

DIGITAL HEALTH REVOLUTION



Introduction

The healthcare system is currently moving from the more traditional, reactive approach towards proactive care, supporting wellness management and the prevention of illness. As part of this development, organization-driven healthcare is changing towards human-centered model, introducing possibilities for the creation of new services that take into account customer needs and actionable data.

In the Digital Health Revolution (DHR) project, we have been studying the formation of the MyData-based service ecosystem with insights into technological, regulatory, ethical, service transformation, and business model research and development activities. The aim was to identify and analyze possible systemic change opportunities in healthcare, new innovations leading to international businesses, and the value of personal data for the citizens, businesses, and public healthcare.

This report of the Digital Health Revolution project presents the major achievements driving person-centric, data-led health care. More information can be found at www.digitalhealthrevolution.fi.

Technology & regulation

To demonstrate and facilitate the flow of personal data from multiple data sources to applications and services, a standard and interoperable technological solution, so-called MyData architecture, meeting the privacy-related

EU juridical requirements, has been constructed. Compared to other user-centric privacy management infrastructure solutions, the reference architecture from DHR aims to provide a more holistic approach with fewer limitations in its use. To support further development work, a MyData Service Development Kit for software developers has been released.

As one of the key findings in technology-related work, we found that the user-centric privacy management infrastructure solutions tend to be specific for a particular use and professional domain. To encourage wider adoption of the new privacy dashboards by citizens, usability is essential. The challenge in developing those dashboards is to find a legally sound middle ground between privacy automation and privacy micromanagement. For adoption by services, the key is in clarifying if and when digital API's are required to be self-descriptive, allowing services to combine and reuse data without a laborious integration effort.

In terms of regulation work, the key finding is that the new European legal setting regarding privacy as a basic human right is changing the digital industry. The EU General Data Protection Regulation will be enforced across the EU in May 2018. At the moment organizations preparing to adapt to GDPR requirements need more and better GDPR-related implementation guidance, as well as new technological solutions. In terms of healthcare-related data, there are also signs of data processing right protectionism, possibly hindering the usage of health data in comparison to other data sources.

Next generation health check-up pilot

The Digital Health Revolution (DHR) Pilot Study was designed to test how deep personal, molecular and electronic health data of an individual (wellness profiling) can be collected, analyzed and returned back to participants under the principles of the MyData approach.

The groundbreaking nature of this study was manifested with the strenuous process of the ethical approval. The study setting emphasized participant consent to the study and limited the risks of people receiving raw data without medical and expert counseling. The biospecimens and data were planned to be stored later in a biobank. For the first time in Finland, approval was granted for such P4 medicine-oriented human research.

Approximately 100 volunteers have been followed up in the DHR Pilot Study over a 16-month period via regular sample collections including clinical laboratory, biomarker and omics analyses. Digital health-related information related to physical activity and purchasing behavior, for example, has also been collected. The questions addressed how integrated analysis will help to understand disease, wellness and individual variability, and how health could be improved by data-driven motivation of health behavior. The deep and holistic health check-up, combined with personalized health and wellness advice and coaching, will pave the way for predictive, preventive, personalized and participatory (P4) healthcare, and for new service models and pathways in healthcare at large.

At the start of the study, the majority of participants showed some health risks, such as elevated BMI, elevated blood pressure, or abnormal levels of cholesterol, glucose, or vitamin D. Study participants were positive and motivated to undertake a MyData-driven health change, and many individuals were able to revert to their abnormal health status. The study continues with deep molecular data analysis and integration with digital health data.

New role of the customer and service transformation

Transformation to MyData-based services in healthcare can enable empowerment of the customers, but there are also a wide range of potential challenges, including ethical concerns related to, for example, equality and individuals' capabilities to control and interpret their own data. To increase the understanding of customers' needs and benefits, and to represent the service transformation, the customer's new role has been demonstrated in service scenarios highlighting data-driven health check-up, data-driven disease management, the biobank donor's journey, online health profiling services, and sharing personal data profile between public and private service providers.

The customers' intentions to use MyData-based preventive health services and products depend on various factors, such as expected performance, expected effort and social influence. Customers are looking for personal data that is understandable and meaningful for their personal lives. Our studies show, that concepts of mobile self-tracking apps that are embedded into everyday life, and contain clearly presented interpretations of the data, were the most appreciated. However, people tend to have different expectations, capabilities and aims, ultimately affecting whether self-tracking devices can produce data that is considered valuable or meaningful. Also, customers may not understand, or may have doubts about, the accuracy of the data, and they may feel left alone with their data, possibly leading to confusion and eventually to disempowering effects.

Emerging service ecosystems and business models

Service transformation and usage of data in healthcare via the transformation of the Mydata approach will open a vast range of new business opportunities. Novel business models are needed for companies aiming to co-create value for the individuals by using the data opened through individual consent and to meet the growing need for personal data management.

We have studied business models for the MyData operator. The MyData operator is a crucial actor in the scenario of data consent management, enabling individuals to manage and share their data, and service providers to access rich data in order to provide personalized services. The MyData operator facilitates data transactions and other interactions among the individuals, service providers and data-generating organizations. Thus, the operator acts as an intermediary in a service ecosystem with no data-locks.

Two primary business models have been identified: service-based and transaction-based. In the service-based model, revenue may be generated by offering value-adding services on top of free services for individuals and companies using the platform. In the transaction-based model, the service allowing to store, access and share one's own personal data is provided to the individuals free of charge; the revenue is generated from the business-side. Revenue can come from taking fees for facilitating data transactions between the stakeholders, for operating the platform, or from charging organizations for the use of or connecting to the platform.

Value co-creation is emphasized as a foundation of business models in the MyData ecosystem with multiple service providers enabling the transformation towards preventive data-driven services. According our studies, the money flow for the service providers and insurance players can come from individuals, specialized service providers, or from both. It is foreseen that the individuals' willingness to pay comes from getting more personalized services in return.

For the businesses, data is an asset which is rarely seen as a shared economy in the ecosystem, and individuals are rarely seen as active participants in the co-creation of value for the business with their data. Data sharing principles and benefits are also difficult to communicate and implement in the present healthcare system infrastructure, where the value of the personal data is slowly starting to be recognized.

Lessons learned

It has become obvious that the usage of data in the person centric service and business development is more complex than was anticipated. Data is not always available as such, and it might not be in a usable format, thus hindering the integration of data from various sources. Furthermore, the holistic, integrative analysis of data is very costly, requiring specific expertise in data analytics and an in-depth knowledge and understanding of the discipline at hand.

An open business environment for data sharing is only now starting to emerge; a major challenge is represented by the identification and application of the most suitable technological solution amongst the many solutions, all of which are still under development.

However, the human-centered approach in the data management has become a relevant topic when developing person-centric data-led care. The management of personal data in different fields of society is competitive advantage, driving the data-led economy in the future.

MYDATA PRINCIPLES

The term MyData refers to the personal data from various sources that the individual can access and control. The concept of MyData and MyData principles are described in more detail in MyData White Paper, with DHR researchers as co-authors.

Human centric control and privacy

Individuals are empowered actors, not passive targets, in the management of their personal lives both online and offline – they have the right and practical means to manage their data and privacy.

Usable data

It is essential that personal data is technically easy to access and use – it is accessible in machine readable open formats via secure, standardized APIs (Application Programming Interfaces). MyData is a way to convert data from closed silos into an important, reusable resource. It can be used to create new services which help individuals to manage their lives. The providers of these services can create new business models and economic growth to the society.

Open business environment

Shared MyData infrastructure enables decentralized management of personal data, improves interoperability, makes it easier for companies to comply with tightening data protection regulations, and allows individuals to change service providers without proprietary data lock-ins.



TOOLS

Software Development Kit

MyData architecture is a manifestation of a consent-centric personal data management framework. Software developers are invited for further development work by the released interactive, Creative Commons licensed MyData Service Development Kit.

MyData Alliance

MyData Alliance is an open community established to increase MyData understanding, share knowledge and resources, and to advance MyData pilots. The Alliance aims to promote real change in businesses and services, also in healthcare sector, by developing internationally scalable interoperability model for personal data management. The MyData Alliance is also the Finnish local hub of the MyData Global Network.

MyData Clinic

MyData Clinic workshop method was developed to help companies to rethink and develop their business and services. MyData Clinic helps to create better understanding of the MyData transformation opportunities, and creates abilities to develop solutions that enable sharing, receiving and combining data from different sources in a novel way as part of future wellbeing and healthcare services. Clinic concept has been tested with real use cases with companies, public and private healthcare providers.

Profiling tool and user interfaces

User research, user interface design and service design are essential when developing new MyData business to make data understandable and services valuable. One example is Omaprofili.fi profiling service, which can assist individuals to understand their behavior and lifestyle choices and thus help in setting and achieving goals for healthy habits. Also other concepts, designs and demos to illustrate what kind of MyData applications and products we could have and how MyData could be visualized, have been implemented.

DIGITAL HEALTH REVOLUTION PROJECT



Digital Health Revolution strategic research project, combining bold visionaries, new perspectives, and multidisciplinary approaches is pointing to a new direction in healthcare, by allowing individuals to control and make use of their personal data to improve their overall health and wellness. In the project technological solution meeting the juridical requirements and facilitating data flow through applications and services has been constructed, open environment business models and service concepts have been created, user interfaces and visualizations have been designed, consumer motivation to use MyData based services has been studied and novel health check-up pilot utilizing comprehensive health, wellness and lifestyle monitoring data together with genomic, metabolic and microbiome data has been set up.

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The project is funded by Tekes, the Finnish Funding Agency for Innovation.

