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Balancing stakeholder interests and paradoxes in health data sharing within health ecosystems

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Abstract

Personal health data sharing can facilitate value co-creation between multiple stakeholders, including individuals, public organisations, private companies, research institutes, and policymakers. Yet, when companies are involved in sharing health data to develop health-related solutions, it can lead to conflicts and contradictions between stakeholders. We apply a qualitative research approach over two cases in the Finnish healthcare sector to explore the tensions and contradictions in sharing personal health data that companies can utilise in the development of new products/or services in the healthcare sector. We identify the tensions and paradoxes from multiple stakeholders' perspectives and provide management approaches on three levels: (I) The micro-level focusing on individuals as users, (II) The meso-level concerns businesses operating within the digital health ecosystem. (III) The macro-level addresses broader societal impact and policies governing the secondary use of health data.

Keywords: health data sharing, tensions, paradox approach, multi-stakeholders, healthcare ecosystem

Introduction

The development of digital technologies, such as big data, wireless communications, social networks, apps, global position systems (GPS), Internet of Things (IoT) and sensor technologies, have played an important role in supporting disease treatment and patient care. With the adoption of digital technologies in healthcare, the large volume of health data, continuously recorded, generated, and archived from clinical treatments and everyday life, offers opportunities to develop diverse solutions for predictive, preventive, and personalised services and create health innovations. Scholars have defined two groups interested in generating and utilising healthcare data: the first group is consumers, including patients, their caregivers, and families. The second group is healthcare providers, comprising hospitals, healthcare centres, doctors, and primary care nurses. Additionally, outside the healthcare-providing sector, companies, universities, research entities, insurance companies, and other legal entities [1,2] are interested in healthcare data.

Personal health data has not yet been fully utilised for use in developing health innovations because of barriers to secondary use of the health data, which include ethical issues, legal uncertainty, the burden of complaints [3], privacy, information security, discrimination, the right to access data, and the abuse of data [4–9]. These challenges are also associated with data management and security when combining data from multiple sources, e.g., registries, biobanks, and sensors, and missing a trustful platform for storing, managing, and controlling the data among different stakeholders [10]. Moreover, sharing health data for secondary use by companies to develop innovative medical products is relatively low [9, 10] as people fear that companies may leak their health data due to a lack of privacy control and for commercial purposes by making profits at the expense of the public. People may doubt the accuracy and transparency of big data solutions. Further, they fear receiving standardised treatment with potential biases towards patient groups that might eliminate the one-to-one relationship between physicians and patients [11].

Personal health data has become a bottleneck asset [12,13] for developing health innovations [12,13] and applications for healthcare products and services [14,15]. Data-driven businesses create more business opportunities in the healthcare sector with connected and ecosystemic business models [16–18]. The digitally enhanced healthcare ecosystem comprises various industry players with technology components that influence the operation, evolution, provisioning, and development of healthcare services [19]. Most of the current studies on health data for secondary use, particularly for companies, are from an individual perspective. An ecosystemic view of the tensions and paradoxes of the secondary use of health data is still fragmented and remains unexplored. To address this gap, we investigate the following research question: *What tensions and paradoxes are captured within the data-driven health ecosystem, and how can the identified tensions and paradoxes be managed?*

Material and methods

Research methods

We opted for a qualitative research method with a case study approach to understand the complex dynamic phenomena of the tension and paradoxes within digital health ecosystems [20]. We selected Finland because its society faces an ageing population and it is highly digitalised, which is evidenced by the widespread application of health innovations. Finland is currently in a critical phase of health reform, which demands a new model capable of effectively leveraging its technological advancements. This highlights the need for a data-driven health ecosystem to structure, integrate, and maximise the utilisation of technological assets within the health context. The empirical setting of this study is built around two publicly funded ecosystems that aim to utilise health data in Finland's healthcare system.

Ethics

This research adheres to the ethical guidelines of the Helsinki Declaration [8]. According to Finnish legislation, research Ethics Committee approval was not required since the study did not involve minors, direct or indirect physical or physiological harm to the participants, or clinical trials (Medical Research Act No. 488/1999). Written informed consent was obtained from all the interviewees. Additionally, before the start of the interviews, verbal confirmation of their consent was obtained before conducting the interview through Microsoft Teams, ensuring that the participants fully understood the study's purpose and willingly agreed to participate. This study was non-interventional, and all data used was anonymised. We did not include any data that could reveal the company's future market opportunities nor the company's market plans outside the consortium agreement to maintain the confidentiality of the participant company's future strategies.

Case introduction

This paper examines two ecosystem cases. First, the *MyData* principles-based scenario health ecosystem enables individuals to control their consent, decide with whom they wish to share data and cancel permissions related to data at any stage through the user interface field [18]. This ecosystem aims to empower citizens, fostering their willingness to manage and share their health data, leading to the co-creation of health value from shared data by multiple stakeholders [21,22]. Also, this ecosystem holds the potential to transform patients from being passive recipients into becoming active participants, enhancing their health awareness and promoting a greater interest in self-care. A MyData principle-based health ecosystem has not yet been holistically applied to the healthcare context, however, if the MyData principles were to be applied in the healthcare domain, it could create value from the personal health data and enable individuals to participate in health-related decisions [23,24].

Second, a digital health ecosystem *StrokeData*, funded by Business Finland, aims to achieve cost savings and better patient care by co-creating novel data-intensive solutions for stroke prevention and diagnostics. The project stakeholders include researchers, companies, hospitals, stroke patients, and their families. StokeData has utilised recent advancements in AI and relies on the richness of health data to develop a data-intensive ecosystem for stroke-related health products and service innovations.

Data collection

For both the MyData and StrokeData cases, we used a purposeful sampling strategy [27] for participant selection and to ensure the participants met the aims of this study [25]. We drew up a list of potential interviewees representing different hospital stakeholders and the Health Technology Companies (HTCs) involved in the StrokeData project. HTCs in the projects had significant involvement in the co-creation process and were well-versed with the nuances of citizen-centric data, including associated challenges and expectations. The data were collected through semi-structured interviews [26] with physicians (targeting those in leadership roles). In addition, we interviewed Information Technology (IT) specialists from hospitals who have an important role in patient data management. We sourced policymakers from ministry health data initiatives, especially those centred on MyData's role in health data economics.

Interview themes were defined before the interview rounds and modified as we progressed in the data collection. We reached the data saturation towards the last interviews in this data collection round [27]. All interviews were recorded in Microsoft Teams and transcribed directly afterwards to begin the analysis process. In addition, some sidenotes were highlighted during the interviews [28], which justifies the inductive nature of this study [29]. The findings emerging from the data were sent to study participants before finalising the study outcomes to ensure that our interpretations matched the respondents' opinions and given pieces of information [30].

Table 1. Data collection summary for recorded interviews.

No.	Field	Profession and Position	Duration
Physicians			
1	Hospital	Ophthalmologist, department head	66 minutes
2	Hospital	Respiratory Medicine and Allergologist, department head	52 minutes
3	Hospital	Orthopaedics and Traumatologist, department head	58 minutes
4	Hospital	Otolaryngologist, department head	47 minutes
5	Hospital	Paediatrics	60 minutes
6	Hospital	Cardiologist	55 minutes
7	Hospital	Head of Procurement	60 minutes
8	Hospital	Medical doctor (Project leader)	60 minutes
9	Research Institute	Director. Centre for Health Technology	72 minutes
IT experts			
1	Hospital	Chief IT officer	62 minutes
2	Research Institute	Coordinator. Medical Co-creation Project	70 minutes
Health Technology Companies Representatives (HTC)			
1	Well-being data solution	CEO and founder	60 minutes
2	Patient monitoring	CEO	54 minutes
3	Homecare	Marketing director	61 minutes
4	Home nursing monitoring	Founder and CEO	59 minutes
5	Rehabilitation	CTO	57 minutes
6	Pre-surgery information APP	CEO	53 minutes
7	Well-being equipment	CTO	49 minutes
8	Ophthalmological equipment	R&D director	58 minutes
9	Medical technology provider	Product development manager	85 minutes
10	Rehabilitation service provider	Project leader and software engineer	90 minutes
11	Cloud services and data analysis provider	Data analyst	61 minutes
12	IT and service-oriented software provider	Project manager and data analyst	66 minutes
13	AI medical solution provider	CEO and founder	56 minutes
14	Healthcare technology provider	Project manager	99 minutes
15	AI-driven analytics solution	Product development manager and software engineer	60 minutes
16	Software solution provider	CEO	50 minutes
Policymaker			
1	Ministry	Director for Data Economy	57 minutes

Twelve citizens participated in an informal, non-recorded interview conducted in a comfortable setting individually. Each interview lasted a maximum of thirty minutes, during which knotes were taken. The researcher introduced the MyData health ecosystem and allowed the participants to share their ideas, thoughts, needs, and perceived risks associated with the MyData ecosystem. Subsequently, the participants were presented with initial research results from professionals, offering insights into the available services. This led the citizens to identify previously unrecognised needs and understand the ecosystem's value, while also validating the preliminary findings obtained from professionals. The decision to conduct the interviews without recording gave the participants a sense of assurance in an environment where they felt comfortable discussing needs and thoughts, they might have been reluctant to share in a recorded session.

Data analysis

We have adopted the thematic framework method to perform our qualitative data analysis in multidisciplinary health research, which has become an important approach in digital health research.

We first conducted desk research to examine the existing literature and familiarise ourselves with the project documents and practicalities. Then, we drew insights from primary interviews. Three rounds of coding emerged from the data analysis. In the initial coding phase, we included all codes related to the tensions and paradoxes related to data sharing, gatekeeping, trust, accountability, quality assurance and legitimation. Then, we searched for the common aspects that connect themes and classified the outcomes into three themes emerging from the data: (I) the micro-level that focuses on individuals as users, (II) the meso-level that pertains to operating businesses within the ecosystem, and (III) the macro-level that addresses the broader societal impact. Subsequently, we mapped our data back to the thematic framework to discuss the tensions and paradoxes at each level, along with potential approaches for managing them, as proposed by the interviewees. Finally, we concluded our findings and mapped them (see Figure 2) to depict the research results.

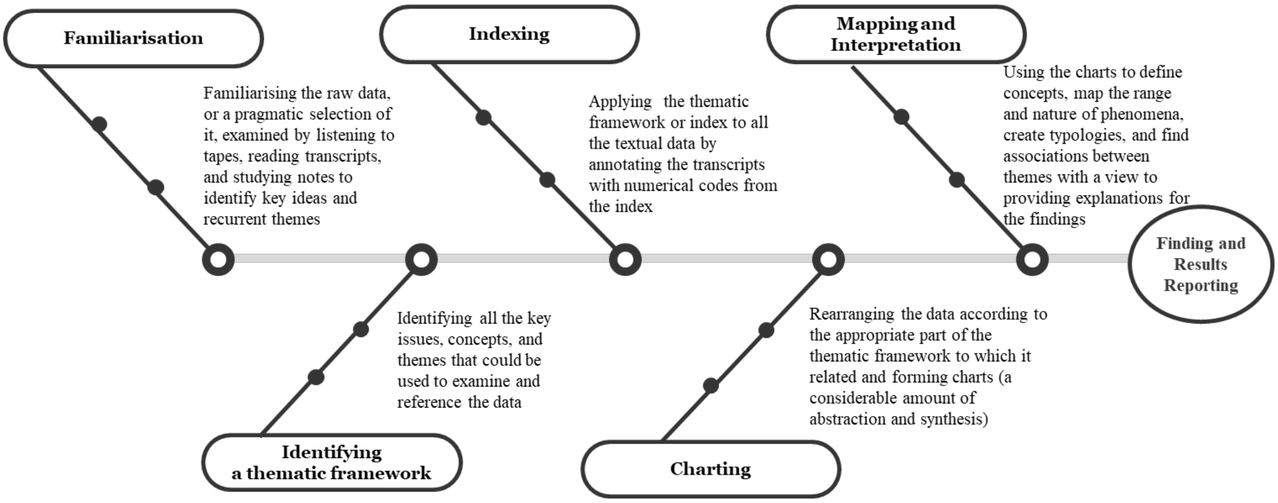


Figure 1. The framework method for the analysis of qualitative data in multidisciplinary health research (adapted from [31]).

Since we opted for a thematic approach towards data analysis, data triangulation was achieved by collecting data from several sources at different times [32], including hospitals and two consortiums operating in healthcare in Finland (see Table 1). To assess the validity of this study, we conducted it with an applied focus [27], by which we collected the tensions and paradoxes from multiple stakeholders' perspectives in the Finnish data-intensive healthcare ecosystem.

Results

The macro level (society as a whole, e.g., nations, legal systems, economies)

Tension #1 Public-funded healthcare and data economy in the health industry.

In Finland, the state finances, arranges and is responsible for the healthcare. When engaging companies in the co-creation process, the greatest challenges are associated with public image and the difficulty of engaging companies in the ecosystem. To control commercial interests, hospitals consider the quality of care the major concern for admitting or buying any new solution. HTC 8 agreed that the process of the company-to-hospital negotiations is long and challenging due to companies' eagerness to pilot their studies, get their patents approved and start the commercialisation process of their technologies. However, hospitals have a different view since they do not have the pressure of commercial-driven outcomes of the R&D trials like what companies have; hospitals strive to provide training for the medical personnel and ensure sufficient medical expertise needed to treat the patients, *"It might take two years of negotiations beforehand for companies to negotiate with hospitals and acquire the ethical permissions to collaborate and pilot their technologies"* HTC 8 concluded. Therefore, there is tension regarding companies potentially misusing human-centred data to further their commercial interests, potentially at the expense of society.

Hospitals have a patient care perspective on everything that includes medical care. Companies take the role of helping in the businesses related to the improvement of the level of care and in providing comfort for patients alongside their treatment journey. Companies' intensions to improve patient care can be less visible for hospitals when it comes to taking companies into collaboration. As hospitals have hard-core data for companies to provide an initial proof of concept, they can insist on concrete evidence before buying any product or admitting companies for further collaborations to test their technologies. Interviewee 7 noted, *"It is very tricky to admit the huge patient populations to the proof-of-concept phase; it is a risky process to utilise the hard-core patient data, also ensuring that we meet the regulations in Finland and European community related to the usage of the hard-core patient data."*

Tension #2 Legal act and secondary use of health data.

At the societal level, a concern pertains to the legal barriers involved in integrating and transferring data among multiple stakeholders and issues of cybersecurity and privacy. Most of the interviewed doctors agreed that they could not share any patient data or recommend digital solutions for patients, especially for secondary health service use. Even the currently adopted digital system, which interacts with patients, cannot share information with health professionals who do not directly treat the patients in the same treatment department at the same hospital due to strict policies and regulations regarding sensitive patient data. As Physician 3 noted: *"Our internal regular meeting cannot proceed further, because the nurse who was* *responsible for the care system and patient data was sick, and we had no right to access the patient data and made a summary of how many and what records the patients had self-archived into the system"* (Physician 3).

Europe's General Digital Protection Rights (GDPR) have created barriers to accessing personal data. The GDPR has greatly impacted the regulation of the data market and increased the transparency of the fair use of personal health data. The interviewed companies utilised patients' data for product research and development (R&D) in Finland to partner with research institutes or hospitals. The case companies criticised the process as slow and inefficient, demanding a new solution for accessing human/patient data. The unbalanced power between hospitals and companies had been addressed by most of the interviewed companies and hindered the co-creation of digital solutions by utilising health data. This aspect was noted by one of the respondents who stated: "*The current law prohibits health profiling from citizens. We have no choice but to partner with hospitals or research institutes to collect patients' data or rely on the data from sensors/equipment from the old production lines"* (HTC 3). *"We cannot directly do research work for our products and services. We can only use the secondary research results conducted by hospitals or research institutes"* (HTC 4).

Similarly, the interviewee from HTC 15 stressed the hardship of using the secondary data that is either developed through the accumulation of anonymised patient data in their servers, which leads to the development of another secondary data platform that can be used to provide new prototypes for the data management and AI-generated algorithms that can improve the overall quality of their solution. However, it is rather challenging to proceed and use the secondary data because there is no defined practice for using it. Interviewee 1 noted, *"We have a well-performing platform that monitors the patients' status either from the hospital or home environment, However, we joined the Stroke-data consortium because we wanted to add value to our existing platform from the Stroke-data integrations by developing AI-based analytics using the secondary generated data and using it as a certified medical solution."*

The Meso level (ecosystem: part of society)

Tension #3 Accuracy in self-reported data and medical data.

There are concerns surrounding the quality assurance and responsibility associated with self-reported data, particularly its application in clinical settings. In prioritising patient safety and experience, the physicians we interviewed had seen the value of combining citizen-centred data in clinical decision-making while questioning the quality of self-reported data and the responsibility to validate the life data for clinical use. One such physician pointed out: *"It would be helpful if we knew patients' living habits and could undercover reasons (onsite of the diseases), but who is responsible for analysing and validating the well-being data?"* (Physician 4). While another noted: *"The measurements taken outside the hospital are not always valid* (Physician 3).

The policymaker participating in this study reinforced the health value of co-creation and delivery as a core in data-driven health industry transformation, noting that: *"There should be trust in care pathways and the sharing of lifestyle data, so I think it's both a legal definition and makes data relevant for individuals. … It's part of personalised (health) services."* Companies have a reverse approach to utilising self-reported data, which is used in medical decision-making. As the regulations related to certifying devices for medical usage mainly emphasise medically generated data (e.g. data entered by doctors and nurses along the digital care pathways), companies find it a risky area to invest in at the outset when it comes to bringing new devices or technology onto the healthcare market. HTC 13 highlighted the financial situation for their SME and the uncertainty related to the usage of self-reported data in the development of their technology, which is why the company had decided to embark on their validation with hospitals first through the utilisation of medically generated data, then expand to include the human-generated data. *"Currently, we have patients providing data in the rehabilitation phase of the digital stroke care pathway, so we are following up on those, and if we put up on that, like in five years, we can see what we need to expand our solution to include the patients themselves since now we are presenting our solution only for the care professionals from doctors to primary level nurses, which is the normal source now for the data but we need and aim to have a solution that involves the patients' themselves"* (HTC 13).

Tension #4 Cooperation and competition

Hospitals resistance to adopting new technology from entrant firms' side places an additional burden on carrying out medical trials and tests required to qualify any new technology for medical use. Also, hospitals are used to the same way of providing the needed care for the patients and dealing with specific partners from the industrial side. It is challenging for start-ups and growth companies to make it alone without collaborating with their direct and well-established competitors in the healthcare market. Despite the new healthcare solutions emerging from start-up firms in Finland, small firms need more experience in healthcare and need successful show cases to show to hospitals as a guarantee of their technology.

Given these conditions, the interviewees from the start-up firms reported that they collaborate with incumbents, their direct competitors, to get into the hospital environment through joint value co-creation with their direct competitors. Interviewee 1 from HTC 10 explained, *"We are going into collaboration with our eyes open to possible opportunities with hospitals and other companies in the Stroke-data consortium."* Although the joint value creation with incumbents enables small firms to enter the hospital environment, small firms are still prone to the incumbent's opportunistic behaviour as they try to access their technology and expand the scope of their product portfolio. At this point, it became apparent from our data that small firms initiate the gatekeeping towards extensive data sharing with incumbents to protect the novelty of their technology, leading to fragmented knowledge sharing, and companies tend to withdraw from the ecosystem agreement in later stages.

Regulations in healthcare provide the roles and common standards for technology integration into the pre-existing system. Additionally, a specific infrastructure and governance framework is needed for electronic health data, which would require joint design between companies that aim to utilise the patient data in R&D projects aimed at product/technology development in later phases of research. HTC 8 highlighted that collaboration on patient data between companies is complex due to the fragmented organisational policies towards data sharing, while HTC 2 concluded that *"traditional approaches for data planning and sharing between companies, that hinder the process of creating common data model where the source data is stored and anonymised for other usage."* All hospital interviewees agreed that the data-sharing timeliness between hospitals and companies were not optimal, meaning that when hospitals share anonymised data with incumbents, it takes a long time to share the data with other dependent stakeholders, and the data becomes obsolete. This exemplifies the gatekeeping tensions concerning the data sharing between stakeholders in healthcare, where companies are in a constant battle for market dominance, and every stakeholder is trying to control specific areas/competence in the healthcare domain.

Tension #5 Trust and accountability of the digital health ecosystem

The health data sharing rate to commercial companies for co-creation is relatively low [33] due to a lack of trust and the difficulty in evaluating the company's purpose and behaviour [4]. Using personal health data to drive economic growth rather than solely benefiting the health industry also challenges public trust in the solidaristic character of the healthcare system [34]. Lastly, there is a focus on the ownership, legitimacy, and accountability of MyData principles, which directly impacts public trust in such a complex data ecosystem.

The human-centric approach to the health data economy required openness, transparency, and digital sustainability. The voluntary sustainability and self-regulation of the MyData health platform should be implemented through improved data literacy and transparency between multiple stakeholders. Accountability was also needed to secure the behaviour of stakeholders. Unlike communication, accountability was a formal procedure like auditing certificates, quality systems, or external auditors. The policy maker interviewed concluded: *"Clear policies explained in layman's language are issued as heavy legal documents. It isn't about communication."* The policymaker mentioned that besides commercial purpose, companies should also have social goals stating what they can bring to society and how they might increase the understanding of citizens and other stakeholders of the importance of data sharing and co-creation in digital health. *"The goal is to show a benefit to the patients of the future. … For example, companies cannot get a data permit for Findata (the Finnish national hospital database) just for their business purposes such as for marketing or developing a new treatment"* (Policymaker).

The sensitivity of the healthcare data and hospitals' approach towards processing the healthcare data initiate gatekeeping between hospitals and companies. HTC 7 agreed that the lack of hospital-to-company trust arises due to the legitimation requirements that enable healthcare to process patient data. Hospitals' resistance to data sharing with the companies comes from the belief that most of the R&D projects from companies are associated with pure commercial goals without acknowledging the number of resources and risks that companies take to get into the hospital environment. All of the case companies' interviewees from the Stroke-data ecosystem agreed that hospitals limit their ability to access anonymised patient data, even if they agree with hospitals to utilise the anonymised patient data through publicly funded projects that aim to improve the overall quality of patient care. Yet, decision-makers from the hospitals argued that they would not share anonymised data with companies in a way that would enable companies to accumulate the data within their servers and then create their own data platforms. HTC 7 noted, *"As we are the data hub (referring to the hospital) for all these companies trying to create digital solutions from the patient data, we will not completely share our patient data with anyone to the extent that we become dependent on them."*

Healthcare places high entry barriers on small firms, requiring association with a legitimate "incumbent" partner to access the hospital environment and use the patient data to develop their technologies.

Interviewee 1 from HTC 13 (SME) highlighted that their approach in healthcare is built around collaboration with incumbent yet competing stakeholders to overcome entry barriers and access the data. Interviewee 1 from HTC 13 continues, *"We need to prove to the other stakeholders in the Stroke-data consortium that we can do it, even if this will change our business structure and pricing models."* Hence, collaboration between multiple stakeholders with the aim accessing data requires small companies to make sacrifices in terms of their autonomy and business practices outside the scope of cooperation with the incumbent firms. This leads to stakeholder disputes in the later stages of collaboration when small firms realise opportunities outside the scope of their collaborations with the incumbent firms.

Stakeholder disputes occur between incumbent and small firms. All the interviewees from the incumbent firms agreed that openness and collaboration with other stakeholders initiate strategic challenges for their technologies and might threaten their position in the healthcare market. The openness enables incumbents to control the growth of start-ups and small firms and maintain their competitive position in the healthcare market. Interviewee 1 from HTC 13 highlighted that the data sharing with the incumbent firms within the healthcare domain has some *"transparency and trustworthiness"* issues when it comes to sharing and sourcing sensitive healthcare data. However, small firms must compromise and adjust to the unfair data-sharing policies and governance mechanisms orchestrated by incumbents. Otherwise, Interviewee 1 from HTC 12 concluded that *"accessing the healthcare market would be a long-lasting process of trials and unbalanced hospital-to-incumbent ties compared to those that small firms have with hospitals."*

Micro (action of individuals)

Tension #6: Reactive or participative health

The interviewed physicians reported that they typically adopt a treatment-centric approach in their clinical practice. Their attention was on their clinical responsibilities, providing guidance exclusively to patients experiencing health concerns, and not to the citizens in good health conditions. As one of the interviewed physicians noted: *"Why should we follow and measure normal people if they stay healthy, eat healthily and maintain their regular fitness?"* (Physician 3). The physicians acknowledged the potential for misinterpretation of both patient data rights and their own position, signalling a hesitance or unreadiness to transition towards a data-driven approach in clinical treatments. Furthermore, most physicians interviewed had no prior experience collaborating with companies in health co-creation activities involving multiple stakeholders. This highlighted a scarcity of opportunities for physicians to participate within the health ecosystem actively and a noticeable lack of empowerment in collaborative decision-making processes with other key stakeholders.

On the patient side, almost all the citizens interviewed felt a need to be more familiar with the available digital solutions for managing, sharing, and utilising their health data for various uses. For them, the patient portal for electronic health records served merely to access information and schedule appointments with physicians. Although some individuals used smart watches or rings to track their athletic pursuits, heart rate, and sleep patterns, the idea of integrating this data with hospital treatment had not crossed their minds. One of the interviewees stated *"I didn't know about the 'Kanta' system (the Finnish national health data system). I got to know it when the coronavirus* *vaccination certificate had to be downloaded from there"* (Citizen 10).

Most citizens reported that they needed to be more aware of existing services, the concept of participating in digital healthcare to contribute to shared decision-making, and the platforms available for managing their health data. The interview responses indicated a need for more proactive attitudes toward self-management and active participation in empowered personal healthcare. Many expressed interest when introduced to the MyData principle-based health ecosystem—a solution aimed at integrating health analyses and enhancing individual empowerment for self-care and health data consent management. However, there was still a noticeable degree of reluctance to engage with these services among some participants. The following quotations illustrate these sentiments: *"I'm not interested in managing and sharing any health data through the platform because I don't need to. Maybe in the future"* (Citizen 2). *"What motivates me to use a service is to make my life easier and healthier"* (Citizen 5). *"If the system needs manual input, I do not have time for it, and I am unwilling to do it"* (Citizen 8).

When we asked what might change their minds about using digital health platforms, many expressed that a sense of social responsibility and the impact of external influences could motivate them towards health data sharing and participation in the health information exchange. Citizen 3 emphasised the important role COVID-19 played in changing his attitude towards personal health and his behaviour: *"Without the coronavirus, I wouldn't be interested in those health apps or offerings, but now I am because I can get health information and want to do good things for society by sharing my health opinions and data."*

One of the citizens who had experience participating in the development of a nutrition app, highlighted that an initiative from a reliable source promoting a human-centric health engagement program could encourage participation. She noted: *"I received a phone call from my occupational health centre and was told about this trial of a free nutrition app development. In return, they would use my data to develop their app. I agreed and took part in it, but if I had been approached by the commercial company itself, I definitely would not have participated because I'd have felt odd and unsafe."* This underscores the potential impact of credible sources and third-party endorsement in motivating individuals to manage their health through digital platforms actively. It highlights the importance of legitimacy and certification from trusted institutions in facilitating citizens' engagement with digital health ecosystems, such as being guaranteed safe by using a bank authorisation code, being referred by hospitals, accreditations from certified medical associations, or considered public goods mentioned by other interviewees.

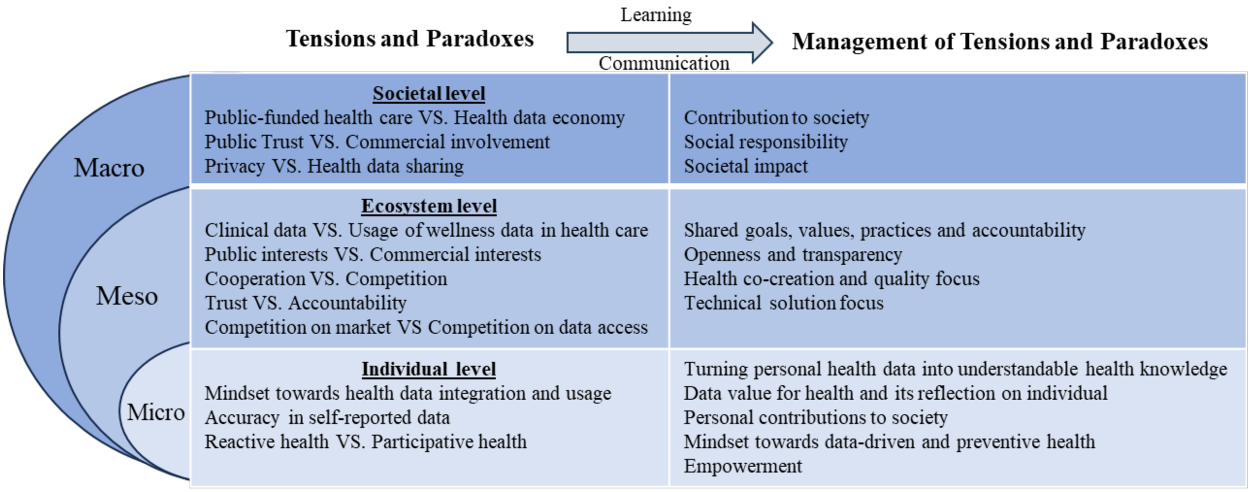
Discussion

Tensions and paradoxes of health data in the health ecosystem

The traditional healthcare model primarily focuses on the supply side to deliver value to end customers. In contrast, utilising health data to motivate selfcare and to encourage patients to move towards a preventive health model is key for data-driven health ecosystem and to engage multiple stakeholders in the delivery of care services, e.g., in the provision of a MyData principle-based health ecosystem. This approach raises debates on the active role companies play in the secondary use of health data in the co-creation of technology-enabled services in data-driven ecosystems. This study focuses on human factors to address the tensions and paradoxes of data sharing in data-driven health ecosystems and provides the approaches to ensure that the outcomes from data-driven health ecosystems align with society's expectations for the return of health data sharing and shared decision-making. Based on our research findings, we have identified tensions and paradoxes at different levels, followed by the discussion on the management of observed tensions and paradoxes, as explained in Figure 2.

Management of tensions and paradoxes

(I) At the macro-level, the policymakers should develop laws and regulations easing the bureaucratic process for medical innovation R&D by utilising health data and emphasising companies' roles in contributing to the sustainable development of society. At the societal level, as research demonstrates, the lack of self-efficacy in these solutions means that healthy young individuals may show little interest in the service despite being a significant demographic in terms of Internet usage, and their engagement is crucial for public health. To address this issue, efforts should be made to increase health awareness and self-efficacy for preventive healthcare. This can be achieved by emphasising the benefits of health data sharing and its contribution to society. From a broader societal perspective, human-centric data enriched health statistics, innovative digital solutions, public health awareness, predictive analytics, and extensive educational programmes should be promoted as contributors to the quality of healthcare enhancement and to enable cost savings. Demonstrating the multifaceted value of health data for different stakeholders would enhance transparency in data usage by HTCs, and will subsequently mitigate tensions related to non-trust for commercial purposes.



	Tensions and Paradoxes	Management of Tensions and Paradoxes
Macro	**Societal level** Public-funded health care VS. Health data economy Public Trust VS. Commercial involvement Privacy VS. Health data sharing	Contribution to society Social responsibility Societal impact
Meso	**Ecosystem level** Clinical data VS. Usage of wellness data in health care Public interests VS. Commercial interests Cooperation VS. Competition Trust VS. Accountability Competition on market VS Competition on data access	Shared goals, values, practices and accountability Openness and transparency Health co-creation and quality focus Technical solution focus
Micro	**Individual level** Mindset towards health data integration and usage Accuracy in self-reported data Reactive health VS. Participative health	Turning personal health data into understandable health knowledge Data value for health and its reflection on individual Personal contributions to society Mindset towards data-driven and preventive health Empowerment

Figure 2. Overview of the research findings.

(II) At the meso-level, a co-defined goal and formal agreement for the use of data among ecosystem stakeholders must be signed. The agreement should include clearly defined legal terms of accountability to regulate and prevent opportunistic behaviours and misuse of data among ecosystem stakeholders. This is crucial to guide the conduct of all participating stakeholders, ensuring a structured and responsible collaborative digital health ecosystem. At the ecosystem level, small firms need to be able to collaborate with incumbents in healthcare to overcome entry barriers and establish themselves as legitimate partners in healthcare industry. The collaboration would occur through coopetitive relationships between stakeholders, which involve simultaneous collaboration and competition. Firms compete to access non-processed patient data, which is considered a valuable resource for advancing their solutions and expanding their overall product offerings. Entrant companies with radical innovations have the potential to reshape market dynamics and the position of the incumbents. However, achieving transparent data-sharing and an open strategy between platforms remains challenging.

Communication, knowledge sharing and learning between stakeholders in the health ecosystem will help transparency and provide the willingness to engage in the health data utilisation process. Companies should increase their openness, transparency, and trustworthiness in the health-value co-creation process. The collaboration with hospitals in terms of developing R&D should increase the trustworthiness and legitimacy of a data-driven health ecosystem and the willingness to share data. Third-party certification, external audits, and demonstrations of excellent use cases from the data-driven health ecosystem could collectively work to strengthen stakeholder engagement in the co-creation process and shared decision-making. The priorities should be put into achieving defined roles, promoting health, empowerment, and social responsibility.

(III) At the micro-level, human factors affect decisions on health data sharing. For health professionals, the quality of patient care significantly affects the willingness to utilise health data in clinical decision-making and patient monitoring. Therefore, the improvement of the co-creation of health by utilising data should focus on the quality of care, and the functionality and integration of different information systems. A central data repository should integrate all health data into one database and realise automatic input from data sources, e.g., from smart watches or sensors, ensuring a seamless and unburdened user experience. Therefore, it should be possible to integrate the data within the existing health infrastructure within the hospitals.

Our study’s empirical evidence suggests that healthcare professionals are yet to be convinced by P4 healthcare approaches, however, physicians provide a credible channel which may encourage individuals to accept the preventive approach to chronic disease [35]. These findings highlight the importance of addressing the concerns and perceptions of healthcare professionals regarding digital health solutions and clinical trials [11]. Efforts should be made to emphasise the value of preventive health and empower the communication between healthcare professionals and solution providers.

Individuals have different approaches to assessing the credibility and trustworthiness of companies. Individuals tend to believe in products and services from companies that closely work with hospitals and are affiliated with trusted third parties. The willingness to contribute to society may override their personal views on privacy for health data sharing. The data-driven health ecosystem increases the behaviour visibility, e.g., the data may relate to the correlation between diet, activities, and health improvement. Usually, information systems, programs, and technological devices are black boxes for the individuals who use them. The algorithms calculating and permutating data are usually invisible to the users [36]. Therefore, making health data and knowledge understandable to citizens is also important. Through the performance of self-tracking and the empowerment of health data decision-making, citizens may learn about the process research by actively providing data, gaining critical knowledge about themselves, and providing valuable feedback that helps companies or researchers incorporate their needs, desires, and insights [37]. Understandable technology and ways of doing will increase health awareness and self-efficacy, as well as the willingness to continuous health data management and sharing. Thus, properly managing consent concerning health data will give citizens a voice, allowing them to gain better ownership of the developed artefacts [38].

Conclusion

The study theoretically contributes to digital health by increasing our knowledge of the data-intensive health ecosystem and the tensions that arise due to data-sharing for companies. Identifying and addressing these tensions and the paradox perceived by various stakeholder provides practical advice for the digital transformation of healthcare in Finland and is also relevant to healthcare reform. This study will help define shared practices, goals, values, and accountability in a data-driven health ecosystem and in turn, ensures stakeholder engagement, transparency, and synergy. The results will facilitate policymakers in expanding private-public partnerships to support the secondary use of health data and encourage the co-creation of health value between multiple stakeholders in the ecosystem.

This study has several limitations. First, the number of interviewees in different groups are not equally represented in the sample data. More data should be collected from policymakers and IT experts working in hospitals. The citizen's results rely on notes taken during interviews and may dramatically reduce information collected from them. This is a country-specific study and may not be representative of and generalisable to other countries with different digital infrastructures, health arrangements, and public trust than Finland.

The data-driven health ecosystem encourages shared decision-making through co-creation and health data sharing [39] and aims to transform health delivery into a predictive, preventive, personalised and participatory model [21,10]. Perspectives from multiple stakeholders open new avenues for a networked understanding of creating new health values, ensuring that society obtains the outcomes it desires from health data sharing and shared decision-making. In conclusion, considering diverse stakeholders' tensions, paradoxes, and requirements is paramount to empowering citizens, businesses, and public entities within the data-driven health ecosystem.

Conflict of interest

All authors declare no conflict of interest.

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