legislation brings own challenges for the data collection.

Data has always been important for healthcare improvement but, only certain types of data like health records and clinical trial data, were on previous years considered to have direct health relevance. In recent years a number of seemingly irrelevant and unrelated information have become important, as it has been noted that they can provide valuable insights into the health and health-related behaviour of individuals and populations. (Horn & Kerasidou, 2020, p. 2). While public sector has health records and clinical trial data, they usually don't have data that is collected from individuals by private companies like grocery stores, companies that offers wearables like watches or information on what kind of discussions individuals have in different chat forums (unless those are totally public), This thesis aims to find out, what would be the reasons that motivates private companies to share their data and on the other hand, what are the biggest reasons they don't want to do that.

2 Theoretical background

"Data helps save lives", says Marta Aguilar in her article that aims to explain, why data analytics is changing the world and why we all should care about it. One of the three topics she points out relates to medical industry, where data has been used to improve research outcomes. By collecting huge amounts of data, and getting a holistic view of patient's health, medical professionals are able e.g. to give recommendations for preventive care. Another reason why we should care about data is that it runs the business world. Data is not only big

corporations interest like in the past and Aguilar thinks that it is impossible to imagine a world without it. (Aguilar, 2022).

According to European Commission, data is an essential building block of modern societies and “if used correctly, data can bring benefits to citizens such as personalised medicines, cheaper public services, safer and cleaner public transport, and much more”. On 2020 EU created a European Data Strategy, that “sets up the goals and rules to exploit data in a clear and trusted way for the benefits of citizens, businesses, researchers and public administrations”. (Commission, 2022). According to European Data Strategy, data-driven innovation will bring enormous benefits for citizens, for example through improved personalised medicine. Citizens should be empowered to make better decisions based on insights gleaned from nonpersonal data. And that data should be available to all – whether public or private, big or small, start-up or giant. This will help society to get the most out of innovation and competition and ensure that everyone benefits from a digital dividend. (Commission, 2020, p. 1).

Usage of data is not seen only as a positive thing. Especially during the past years data sharing and the usage of data has caused a lot of concerns among individuals, researchers and lawyers. On year 2018 Geoff Watts brought up a contrast between UK Health Data Research press release and The Guardian newspaper’s headline. Press release was titled “Pioneering data research centres to enable cutting-edge research and innovation” and Guardian’s headline on the same development was titled “Privacy fears as millions of NHS patient’s records go to ‘data hubs’”. Researchers wanted to point out the benefits of sharing data, while the newspaper wanted to draw attention to the risks. (Watts, 2019). Year 2018 was important for data protection perspective, because new EU General Data Protection Regulation (EU) 2016/679, (GDPR) came into force, and it caused a lot of work for both public and private sectors. What GDPR means in practise is, that all companies, researchers, and public

organizations needs to take data protection aspects into account, when they plan to use data, which is linked to individuals either directly or indirectly.

Now it seems, that there are two contradictory views on the data usage. One part highlights the benefits of it, the other part raises risks that data collection and usage might cause especially for individuals. In addition, there are parties, that aim to share both sides of the topic. For example Deloitte has written an article where it raises data sharing challenges from many perspectives, but discusses also positive aspects. (Deloitte, 2023). Another aspect that shares opinions is the ownership of data. Should the data be open for everyone or should the data holders have the right to decide if they want to share the data or not. The answer for this varies also depending on the data that is in the scope of discussion. For personal data both legal and public opinions are stricter than for other types of data. Public opinion can be seen in research articles that has been selected in the scope of this thesis. Legal aspects come mainly from GDPR.

2.1 Definition of data

According to Merriam-Webster, data has three meanings:

- 1) actual information (such as measurements or statistics) used as a basis for reasoning, discussion, or calculation,
- 2) information in digital form that can be transmitted or processed and
- 3) information output by a sensing device or organ that includes both useful and irrelevant or redundant information and must be processed to be meaningful (Merriam-Webster, 2023).

Data Governance Act (EU) 2018/1724 is one of the newest data related regulations in EU. This regulation sets the boundaries of certain categories of data held by public sector bodies. Therefore, it's not directly applicable for the

scope of this thesis, but the definitions of data give a good view on how legislator sees data at the moment. According to article 2, 'Data' means any digital representation of acts, facts or information and any compilation of such acts, facts or information, including in the form of sound, visual or audio-visual recording.

EU regulation on a framework for the free flow of non-personal data in the European Union (EU) 2018/1807 has a following definition for data in article 3.1: 'data' means data other than personal data as defined in point (1) of Article 4 of Regulation (EU) 2016/679. By this legislation EU wants to ensure "a free flow of data in Europe, allowing companies and public administrations to store and process non-personal data wherever they choose". The regulation aims at removing obstacles to the free movement of non-personal data between different EU countries and IT systems in Europe. (Commission, 2022). With this regulation EU wants to emphasize the value of the data and ensure that EU countries and companies will use data effectively and get the benefits out of it. Because GDPR has clear definition on personal data, it has been easy for legislator to say, that this law applies to everything else.

Like these examples shows, data has broad definitions, and the meaning depends on the context. Sometimes data is also used as a synonym for information and that's visible also in the Data Governance Act. Because data needs always a context to get a reasonable meaning, term data itself doesn't actually answer to the question on what does data mean. It can be numerical information like statistics or codes, it can be text, results from laboratory samples or it can be audio visual recording. It can also be in different formats like paper, computer software, crypted or in clear format. It can be only attributes that are part of some bigger data sets, or it can be part of huge storages, where different types of data is stored. While we now have an idea of a data, next section will have a closer look at the types of data that will be applicable for this thesis.

2.2 Different types of data

Health data or health-related data

GDPR article 4 paragraph 15 talks about 'data concerning health' that means personal data related to physical or mental health of a natural person, including the provision of health care services, which reveal information about his or her health status.

Data collected in contexts of public health and health care, is the most obviously considered health-related data, but awareness is emerging about health-related uses of data collected outside of these contexts as well (e.g., through digital commerce or social media (Shaw & Sekalala, 2023)). This is a concrete example on linking data to certain situation or context. While traditionally only e.g., laboratory test results were seen as a health-related data, now also information about the age, gender or a country where a person is living can be seen as a health-related data.

Personal data

Personal data is defined in General Data Protection Regulation (GDPR) in article 4 paragraph 1 'personal data' means any information relating to an identified or identifiable natural person ('data subject'); an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person. Although the scope of this thesis was not limited to personal data, it's a key term when one is discussing on health-related data, because the used data has often some kind of link to personal data. Like seen in the definition of the GDPR, personal data is defined really broadly and almost all data that can be linked to an individual person can be seen as a personal data.

And that's important to notice, because in those cases data owners needs to follow the data protection legislation like GDPR.

Non-personal data

The term non-personal data has been developed over the years to describe data that does not contain any link to personal data. In legislation, non-personal data is often defined through GDPR that has a definition for personal data in Article 4 paragraph 1. For example, Regulation on a framework for the free flow of non-personal data in the (EU 2018/1807), says in article 2 paragraph 1, that the regulation applies to the processing of electronic data other than personal data in the Union. There is sometimes quite a fine line between personal data and non-personal data, and it also changes over time due to different legal interpretations and technical development. Ten years ago, it was possible that if we removed from a certain dataset all indicators to an individual person's name, the remaining data could be treated as a non-personal data. Today it is likely, that if the data removal would be done in a same way than ten years ago, it could be easily linked again to the identifiable person, which means, that all GDPR rules applies. GDPR talks about 'pseudonymization' in article 4 paragraph 5 which means processing of personal data in such a manner that the personal data can no longer be attributed to a specific data subject without the use of additional information, provided that such additional information is kept separately and is subject to technical and organisational measures to ensure that the personal data are not attributed to an identified or identifiable natural person. In practise this means, that this kind of data cannot be categorised as non-personal data, because the link exists.

To receive a status, where data can be seen as a non-personal data it requires that a) all identifiable information has been permanently removed from original data sets and data has been anonymised by this process or b) data didn't have any link to any identifiable persons at any stage.

2.3 Secondary use of data

Secondary use of data has at least two different meanings. It can relate to usage of any data that the owner wants to use for other purposes than which it was originally collected. This is how data is used e.g., while developing artificial intelligence. For example, google uses the data it has gathered via google searches to train software. Secondary use can also mean that the company finds out, that the data they have collected for offering better customer service for their own customers, can be used by public organization some other purposes.

If secondary use of data relates to social and health care or personal data, there are regulation that states, what secondary use means and what are the boundaries on how data can be shared. According to Social and Health Data Permit Authority (Findata), primary use of health and social data means the purpose for which the data was originally saved in the customer register and/or patient register. Secondary use means the use of the same data for purposes other than the primary use. Legitimate secondary purposes of use include scientific research, statistics, development and innovation activities, education, knowledge management, steering and supervision by authorities and the planning and reporting duty of an authority. (Findata, n.d.). By stating legitimate secondary purposes, Findata refers to GDPR and Act on Secondary Use of Health and Social Data 552/2019 (Secondary Use Act).

GDPR sets strict rules on sharing personal data and while health related data belongs to special categories of data, there are even more strict rules on sharing that. On the other hand, GDPR article 9 has an exception for using personal data to scientific research purposes. Because GDPR allows member states to have additional regulation concerning health related data, Finland has taken into use the Secondary Use Act that was mentioned already in previous chapter. In Finland, social welfare and health data have been used for secondary purposes for decades but there have not been uniform practises for

the processing of data. The new act brings centralized authorisation procedure and processing of data that will improve data security and citizens' data protection. (Findata, n.d.). This law applies only for certain type of health and social data, and it does not cover all private sector companies. This is one of the reasons, why the law does not help public sector in receiving other data that the one which is defined in the law. Although this law has been a big step forward in health data sharing, it does not solve the problem on how public sector could get other types of data for research purposes. It also indicates that there has to be challenges in sharing company data without regulation, if that was needed even for public sector that already had processes and experience on data sharing.

2.4 Data sharing

The value of data lies in its use and re-use (Commission, 2020, p. 7). This is the key of this thesis as well. It aims to find out the motives and obstacles for private companies to share the data they have already collected for their own use, to be re-used for research purposes. In practise it means re-usage of the data.

Currently there is not enough data available for innovative re-use, including for the development of artificial intelligence. The issues can be grouped according to who is the data holder and who is the data user, but also depend on the nature of data involved (i.e., personal data, non-personal data, or mixed datasets combining the two). Commission has listed the main issues related to data availability:

1. Use of public sector information by business (government-to-business – G2B – data sharing)
 - Data has been produced with public money and should therefore benefit society. The challenge is, that high-value datasets are often not available under the same conditions across the EU

2. Sharing and use of privately-held data by other companies (business-to-business – B2B – data-sharing).
 - In spite of the economic potential, data sharing between companies has not taken off at sufficient scale. This is due to a lack of economic incentives (including the fear of losing a competitive edge), lack of trust between economic operators that the data will be used in line with contractual agreements, imbalances in negotiating power, the fear of misappropriation of the data by third parties, and a lack of legal clarity on who can do what with the data
3. Use of privately-held data by government authorities (business-to-government – B2G – data sharing).
 - There is currently not enough private sector data available for use by the public sector.
 - Based on the expert groups recommendations it can be assumed that the reason for lacking data is the lack of data-sharing culture, the lack of appropriate incentives for sharing data and unclarities on regulatory frameworks related to public sector's re-use for the public interest of privately-held data. (Commission, 2022, p. 7 to 9).

Sitra brings another view on data sharing and discusses about trustworthy sharing and usage of data. It sees that although EU has brought new legislation like Data Act and Data Governance Act to boost data sharing and usage between organisations, it does not help companies due to an overwhelming legislation. New data sharing rules are developed at the same time in a different levels which makes it difficult for companies to follow the rules. Sitra states that “For businesses wishing to participate in data sharing, it shouldn’t be necessary

to understand all the complexities. Ideally, complying with the data-sharing rules should be effortless, even automated”. (Pol & Lehtonen, 2023).

Data sharing is not an easy subject, because of broad and new legislation and different interest of the parties that owns the data. It seems, that there’s a common understanding about the value of data sharing, but after that there seems to be more challenges than results at the moment. In this short introduction we have discussed about two challenges, but there is still one big topic that relates to data ecosystems and data sharing technical challenges. These cannot be presented at this thesis but needed to mention to give a view on the different angles of the data sharing field.

3 Aim, purpose and research questions

Aim of the thesis is to find out if this topic has been studied before and if yes, are there some big obstacles or positive signs towards data sharing found in previous studies.

The purpose of the thesis is to find out what motivates private companies to share their data for health care purposes and to see what are the obstacles that prevents these organizations to share their data.

Research questions are:

1. What are the reasons that prevent private companies from sharing their data for health care research?
2. What are the reasons that motivate private companies to share their data for health care research?

4 Research methods and data collection

At the beginning of this thesis project, the plan was to do a literature review to find out what would be the motivation for private sector to share their data. Quite fast it came obvious that there is not enough academic research or books written about this topic in a way that it would have been possible to do the thesis with that method. The method was changed to scoping review. Scoping reviews draw on evidence from any research methodology and may also include evidence from non-research sources, such as policy. In this manner, scoping reviews provide a comprehensive overview to address broader review questions than traditionally more specific systematic reviews of effectiveness or qualitative evidence. (Peters, et al., 2020). While systematic reviews are useful for answering clearly defined questions, scoping reviews are useful for answering more broader questions. Because of the different nature of these two methodologies, also reporting items are different. PRISMA extension for Scoping Reviews (PRISMA-ScR) was developed to better describe the research methods and results (Tricco, et al., 2018). The assumption is that the scoping review that consists of systematic search from selected professional databases will bring information about the key definitions in the literature, examine what kind of research has been conducted in the health care sector around this topic and identify if there are gaps in the literature.

4.1 Search strategy

The search strategy aimed to find studies, articles and opinions that contains selected pre-defined terms in titles, abstracts and key words. The identification of key words was selected via research questions by using PIO model. P indicates population (organization), I indicates participants and O outcome.

- 1 What are the reasons that prevent (O) private organizations (P) from sharing their data for health care (I) research?

- 2 What are the reasons that (O) motivate private organizations (P) to share their data for health care (I) research?

4.1.1 Key words

Search protocol started with pilot search that was done by using the terms from PIO model. Initial pilot search was done with the informaticist on September 2022. It came out that it was difficult to find material with the original key words (prevent, private organization, data sharing, health care research). After pilot search, a few more test searches were done in the selected databases. Private organizations were replaced by private company, while it brought better matches in searches. Other synonyms were also tested, but those didn't bring any valuable references and for that reason the key words were limited to the words shown in table 1.

Table 1. Key words used in database searches.

PIO 1		Key words
P	private organization	private company
I	share data for health care research	sharing data, data sharing, sharing of data
O	prevention	prevent
PIO 2		Key words
P	private organization	private company
I	share data for health care research	sharing data, data sharing, sharing of data
O	motivation	motivation

Key words were used by different combinations in different databases to ensure that all potential sources can be found. One of the initial findings was, that the term health care research brought a lot of articles that focused on research as such but didn't bring any articles where data sharing would have had some role. To avoid too wide search results, that do not answer to the research questions, it was decided that the combinations used can vary in different databases.

4.1.2 Inclusion and exclusion criteria

Inclusion and exclusion criteria set the boundaries for the systematic review. They are determined after setting the research question usually before the search is conducted, however scoping searches may need to be undertaken to determine appropriate criteria (The University of Melbourne, 2023). This thesis contains only a few criteria, due to the reason that the pre-search indicated, that there is quite a few studies that fit to the scope of research questions. By widening the search scope, the assumption was that there will be more potential articles, that can be taken for closer review. Concrete criteria are show in in table 2 below.

Table 2. Inclusion and Exclusion Criteria.

Criteria	
Inclusion	Exclusion
Language: english or finnish	Books
Timeframe: 3 yers from April 2023	Bachelor-level thesis, articles that are categorized to other fields than health care or similar - e.g., business
Studies, reviews, editorials, articles	Dublicates
Source contained more than one key words	

4.2 Databases

Databases were selected based on initial searches and the nature of the database. Databases with descriptions are listed in table 3. Databases were selected in a way, that the aim was to find sources that are written in health care field to ensure, that the search results would better fit to the research questions. Data sharing as a topic will bring a huge amount of hits, if databases contain also e.g. legal articles. In addition, the selected databases are in professional use and in majority contains high quality articles, although the inclusion criteria made it possible to take also commercial articles into account.

Table 3. Databases used in search process.

Database	Description (Metropolia LibGuides, 2022)
PubMed	Medicine, biomedicine, and life sciences
CINAHL Complete (Ebsco)	Nursing, biomedicine, health sciences, and many allied health disciplines
ProQuest Central	Multidisciplinary. e.g., health and medicine, social services, arts, education, psychology.

4.3 Search results

The concrete search process and used key words is described in table 4. The first search in CINAHL and ProQuest brought huge amount of hits when the same key words combination was used than in PubMed. In CINAHL initial search brought 2915 hits and to lower that, search result were limited to “full text + abstract available. That lowered the number to 981. Only those 50 first hits were reviewed where the source contained more than 1 key words. With ProQuest, initial search had 9257 hits and there the search was limited only to health care related sources and scholarly journals. That lowered the number to 2990. In this case only those 80 first hits were reviewed where the source contained more than 1 key word.

In a first phase the sources were selected based on header and all duplicates were removed. In a second phase, all selected articles abstracts were reviewed, and sources were selected for full text review. At the full review phase, there were still a few sources that were decided to out scope, due to the reason that it didn't answer for the research questions, or the content of the paper didn't brought any new information for the topic. Search results management was handled by Zotero-software.

Table 4. Key words and number of selected sources

Database	Key words and combinations	Search result	Sources selected based on header	Sources selected based on abstracts	Sources selected for final analysis based on full texts
PubMed	private company AND data sharing AND health care research private company AND sharing data AND health care research AND prevent* health care data AND sharing AND research AND private organization AND motivation	165	18	10	6
CINAHL Complete (Ebsco)	private company AND data sharing AND health care research	981	8	2	1
ProQuest	private company data sharing to public health care research	2990	5	4	2

5 Data charting

Scoping review authors should only extract data items that are relevant to the scoping review questions. Given the breadth of scoping review questions and the varied sources of evidence that can be included, additional relevant data items may be identified by scoping review authors during the process of extraction from included sources. (Pollock, et al., 2023). Data charting for this thesis was prepared before data search. Key characteristics selected were author/reference information, aim and purpose, design, data and methods and main results of the selected source. After full review of the sources, it was decided that the country information would be valuable information to put the research findings in a right context and for that reason it was added to final chart. The entire data charting can be found in appendix 1.

In total nine articles were selected for the final analysis. Among these articles three were theoretical analyses, three were different types of surveys, and then there were one review, one study, and one research. All articles were published between 2020 and 2022. The origin of the sources were from England (n=4), Australia (n=2), USA (n=2), Denmark and Brazil (=1).

5.1 Quality appraisal

Because of the scope of this study there was not any quality appraisal tool that would have directly fitted to this study. After reviewing several quality appraisal checklists like PRISMA, AMSTAR, MMAT and SANRA, the JBI Critical appraisal checklist for text and opinion papers were selected to be used in this thesis. The nature of textual or opinion-based reviews is that they do not rely upon evidence in the form of primary research and, therefore, elements of the protocol will vary from reviews drawing on primary research as the types of papers of interest. However, the principals of developing a clearly documented protocol, incorporating a priori criteria and methods are – as for any systematic review – considered essential (McArthur , et al., 2020).

The quality questions were following:

1. Is the source of the opinion clearly identified?
2. Does the source of opinion have standing in the field of expertise?
3. Is the stated position the result of an analytical process, and is there logic in the opinion expressed?
4. Is there reference to the extant literature?
5. Is any incongruence with the literature/sources logically defended?

All sources selected based on full read of the article passed also the quality assessment. Articles were professional papers and while there wasn't any newspaper articles, or other similar non-academic papers, no significant quality issues were found and all sources were selected to final analysis. See details on table 5 below.

Table 5. Quality assessment of the selected articles.

Quality assessment						
Date: 4.5.2023						
Name	Assessment criteria of the studies					Decision
	1	2	3	4	5	
(Bradley, et al., 2022) Healthcare systems must get fair value for their data	Yes	Yes	Yes	Yes	N/A	Include
(Braunack-Mayer, et al., 2021) Sharing Government Health Data With the Private Sector: Community Attitudes Survey	Yes	Yes	Yes	Yes	N/A	Include
(Davis, et al., 2021) Public-Private Partnerships: Compound and Data Sharing in Drug Discovery and Development	Yes	Yes	Yes	Yes	N/A	Include
(Giovanna, et al., 2021) Public Attitudes to Digital Health Research Repositories: Cross- sectional International Survey	Yes	Yes	Yes	Yes	Yes	Include
(Hendricks-Sturup & Lu, 2020) What motivates the sharing of consumer-generated genomic information?	Yes	Yes	Yes	Yes	N/A	Include
(Horn , R. & Kerasidou, A., 2020) Sharing whilst caring: solidarity and public trust in a data-driven healthcare system	Yes	Yes	Yes	Yes	N/A	Include
(Jones , et al., 2022) Public opinion on sharing data from health services for clinical and research purposes without explicit consent: an anonymous online survey in the UK.	Yes	Yes	Yes	Yes	N/A	Include
(Lounsbury, et al., 2021) Opening a “Can of Worms” to Explore the Public's Hopes and Fears About Health Care Data Sharing: Qualitative Study	Yes	Yes	Yes	Yes	N/A	Include
(Street, et al., 2021) Sharing administrative health data with private industry: A report on two citizens' juries	Yes	Yes	Yes	Yes	N/A	Include
1. Is the source of the opinion clearly identified?						
2. Does the source of opinion have standing in the field of expertise?						
3. Is the stated position the result of an analytical process, and is there logic in the opinion expressed?						
4. Is there reference to the extant literature?						
5. Is any incongruence with the literature/sources logically defended?						
Questions 1-5 : Yes / No / Not applicable (N/A)						
Decision: Include / Exclude						

6 Findings

Surprisingly, the database searches didn't bring any sources that would have been discussing about data sharing from private sector/ private companies' perspective. There was only one article that discussed what would be the benefits for the company for sharing data with other parties, but even that was more focused on data sharing in partnership type of arrangements. Davis et al. presented a public-private partnership (PPP) model where the idea is that parties in this partnership share their data to because that has been seen as a one method for getting new innovations and increase value through development activities. (Davis, et al., 2021).

Three articles discuss about the data sharing mainly from public sector point of view. On one side, research focuses on the benefits that public sector gains in data sharing, especially on research and development side. Public organizations share also data for private companies or private organizations and a few articles discussed about the rationale behind that. It seems that especially the data sharing from public to private sector has caused some discussion on the motives and public trust towards public health care organizations. Bradley et al. stressed also that data has a value, and it should not be given for private sector without getting benefit for that. (Bradley, et al., 2022). This leaves an assumption that private company didn't give their data to public sector in return. Private companies were also mentioned in almost all articles when the discussion was about individuals' willingness to share their own data for private companies through public organizations. See e.g., article on from Street et al. who studied the circumstances in which citizens would feel it is permissible for governments to share administrative health data with private industry (Street, et al., 2021).

Seven articles of 7 raised a finding that individuals don't feel comfortable of sharing their data for private companies. There was a clear difference on attitudes if the data sharing was aimed for public sector such as health care

service providers or public research purposes versus data to be shared to private companies that make profit. It seems, that the need for this kind of research have raised in many countries from public sector actions, where public organizations have shared health data for private companies that do business with the data. See e.g., the article written by Bradley et al. They say that several high-profile transactions involving patient data were done in England and USA with big companies like Google and Amazon, but these data sharing arrangements came to light only after investigations by journalists. (Bradley, et al., 2022, p. 1). Also, Horn and Kerasidou explore how the opening of the healthcare sector to private digital companies challenges the existing social contract and the NHS's solidaristic character, and impacts on public trust. They raised as an example one project that NHS had in 2013. UK government tried to expand the NHS data sharing practice, by introducing a new scheme called care.data. Within a few months of the announcement of the new scheme, however, more than a million of patients opted-out of the care.data system, and by 2016, the scheme was discontinued. One of the main reasons for this was that people were concerning that NHS data will be shared with private commercial companies. (Horn & Kerasidou, 2020, pp. 2-3).

Figure 1 below illustrates how parties' willingness to share their data with other parties has been studied. Six articles discuss about individuals' willingness to share their data with public sector, mainly for research purposes. Three articles discuss about public sector willingness and possibilities to share the data. Here the data usage was shared mainly for two purposes, research and development and private organizations that uses data for profit purposes. Only one article had a view from private company point of view.

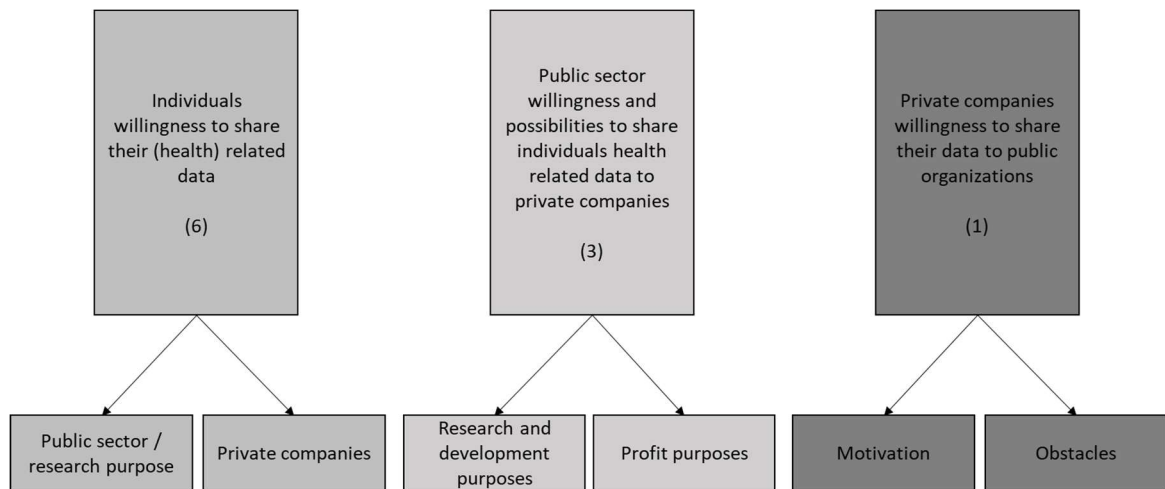


Figure 1. Public sector, private sector and individuals' willingness to share their health data.

Based on articles reviewed, it can be said that the research focus at the moment is on individuals' willingness to share their health care data, but also their expectations towards government and public sector bodies. Individuals expect that their data is on better care when it's on the government side and if it's shared with private companies, there comes trust issues. Public organizations need to pay attention to individuals' expectations and put efforts on transparency of their actions. A more detailed description of articles analysed, and the main findings can be found in appendix 1.

7 Discussion

While the database search didn't bring answers to research questions, now it is time to ask why. Based on theory one could have assumed that there would be research on data sharing from private companies' point of view. European Commission has reported that there's a need to create a data-sharing culture and resolve the unclarities on regulatory frameworks related to privately held

data sharing (see chapter 2.4). Gartner write an article already on year 2021 and stated, that “Data and analytics leaders who share data externally generate three times more measurable economic benefit than those who do not” (Goasduff, 2021). Gartner also argues, that the traditional “don’t share data unless” mindset should be replaced with “must share data unless.” attitude. The article was based on survey and data expert interview. Gartner’s solution is, that we should “Foster a data-sharing culture — not a data “ownership” culture — by identifying the emotional impacts and inherent biases that hamper data sharing. (Goasduff, 2021)”. Open data institute has identified seven reasons, why businesses should share their data: 1) Improving market reach, 2) benchmarking and Insights, 3) open innovation, 4) benefits of regulated sharing, 5) supply chain optimization, 6) addressing sector challenges and 7) building trust. (Open data institute, 2020). Either of these sources don’t discuss about the benefits of sharing data with public sector’, but some of the benefits will most likely realize also in this that context. We would need more studies on the private companies own reasoning for data sharing to be able to find out, what are the real obstacles and is there something that public sector can do.

When this study was started and research questions were prepared, there was an assumption, that research would bring topics like corporate social responsibility, willingness to be part of important research projects, data protection legislation and lack of business benefits. None of these came out. One explanation for that might be that many researchers focus seems to be on finding out, how individuals see health data sharing. Common finding was, that people are willing to share their data for research purposes and for public bodies especially if they know, what is the purpose of the data usage and they know, who has access to their data. But the same didn’t apply for private sector and for the companies that makes profit. People don’t trust that their data is safe on private sector, and they don’t like the idea that someone can get monetary benefits of their data. If we take this mistrust into consideration, it might be, that this could be one reason, why private companies would not be

willing to share their data. What would be the benefit of sharing, if there is no possibility for private company to get any information back?

There were also researches that studied, what are the motives of public health care organizations to share their data to private sector. If this discussion continues, it might be, that it brings some clarity for the motivation on private sector data sharing. At the moment it seems, that private companies can get data from public sector without the need of compensating that. See for example the cases of Google and DeepMind in Bradley's article. (Bradley, et al., 2022). If private companies would need to start giving something back, it could have a positive influence on public opinion. If public opinion would be more positive towards data sharing with private companies, maybe it could motivate also private companies for data sharing also with public organizations.

Although it was not possible to answer to the research question directly based on the articles found, there are aspect that could indirectly influence on private companies' willingness to share their data. It was a bit surprising that although data protection was naturally mentioned and some individuals were worried about their privacy, the key challenge seems to be individuals' willingness to share their data with private companies that benefits of data sharing. Could it be, that individuals' attitudes and fears for data sharing to private companies can have affected to private companies' willingness to share their information to public sector. This is one topic that could be research more in the future.

Private companies' motivation to share their own data was indirectly answered in article reference number 10. Article introduces PPP, public-private partnership that is a common term used to describe alliances. In a common definition, a PPP involves at least one public (nonprofit, academic, or government) unit and at least one private for-profit partner. It is expected that the impact of PPPs will grow in the future considering the increase in both data that need to be analyzed and continuous public investment in research. According to the article, it is difficult to estimate the monetary value of

precompetitive collaboration, but the accelerated collaborative response to COVID-19 is a clear piece of evidence that the effective use of combined resources can truly advance medicine and benefit public health on a global scale (Davis, et al., 2021).

The purpose of research is to answer to the research questions. At this thesis it was not possible to give direct answers that would have bases on existing research. This discussion section consists of assumptions that have been made from the research material that focused on data sharing from different aspects. If we think that there are three different parties that could share their data for public good, it is interesting that one part – the private companies – has not been on the focus of researchers. Maybe this will be the topic for coming years. It would be interesting to see e.g. interview studies, where private companies would share their views on the positive and negative sides of data sharing. This would bring valuable information also for legislators in different countries.

8 Conclusions

This thesis had two research questions. 1: What are the reasons that prevent private companies from sharing their data for health care research? and 2: What are the reasons that motivate private companies to share their data for health care research? Surprisingly the database search didn't bring any sources, where data sharing from private companies' perspective would have been studied. Research focus on data sharing seems to be on individuals' attitudes and public organisations activities related to data sharing. There are a few indications in the data analytics and data sharing filed, that also companies' perspective could be in focus at the future, but this thesis couldn't answer to those questions directly based on the existing research done in this field.

Based on the analysis done on the articles selected to this research, it can be assumed that one of the big obstacles could be individuals' attitudes towards private companies. Individuals didn't feel comfortable by sharing their data with

private companies. Taking this into account, it seems that public bodies might be cautious about sharing their data to private companies in the future and that might influence on the private companies' willingness to share their data. On the other hand, if public organizations could compensate for data sharing by other ways, it could motivate private sector for data sharing. But these are all assumptions, and more research is needed to be able to answer to the original research questions in this thesis.

Scoping review as a research method fitted to this theme in that sense, that it made it visible, that there is not enough research that could be used for answering to the research questions. At the same time, it was possible to identify, what aspects of health-related data sharing has already been studied. It would be interesting to see research where companies in different countries would be interviewed to get insights into their own motivations and obstacles they see related to data sharing.

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2. Braunack-Mayer, A., Fabrianesi, B., Street, J. & O'Shaughnessy, P., 2021. Sharing Government Health Data With the Private Sector: Community Attitudes Survey. *Journal of Medical Internet Research*, 23(10).
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Description of selected studies and main results

Reference	Country	Aim and purpose	Design	Data and methods	Main results
(Bradley, et al., 2022) Healthcare systems must get fair value for their data	England	Raise awareness and call for action to ensure equitable returns for patients and taxpayers when public healthcare data are shared for commercial research.	Theoretical analysis	Literature review.	Public bodies have given health data to private companies with almost nothing in return (a few concrete examples presented). Data sharing agreements must ensure fair benefit for health systems and the public. Data has value and it should not be given for private sector without getting benefit for that. Governments must establish terms for sharing data and ensure the visibility of the terms.
(Braunack-Mayer, et al., 2021) Sharing Government Health Data With the Private Sector: Community Attitudes Survey	Australia	Study aims to explore public attitudes in Australia toward sharing government health data with the private sector.	National survey	A web-based survey. The survey was completed by 2537 individuals residing in Australia. Survey were developed by literature review and by identifying demographic and sociocultural factors that might that might influence how the public view sharing personal health information with the private sector.	Although international evidence demonstrates broad public support for the secondary use of health data, this support does not extend to sharing health data with the private sector. Although just over half of all the respondents supported sharing health data with the private sector, there was also strong support for strict conditions on sharing data and for opt-in consent and significant concerns about how well the private sector would manage government health data.
(Davis, et al., 2021) Public-Private Partnerships: Compound and Data Sharing in Drug Discovery and Development	USA	Introduce different public-private partnership (PPP) models and discuss different aspects of such partnership. Objective is also to open models of asset sharing especially on drug discovery and development side.	Review	Data obtained from various public and peer-reviewed sources.	The sharing of physical compound samples as well as compound-associated data is a common form of contribution from pharmaceutical companies to precompetitive collaborations. Typically PPP involves at least one public (nonprofit, academic, or government) unit and at least one private for-profit partner. Partners share pre/clinical data. Sharing of assets, often through PPPs, has become an established tool for pharmaceutical innovation, which can deliver increased value throughout drug discovery and development.

(Giovanna, et al., 2021) Public Attitudes to Digital Health Research Repositories: Cross-sectional International Survey	Denmark and Brazil	Survey was conducted examining public attitudes to research repositories storing health information, biosamples, personal sensing, and behavioral data.	Survey	Participants were from Denmark and Brazil. Research material were collected via questionnaires that were developed based on previous surveys, previous qualitative studies and the input from the research team, clinicians and participants of the target population. Data were analyzed and visualized using the R Project for Statistical Computing (software environment for statistical computing and graphics).	Most participants feel very motivated about helping future patients, helping researchers, and receiving results about their health; most also feel comfortable sharing data sources usually associated with health research, except DNA data. However, most respondents feel very concerned about the risk of cyberattacks, the possibility of data being used for unethical research goals or for-profit without consent, and the prospect of sharing personal sensing data, especially social communication and location.
(Hendricks-Sturup & Lu, 2020) What motivates the sharing of consumer-generated genomic information?	USA	Purpose is to examine three scenarios in which individuals can become motivated to exchange their genomic information beyond their initial interface with direct-to consumer genetic testing (DTC-GT) companies.	Theoretical analysis	Literature review and by examination of centralized genomic databases/open platforms that are publicly available.	Writers highlighted circumstances under which individuals are or can become motivated to share their genomic information: to satisfy personal curiosity, to provide a social good, and to receive financial return.
(Horn, R. & Kerasidou, A., 2020) Sharing whilst caring: solidarity and public trust in a data-driven healthcare system.	England	Explore on how the opening of the healthcare sector to private digital companies challenges the existing social contract and the NHS's solidaristic character, and impacts on public trust.	Theoretical analysis	Analysis on bioethics literature, surveys on public trust in health care and/or data sharing, prominent case studies that gave rise to relevant debates in the UK, and official reports.	A solidarity grounded partnership model will help establish a social contract or licence that responds to the public's expectations and to principles of a solidaristic healthcare system.

<p>(Jones , et al., 2022) Public opinion on sharing data from health services for clinical and research purposes without explicit consent: an anonymous online survey in the UK</p>	<p>England</p>	<p>Measure public opinion on health data sharing by UK National Health Service/Health and Social Care data. Study focused on measuring data sharing preferences.</p>	<p>Survey</p>	<p>Pre-registered anonymous online survey, measuring expressed preferences, recruiting February to September 2020. Participants were randomised to one of three framing statements regarding MH (mental health) versus PH (physical health)data.</p>	<p>Support for healthcare data sharing for direct care without explicit consent is broad but not universal. There is net support for the sharing of deidentified data for research to the NHS, academia, and the charitable sector, but not the commercial sector.</p>
<p>(Lounsbury, et al., 2021) Opening a “Can of Worms” to Explore the Public's Hopes and Fears About Health Care Data Sharing: Qualitative Study</p>	<p>England</p>	<p>This study aims to explore the views of the public, particularly their hopes and concerns, around health care data sharing.</p>	<p>Study</p>	<p>Participants were prompted to reflect about data sharing through listening to individual stories around health care data sharing. Participants were asked to fill self-administered feedback cards and to describe their hopes and fears about the meaningful use of data in health care. The transcripts were compiled verbatim and systematically reviewed by four independent reviewers using the thematic analysis method to identify emerging themes.</p>	<p>Involving the public is critical to create a patient-centric culture in health care systems. Thematic analyses identified six themes under hopes: enablement of personal access and ownership, increased interoperability and collaboration, generation of evidence for better and safer care, improved timeliness and efficiency, delivery of more personalized care, and equality. The five main fears identified included inadequate security and exploitation, data inaccuracy, distrust, discrimination and inequality, and less patient-centered care.</p>
<p>(Street, et al., 2021) Sharing administrative health data with private industry: A report on two citizens' juries</p>	<p>Australia</p>	<p>Under what circumstances is it permissible for governments to share health data with private industry for research and development?</p>	<p>Research</p>	<p>Two citizens' juries were held in February 2020 in two locations close to Sydney, Australia. Jurors considered the charge: ‘Under what circumstances is it permissible for governments (Australia state and federal level) to share health data with private industry (companies developing, producing and selling pharmaceutical and medical devices) for research and development (focus on the development and evaluation of new and existing medicines and medical devices)?</p>	<p>Consistent with international systematic reviews, this work indicates that the purpose of sharing data is critical to community acceptance. In addition, in common with previous studies, the jurors in this study identified a number of concerns about sharing data with private industry.</p>