7-8-2023

Exploring factors influencing actor engagement in MyData health platform: A case study from Finland

Fan Wang
University of Oulu, fan.wang@oulu.fi

Pasi Karppinen
University of Oulu, pasi.karppinen@oulu.fi

Petri Ahokangas
University of Oulu, petri.ahokangas@oulu.fi

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Completed Research Paper

Fan Wang
Martti Ahtisaari Institute
University of Oulu, Finland
Pentti Kaiteran katu 1, 90570 Oulu,
Finland
fan.wang@oulu.fi

Pasi Karppinen
Oulu Advanced Research on Service
and Information System
University of Oulu, Finland
Pentti Kaiteran katu 1, 90570 Oulu,
Finland
pasi.karppinen@oulu.fi

Petri Ahokangas
Martti Ahtisaari Institute
University of Oulu, Finland
Pentti Kaiteran katu 1, 90570 Oulu, Finland
petri.ahokangas@oulu.fi

Abstract

In the digital era, a large amount of health data has been documented, generated and stored in clinical evaluation and daily life, but citizen-generated health data has yet to be combined, interoperated, analysed, and made available for professionals, citizens, research institutes, and companies for secondary use. Finland tries to build the MyData health platform, which links multiple actors to co-create health value and make it understandable for citizens. Engaging multiple actors plays a key role in transitioning to the MyData health platform in terms of continuous data sharing and co-creation. This study therefore investigates enablers, barriers, and expectations that influence the actors' engagement with the MyData health platform. This study applied a single case study based on 30 interviews, and identified the four themes that influence actor engagement: 1) perceived technology; 2) health value co-creation; 3) perceived empowerment and social influence; and 4) perceived trustworthiness and legitimation.

Keywords: MyData platform, actor engagement, human-centric data, personal health data

Introduction

Digitalisation enables the remote tracking of people's lifestyles and monitoring of patients' health outside hospitals using sensors, smartphones, wearable devices, cameras, and other data-acquisition medical devices and systems (Chourabi et al. 2012). Combining individual well-being and clinical data can help identify high-risk and low-risk patients (Bates 2014), make decisions on treatment based on diagnostic informatics (Georgiou et al. 2021), provide personalised rehabilitation services, rationally allocate health resources (Galetsi et al. 2019), and shift the locus of care from hospitals to homes. Citizen-centred data

management, analysis, and interpretation open new avenues for modern, efficient, and cost-saving healthcare and may convert the big data-driven medical care potential into better services and financial advantages (Alexander 2018; Bates 2014; Bedenkov et al. 2021) in the predictive, preventive, personalised, and participative (P4) healthcare model (Hood and Flores 2012). One example of P4 is the provision of personalised early intervention based on citizen-centred data for lifestyle changes (Al-Azzam and Alazzam 2019).

Driven by citizen-centred data, Finland is attempting to build the MyData approach to delivering health services, embracing the P4 model and reaching a larger population in the healthcare context (Ruckenstein 2017a). MyData principles empower individuals to control their consent, decide with whom they are willing to share data, and cancel permissions related to data at any stage of the process through the user interface (Ruckenstein 2017b; Su et al. 2016). Implementing MyData principles can help convert passive patients into active customers by increasing their health consciousness, awareness of and demand for self-care, and achieving the goals of the P4 model. MyData is a human-centric approach to personal data supporting "a fair, sustainable, and prosperous digital society, where the sharing of personal data is based on trust as well as a balanced and fair relationship between individuals and organizations" (Poikola Antti, Kai Kuikkaniemi 2020).

The MyData platform is not centrally controlled by a legislated focal form (Blasco-Arcas et al. 2020). The multiple actors are self-organised on the MyData health platform, with the assumption that all actors are both service providers and beneficiaries contributing to value creation and expect value capture in return (Brodie et al. 2019; Vargo and Lusch 2014b). However, what motivates the multiple actors in building the MyData health platform has yet to be clarified (Lehtiniemi and Haapoja 2020). Indeed, engagement has been found to be the key challenge in the P4 healthcare model (Golubnitschaja et al. 2014). To better understand this under-researched actor engagement and its influence on synergistic and iterative effects, this paper explores the antecedents of multiple actors' engagement and investigates the factors that affect engagement in the MyData health platform transition. The present study addresses the following research questions: *What factors (enablers, barriers, and expectations) influence actor engagement in the MyData health platform transformation, and how?*

Literature review

Digital healthcare platform

The digital healthcare platform comprises a network of health industry players with technology components that influence the operation, evolution, provisioning, and development of healthcare services (Oshni Alvandi et al. 2021). From the MyData perspective, the digital health platform is transitioning to citizen-centred health data management and utilisation, i.e. individuals are becoming the controllers of their own data (Pikkarainen 2020). In this research, MyData is considered a health platform that uses citizen-centred data as a resource for different purposes among individuals, private and public organisations, and research institutions (Koivumäki 2017).

In recent years, Finland has focused on creating a conducive environment for utilizing health and welfare data collected through public services and registers. The aim has been to facilitate faster and more efficient utilization of social and health data, along with other types of data that can be interconnected (Tupasela et al., 2020). The ultimate goal is to build a thriving data ecosystem that can support a platform-based economy, as well as knowledge management. The use of digitalization and healthcare data is viewed as a solution to the challenges posed by an aging society. The expected benefits include improved efficacy in healthcare processes and support for the work of medical professionals (Ministry of Economic Affairs and Employment). However, these innovative solutions are also intended to be scalable to global markets. In relation to the data economy, the sourcing of data from patients in Finland presents a tension between citizens and commercial interests (Tupasela et al., 2020). Given power back to citizens as in MyData health platform would potentially solve the tensions and act upon the interests of citizen´s own. Survey studies experimenting with the MyData-driven health platform potential for future digital healthcare models in Finland (Koivumäki 2017) and Korea (Choi et al. 2021) have received positive responses from most of the participants.

The MyData health platform is a venue linking multiple actors in the participatory process of value co-creation. The MyData health platform places the citizen at the centre of making personal health data-sharing decisions regarding the offerings announced by the service, e.g. for clinical trial recruitment, insurance company claims, professional health coaching, and participation in shared decision making with health professionals. Citizen engagement therefore plays a key role in adhering to the use of technology for early intervention by health knowledge generation (Kelders et al. 2020) and becoming a continuous source of health data for service co-creation.

Actor engagement

Engagement has been studied across the field for decades. In organisational management research, studies on engagement are rooted in psychology and discuss the relationship between employees' engagement and work performance as "employee engagement" (Kahn 1990). In marketing studies, engagement research emphasises "customer engagement" with a brand in online and offline businesses. There is a strong connection between engagement and profitability through customer satisfaction, employee retention, productivity, and turnover (Harter et al. 2002). To increase the user's engagement for business success, organisations build an environment that fosters engagement through attributes of challenges, positive affect, attention, feedback, novelty, interactivity (Kelders et al. 2020; O'Brien and Toms 2008), and gamification (Bitrián et al. 2021), and capitalise on customer-owned relational capital, knowledge, and creativity (Harmeling et al. 2017). In the urban planning context, "citizen engagement" has also been found important in taking collaborative action and solving societal issues, e.g., by providing new insights. Engagement is a multidimensional concept, consisting of cognitive, affective (e.g. intrinsic motivation), and behavioural aspects when interacting with a digital system. Today's healthcare is implemented by IoT technology that connects people, services, places, and things to improve the health industry rather than restructuring the healthcare system (Ahmad et al. 2022). The views and needs of citizens should be considered to incorporate use-specific requirements and insights into the process and resolve citizens' requirements (Thinyane et al. 2020) for health services. In this article, we see engagement as an ongoing process of increasing actors' energy, involvement, efficacy, attitudes, and intrinsic interests.

At the platform level, the extant literature on engagement discusses the critical role of engagement in networks of diverse actors, and the group of actors based on the theoretical basis of S-D logic (Lusch and Vargo 2014). The notion of connectedness among actors in the service platform becomes the central domain of engagement research (Brodie et al. 2019; Fehrer et al. 2018). Actors can be humans or a collection of humans, e.g. organisations or even non-human objects, e.g. Artificial Intelligence (Storbacka et al. 2016), that involve the logic of the human exchange system, including economy and society, according to their discrete roles and functions (Lusch and Vargo 2014). Non-human actors increase the opportunity to reshape actor-to-actor interaction, replacing the human-based interaction with technology-to-technology interaction or human-to-machine interaction (Storbacka et al. 2016). Actors' engagement emphasises exchange, resource integration, service provision, and value co-creation at multiple levels (Alexander et al. 2018; Blasco-Arcas et al. 2020; Brodie et al. 2019; Storbacka et al. 2016). It involves the engagement process of informing, consulting, involving, collaborating, and empowering (Covello 2021). Beyond customer-focal firm dyad relationships, actors need an engagement platform, facilitating and orchestrating connections among each other in the service system (Blasco-Arcas et al. 2020). Earlier discussions on engagement platforms have emphasised the firm-centric, purposeful design, and technology-enabled nature of the platform to enable companies to interact with customers in the social community (Leipämaa-leskinen et al.,2022), as exemplified by e.g. Apple, Google and Microsoft. More recent discussions have gradually moved towards an understanding of the nature of multisidedness on the platforms and in the interdependencies in multiple actors' interaction to integrate resources in a decentralised and self-organised manner.

Leipämaa-Leskinen et al. (2022) define the decentralised and self-organised engagement platform as a collaborative engagement platform that includes heterogeneous actors implementing relational exchanges for long-term relationship development without a legislated focal firm. The multiple actor's role has also been confirmed by the balanced centricity literature, arguing that all the actor's needs should be balanced and fulfilled so that a long-term relationship and well-functioning market can be achieved (Gummesson 2008). All actors are both service providers and beneficiaries contributing to value creation and expect value in return (Brodie et al. 2019; Vargo and Lusch 2014a, 2014b). The service should therefore focus on a balanced multiple-actor centricity instead of a single actor (Letaifa and Reynoso 2015). This decentralised

multiple-actor platform requires more norms, rules, and values in platform operations (Hollebeek et al. 2017). In this study, we adopt the actor-centric and balanced centricity of the collective engagement platform as a perspective to explore the factors affecting actor engagement in MyData health platform transformation, and how actors interacted during the emergence of the MyData health platform.

Methods

We use a single-case study (Yin 2014) to analyse the MyData digital health platform in Finland in the conceptual/initial development phase. The single-case method provides the necessary flexibility and sensitivity to less explored contexts and allows an in-depth study of phenomena representing the real-life context. Finland is an excellent country for healthcare innovations because it is highly digitalised and has wide wireless network coverage. Most of the health data in the country are available in digital format. However, Finland still urgently needs a cooperative to structure, integrate, and utilise these technological advantages together, as Finnish society is facing an aging population and needs a new model of healthcare reform.

We explored the literature on engagement at the individual and platform levels and predefined topic lists, focusing on technology, health value co-creation, balanced relationships and empowerment, trustworthiness and legitimation as themes yet allowing flexibility and adjustment by semi-structured interview strategy. We conducted 30 semi-structured interviews with physicians, health technology companies' representatives, IT experts, policymakers, and citizens to broaden the understanding of the MyData platform from multiple actors' viewpoints between November 2021 and February 2022 so that the motivation for actors' engagement could be captured and pinpointed. We gave a short introduction for interviewees who were unfamiliar with the MyData principle, and we directly approached the topic with those who were already familiar with MyData. We used a purposeful sampling strategy for the physicians who have managerial positions for medical service procurement and context knowledge about research work and for company representatives who have been involved in multidisciplinary projects with medical, business, and technology schools for medical AI solutions. For policymakers and IT experts, we have been recruited from our network for making sure they have extensive knowledge about MyData technically and practically. During the interviews, we asked questions such as: How would you describe the current development of using citizen-centered and self-reported data in the healthcare field? What do you consider to be the benefits or risks of using citizen-centered data in healthcare – and why? How have you seen the MyData platform relevant to how patient data is regulated or received?

We followed the guidelines of (Myers and Newman 2007) to describe the principles during the data gathering. At the beginning of the interview, we emphasised why and how the interview data would be used and for what purpose, asked for consent for tape-recording, and agreed to keep the interviewee's information anonymous. The interviewees agreed to be contacted later for additional information if necessary. We recorded all the interviews with professionals (physicians, company representatives, IT experts, and policymakers). We talked with the citizens and took notes on the important facts, as our design aimed to create a relaxing atmosphere for them to share their opinions. The interviews with professionals were conducted before those with citizens. This allowed us to verify the preliminary findings of professionals with citizens. In Finland, where the interviews were conducted, society is relatively "flat", so no extra preparatory effort was made to minimise social dissonance. The strategy for choosing the interviewed subjects was to obtain as much variety as possible in a narrow research topic. Although we had a semi-structured list of questions, mirroring was used whenever necessary. In other words, during the interviews, the order of questions varied according to the themes the subject described. A single interview with a professional took approximately sixty minutes; the interviews with citizens lasted about thirty minutes, as designed. Most of those interviewed could give all the time required for the interview. A variety of secondary data was also collected through ethnographic observations, workshops, Sitra's data economy forums, publications, and academic discussions to supplement the primary data. The recorded interview list is shown in Table 1.

Twelve citizens were interviewed in a relaxing environment about their expectations, wishes, ideas, requirements, and needs for the MyData platform. Afterwards, briefing findings from professionals about the service offering on the MyData platform helped reveal the unknown needs when the citizen only realised

the value once explained to them, while verifying the preliminary findings from professionals. The non-recorded situation made them confident about uncovering the unarticulated needs they did not wish to express in the tape-recorded interview.

No.	Field	Profession and Position	Interview 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	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			
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
Policymaker			
1	Ministry	Director for Data Economy	57 minutes

Table 1. Interviewee information

The data analysis was done in two phases: the first phase focused on variations of perceptions and interpretations between each actor's group, while the comparative analysis was performed to explain variations due to different interests in utilising personal health data (Eisenhardt 1989). Following Miles et al., 2019 principle, we utilised the bottom-up sequence of coding moments as the approach to analyse our case. The coding process was facilitated using Nvivo V.13 software. We started with interview transcripts, fieldnotes, and secondary data by assigning the open codes, using short descriptions for each actor group. We then generated a list of emerging issues related to enablers, barriers, and expectations on the MyData health platform, e.g. technology, infrastructure, certificate and standards, performance expectancy, ease of use, data quality, privacy, data literacy, data security, rules and regulations, transparency, shared goals, and empowerment, and we defined them as the initial categories. We studied the linkages of initial categories and merged the relevant categories into one, e.g. data quality, literacy, security, privacy, quality, ease of use, and infrastructure into "technology and data". Through a comparative analysis of actor groups, we were able to address perceived technology, health value co-creation, perceived empowerment and social influence, and perceived trustworthiness and legitimation as themes influencing actor engagement in our study, and we presented the empirical analysis results as a framework.

Results

The perception of the MyData health platform is created on the premise that it can use citizen-centred data which can in turn open an array of opportunities or potentials for multiple stakeholders' use, e.g. for health professionals, researchers, citizens, and research and development (R&D). The platform ideally enables the emergence, expansion, and growth of new applications associated with health.

Findings from physicians

All the interviewed physicians mentioned that the technology should be easy to use, patient safety should be ensured, and the technology should be clinically approved. They expected the patient data to be connected and integrated into one interface and be useful for monitoring rehabilitation after hospital

treatment. The integration of databases played an important role in improving physicians' work process. Physicians saw the value of generated life data, but no well-being data were currently available for clinical use. The MyData health platform should be able to connect different datasets to one interface for clinical use. Connectivity between physicians and patients was needed. The data were a facilitator in reducing the gap between them through the timely assessment of real-time patient data without being physically present in hospitals, remote control of the equipment, and offering advice. The physicians also mentioned the equality of using the service and expressed concerns about the elderly. Technology-enabled optimised data connectivity was important for physicians to engage in the MyData platform.

"There are altogether nine databases in use, but not connected and functioing together. I need to search for information from different databases, and it's inconvenient" (Physician 3). "New discoveries of therapies, processes, or diagnostic procedures based on data will bring benefits to the patients" (Physician 2). "The travel distance between rural areas and cities is long for the elderly living in the countryside" (Physician 6). "Our patients are usually very old people living alone and far away, and they may not know how to use the digital service. Maybe the situation will be different in the next ten years" (Physician 4).

In prioritising patient safety and experience, the physicians had seen the value of combining citizen-centred data in clinical decision making, while questioning the quality of self-reported data and the responsibility for the validation of the life data for clinical use.

"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). "The measurement taken outside the hospital isn't always valid – for example, blood pressure measurements, how and when to operate, affect the score of the blood pressure" (Physician 3).

Instead, physicians would prefer to focus on groups at risk of severe health problems in the near future. According to the physicians' responses, these citizens were the ones who wanted to receive support from health professionals for lifestyle change coaching and monitoring and in turn, share their data for shared decision making in the MyData health platform.

"Why should we follow and measure normal people if they stay healthy, eat healthily and maintain their regular fitness?" (Physician 3).

In the physicians' opinion, perceived health value and usefulness influenced the perception of engagement. The physicians were clinically treatment-oriented and did not even recommend the monitoring of the health conditions of normal healthy citizens. In addition, most of the interviewed physicians had never worked with companies in the co-creation process with citizens and companies. There was a lack of possibilities for physicians to be involved in the health platform, and they had not been empowered in the shared decision-making process with other platform actors.

"It isn't a question of data sharing on paper or in digital form – it's about the patient's rights. The regulation doesn't allow us to connect patient data with companies' use, and nor do we have the right to ask for consent for the secondary use of their personal data" (Physician 7). "I don't think the physician should play any role in the digital health business ecosystems. The physician should remain neutral – if they collaborate with companies, they must leave the physician's role" (Physician 1). "We will face spending extra time reviewing the data and explaining why the data are right or wrong to the patients" (Physician 4). "It's good to know the statistics, but I haven't used them" (Physician 7).

Physicians were aware that patient data rights and the physicians' stance might be misunderstood, and/or they were reluctant to adopt the new approach to working with health data.

Findings from health technology companies

The companies commonly worked with patients' data for product research and development (R&D) in Finland to partner with research institutes or hospitals. The 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.

"Having to partner with research institutions and hospitals for recruiting patients or test users is inefficient. The sample size is too small to train our AI. The progress is slow to work with public hospitals due to bureaucracy" (Company 1). "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" (Company 3). "We cannot directly do research work for our products and services. We can only use the secondary research result conducted by hospitals or research institutes" (Company 4).

Companies perceived the MyData health platform as a new logic to fairly use citizens' data and engage with different actors on the platform. The MyData health platform offered companies an opportunity to gather health data at the initial stage with those citizens who gave their digital data consent for participation. Engaging patients early in the human-centric R&D process and testing their solutions with interested real patients would improve the quality of their offerings.

"It would be helpful if we could access data directly from patients and make them interconnected with the hospital" (Company 6). "From R&D to the market takes longer, more than five years, so continuous data are needed to support medical AI development" (Company 2).

To increase customer engagement and succeed in public procurement for the co-creation of medical products and services, the companies emphasised the data-driven customer value delivery, data privacy, and transparency of business operations.

"My feeling is that in the data you start to realise the actual relevance, and your behaviour has effects based on the data" (Company 3). "We're a small company – we don't have much power to influence the hospital's (management's) decision making, but as I said, we're small, so we don't have much to lose. I openly explain our target, process, and what we can do and offer. Within years, they get to know you and your business. In the end, it is people's business, and they can be influenced" (Company 4).

They faced a lack of trust from hospitals and citizens in the secondary use of data and emphasised the health outcomes as a return of sharing personal health data. An effort was being made to increase its reputation and trustworthiness in the health market.

Findings from hospital IT experts and policymaker

From the technical perspective, the interviewed IT experts pointed out major challenges for engagement on the MyData health platform. They stated that the infrastructure might not be available or interoperate with each other. There was a lack of tangible and intangible resources in hospital spending on the maintenance of so many databases and integration into hospital interfaces. The authentication and storage of MyData was another issue, especially given most of the data were unstructured.

"We've made a great effort in the authentication of users using different technical methods, but it's still a big issue to identify the people while securing data safety. ... The data is unstructured" (IT Expert 2).

"They (the companies) can participate in our living-lab programme to develop ideas further. We have hospital data and they can be used in the closed environment" (IT Expert 1).

To achieve personal health data management on the MyData health platform, the policymaker participating in this study reinforced the health value co-creation and delivery as a core in data-driven health industry transformation. The policymakers also mentioned that besides the commercial purpose, the companies should also have social goals stating what they can bring to society, and how they might increase the understanding of citizens and other actors of the importance of data sharing and co-creation in digital health.

"There should be trust in care pathways and the sharing of their lifestyle data, so I think it's both a legal definition and makes data relevant for individuals. ...It's part of personalised (health) services". "The goal is showing a benefit to the patients of the future. ... For example, companies cannot get a data permit from Findata (the Finnish national hospital database) just for their business purposes like you would need to market or develop a new treatment" (Policymaker).

The policymaker was concerned about legal issues. The General Digital Protection Rights (GDPR) in Europe had created barriers to assessing personal data but had had a great impact on the regulation of the data

market and increased the transparency of the fair use of personal health data. 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 among multiple stakeholders to engage with the platform actors. 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.

"Clear policies that are explained in layman's language are issued as heavy legal documents. It isn't about communication" (Policymaker).

Findings from citizens

Almost all the interviewed citizens had never heard of the solutions for managing, sharing, and utilising their health data for different purposes. The patient portal for electronic health records was just a channel for receiving information and perhaps booking an appointment with a physician. Some had smart watches or rings to monitor their sporting activities, heart rate, and sleep data but never thought of linking them with hospital treatment.

"I didn't know 'Kanta' before (the Finnish national health data system). I got to know it when the coronavirus vaccination certificate had to be downloaded from there" (Citizen 10).

Citizens might be unaware of the availability of services, the ideology of participation in digital healthcare for shared decision making, and the available platforms for managing and sharing their own health data. According to the interviews, citizens still lacked the mindset of self-management and engagement in individual-empowered healthcare. This might also result from a lack of sufficient communication in public health and promotion.

After introducing the MyData health platform as a solution for combined health analysis and empowerment for self-care and the management of health data consent, most felt it was interesting, but some were reluctant to use the services.

"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 a manual input, I don't have time for it, and I'm not willing to do it" (Citizen 8).

Social responsibility and influence would change their attitudes about sharing health data and engaging in information sharing and exchange. Citizen 3 pointed out the importance Covid-19 had in influencing their focus on personal health:

"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".

When asked about the kind of services or health apps they would be interested in using and the motivation for sharing their health data, and how they evaluated the trustworthiness of apps, people had different views. Some citizens checked the apps according to their needs and looked at the internet for reviews and comments and ratings in app stores. The use of bank authorisation systems to sign in to personal folders and make transactions increased their trust in the company's service. If the apps had been co-developed and used by hospitals, certified with different standards, or considered a public good, it was likely citizens would be engaged on the MyData health platform. An approach from trusted partners about a citizen-centric health engagement programme was also a credible method mentioned by one of the interviewed citizens, who had joined a nutrition app development:

"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'd been approached by the commercial company itself, I definitely wouldn't have participated because I'd have felt odd and unsafe."

In this situation, the occupational health centre played a central and legitimating role in engaging citizens in the joint health programme.

Discussion

The perceived technology of the MyData health platform influences actors' engagement with the technology-optimised connectivity of data, perceived equality and ease of use, perceived expectance of performance, data privacy, safety, and privacy. In detail, data-enabled connectivity should shorten the distance between users and physicians, considering different age groups, patient conditions, and areas. It should be easy and legal to access data for every actor and provide reliable services facilitating clinical decision making and personalised treatment. The ability to access data is particularly important for health technology companies to solve the problem of data shortcomings – for example, in building AI models.

The findings identify that health value co-creation is of particular importance in engaging various actors on the MyData health platform. The health value defined by the actors may vary, but all seek affordable, accessible, and quality healthcare services. For citizens, awareness of their own health and avoidance of onsite diseases based on the data are important for health and risk groups. Patients would certainly appreciate better treatment and follow-up plans. Physicians need integrated real-time data and new discoveries of medicines, therapies, digital equipment, and services for better clinical decision making, treatment, and patient monitoring, as well as improved work efficiency and the reasonable management of resource allocation, e.g. nurses. Companies can utilise both clinical and well-being data without the complex application process for permission from the authorities and can therefore react quickly to the market and reduce the cycles of R&D development, increasing the validity of digital products by accessing data. Society will benefit from health statistics, digital solutions, public health awareness, predictions, and further public education to save health expenditures.

Achieving health value co-creation is not an effortless process. The MyData health platform has its challenges and risks in data sharing for shared decision making. Motivating healthy citizens to manage consent for their health data sharing and continuously engaging in the process is a challenge from the user's perspective. The MyData health platform for citizens entails a technological approach that can integrate their generated life data automatically into the system with their consent, e.g. sleep data from a smartwatch. The empowerment of the management of their health data consent should not burden the citizen with the responsibility of importing data. The focus should be on consent management to select different health service providers and offerings according to their interests and needs. As the research shows, the solutions' lack of self-efficacy means healthy young are not interested in the service, but they are a major force in internet use and are important for public health. Moreover, the physicians have yet to be prepared to make changes and develop the work process utilising data from different sources for clinical decision making. The perceived empowerment and social influence therefore raise the awareness and consciousness of citizens to focus on their own health and contribute to society. Empowerment should be achieved through activities by enforced customer health value delivery. Reflection on the needs of many actors is key to empowering citizens, businesses, and public organisations (Kotsev et al. 2020).

Indeed, citizens are diffuse and weakly coordinated, often lacking resources, motivation, and the collective power to deploy resources effectively to healthcare. The MyData health platform can make their contribution visible and concrete through empowerment activities such as data consent decisions, communication, health consultancies, and value in concrete products or services. The MyData platform is transparent, so citizens know where, how, and who has used their data and for what purposes. This drives the intrinsic motivation by the self-efficacy-pull force and altruism for the MyData health platform for shared decision making for citizens; in addition, extrinsic motivation can also be encouraged by the technology push force (Hung et al. 2011; Vilnai-Yavetz and Levina 2018) and reimbursement programme, e.g. smooth transfer of the health documents to claim insurance and free consultation on diets and lifestyle.

The MyData health platform also empowers health technology companies to access data directly from citizens. Not relying heavily on the hospital for health data assessment motivates health technology companies to proactively increase trustworthiness and transparency for the public in encouraging health data sharing from citizens, engaging citizens early in human-centric design for companies' offerings, and continuously accessing data for testing and validating their products and services. Involving citizens in design and consent management gives them a voice, allowing them to gain better ownership of the developed artefacts (Bowen et al. 2010). Usually, information systems, programmes, and technological devices are black boxes for the individuals who use them. The algorithms calculating and permutating data especially are usually invisible to the users (Burrell 2016). Through the performance of self-tracking and

the empowerment of health data decision making, citizens may learn about the process of performing 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 (Greshake Tzovaras et al. 2019).

Predictive healthcare is ensured by the constant interaction between multiple actors, real-time monitoring, the response to changes, and health decision making (Schiavone et al. 2021). The current extent of digital connectivity gives rise to the phenomenon of behavioural visibility (Leonardi and Treem 2020). The MyData health platform enables the behaviours of people and the effectiveness of care to be seen; the produced outputs are ideally created transparently so that the individuals can learn what the algorithms are doing, leading to increased interest in engagement.

Empowerment and social influence can also be achieved through communication. Communication abilities facilitate dialogue and interaction, enabling one to consult, include, and collaborate (Nambisan et al. 2013). Communication plays an important role in successful engagement (Dobos and Jenei 2013) and empowerment for shared decision making on the MyData health platform. Only through exchange and interaction during the data sharing process would citizens become more proactive and engaged in self-care and producing new health data and evidence to further the co-creation process for shared decision making. Communication also shortens the distances between actors, helps disseminate health knowledge, provides peer support, delivers value, and increases data literacy and transparency among multiple stakeholders on the MyData health platform.

Technical barriers exist that cannot make data interoperable and move between disparate organisations. Technology is never neutral (Karppinen and Oinas-Kukkonen n.d.), and a carefully designed ethical framework for citizens' digital data consent management digitally by citizens is needed. Health technology companies and health service providers may need to tailor their business model for the MyData platform, leading to the reconfiguration of resources and capabilities and increased costs, e.g. for communication coordination among actors. The organisations may also create barriers to protect their business from competitors. Value co-creation processes between interdependent human economic actors on engagement platforms are influenced by shared practices and will be generated by differing engagement practices, intensities, and valence over time (Blasco-Arcas et al. 2020; Jonas et al. 2018).

The health data sharing rate to commercial companies for co-creation is rather low (Trinidad et al. 2020) due to a lack of trust and the ability to evaluate the company's purpose and behaviour (Graham 2021). The use of citizen-centred data for driving economic growth rather than solely benefiting the health industry's also challenges public trust in the solidaristic character of the healthcare system (Horn and Kerasidou 2020). The social context and reciprocal role of shared goals, values, and practices will therefore become of particular importance to increasing the trustworthiness and legitimacy of the MyData platform. Legitimating with hospitals and research organisations increases the public image of the MyData health platform and trust in data sharing for companies in the co-creation process. Third-party certification, external auditing, and the demonstration of the excellent users' case achieved on the MyData health platform further enhance the engagement of multiple actors in the co-creation process and shared decision making.

Based on the findings from each interviewed group and a comparative analysis of the findings, we propose a framework for building the MyData health platform. As Figure 1 shows, four themes that influence actor engagement in the MyData health platform have been identified: 1) perceived technology; 2) health value co-creation; 3) perceived empowerment and social influence; and 4) perceived trustworthiness and legitimation.

The identified four key themes affect the degree of multiple actors' engagement on the MyData health platform (Witjas-Paalberends et al. 2018) and the possibility of turning citizen-centric data innovation appropriability into appropriation. At the individual level, the MyData health platform contributes to patient knowledge generation and citizen-centred health data sharing for personalised services. Through empowerment activities, e.g. consent management, public coaching, and communication, citizens would be more interested in their own health and that of the public. The increased awareness and consciousness of health make citizens altruistic in continuously sharing their health data on the MyData platform. The utilisation of citizen-centred health data further fosters the process of co-creation between health technology companies, health service providers, and citizens at the interorganisational level. To ensure

actor engagement, a clear data strategy and guidance for the utilisation of citizen-centred health data should be available and transparent to all actors. Defining the goals, value, and accountabilities at the emergence of the MyData health platform will help set boundaries for the behaviour of multiple actors and increase the trustworthiness of the MyData health platform at the institutional level.
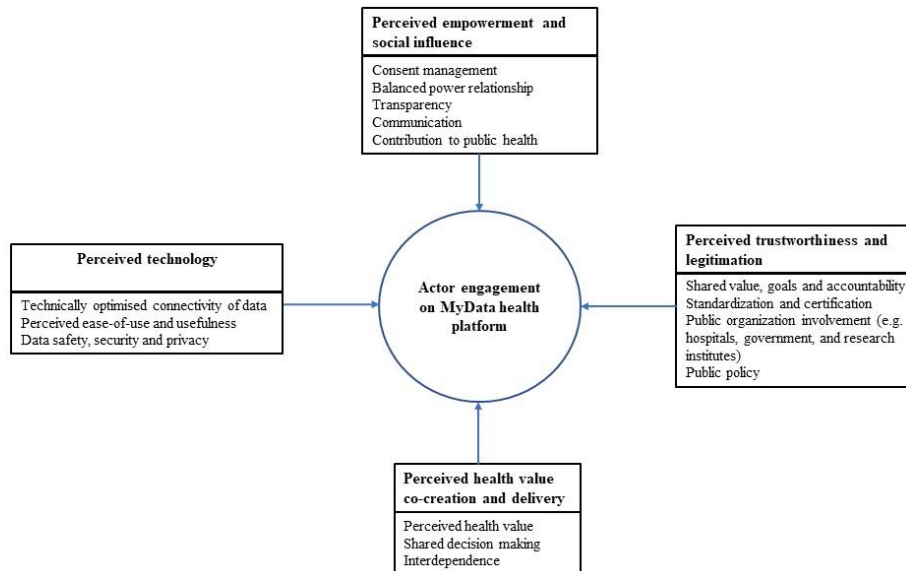

Figure 1. Factors that influencing an actor engagement in MyData health platform

This study has several limitations. Firstly, the sample data does not equally represent the number of interviewees in different groups. Secondly, the level of analysis is multifaceted as opinions were shared at different levels such as individual, organizational, and institutional. Thirdly, as this is a country-specific study, it may not be representative and generalizable to other countries with different digital infrastructures, health arrangements, and public trust than Finland.

The study contributes to digital health by increasing knowledge of a new data management model for health services, identifying data-related challenges, opportunities, values, and capabilities for personal health data management, and highlighting the prerequisites for engaging multiple actors on the MyData health platform. Unlike firm-centric engagement-focused platform studies, the MyData health platform emphasizes the balance of power, decentralized and actor engagement, and the fair use of personal health data. The multiple actors engaged in the MyData health platform approach embrace citizen-centered health decision-making, data-driven open innovation, value co-creation, and service delivery in the healthcare context.

This study provides policymakers with valuable insights into expanding private-public partnerships to support the secondary use of health data and encourage health value co-creation among actors on the platform. The study suggests that reimbursement for the MyData platform should focus on health value co-creation and societal contributions rather than monetary incentives. Therefore, an appropriate health education program should be designed as an outcome to improve health awareness and self-efficacy for preventive healthcare and to motivate citizens to actively and continuously engage in health data sharing. Efforts should also be made within hospitals to shift physicians' mindsets from traditional clinical-driven approaches to more data-driven approaches in order to achieve the P4 model.

Conclusion

MyData is an approach to proactive data activism that offers "a pathway to empowerment, equal participation, and action" (Milan and Gutierrez, 2018: 58), aiming to re-decentralise and redistribute personal data from companies to individuals for remunerated sharing (Lehtiniemi and Haapoja, 2020). The integration of citizen-centred data into a digital health platform increases the level of citizen involvement and their attitude towards technology and system use (Ahmad et al., 2022). The MyData transition process requires the development of a mindset of engaging in self-care and preventive health for both health professionals and citizens. The evidence-based health value co-creation and delivery perceived on the MyData health platform increase the awareness and understanding of citizens for personal health management. This can be further enhanced by communication, empowerment, and legitimation.

The present study focuses on a decentralised engagement platform model, focusing on MyData management and utilisation, to understand the ideology of engagement, shared decision-making, and delivery in the healthcare context. Views from multiple actors open new avenues for a networked understanding of new health value co-creation, ensuring the outcomes that society wants from citizen-centric health data-sharing and shared decision-making. It is therefore important to incorporate shared practices, goals, values, and accountability at an early stage to ensure actors' transparency and synergy. Perceived health value co-creation, technology, empowerment, social influences, and trustworthiness and legitimation are the prerequisites for actor engagement on the MyData health platform.

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