

Digital Health Revolution

PERSON CENTRIC DATA
MANAGEMENT MODELS AND
OPPORTUNITIES IN THE
HEALTHCARE SECTOR

THE NORDIC WAY



Foreword

The accelerating pace of technological development is changing many aspects of both the society and how we live as individuals. We are entering the 4th Industrial Revolution with the combination of data, biology and materials that greatly impacts many domains of health. Data can be produced in an increasing number of settings and the ability to use data for knowledge, services and treatments expands every day.

In recent years a new paradigm of personalisation has been born. Our ability to characterise diseases on a genetic level, unique to each individual, signalled the end of ‘the average patient’. In 2015 former US President Barack Obama called precision medicine “one of the greatest opportunities for new medical breakthroughs”¹. In this new approach, improvements in health and treatments would be derived from personalized care, tailored to an individual’s genes, environment and lifestyle.

These are remarkable visions for the future, but how do we get from our current, often fragmented, state of healthcare to this new era? And as healthcare becomes increasingly digitalised, all aspects of data including storage, security, privacy and operability will come under greater scrutiny. Governments will face increasing pressure to fulfil the promises of precision medicine while protecting citizen rights. This task can only be achieved with a more cohesive and transparent data infrastructure and protections that balance privacy with innovation. Furthermore, in our increasingly globalised societies, data interoperability between nations will be crucial to capitalise on population insights as we tackle some of the most pressing public health issues of our times.

In light of this, the urgency for a “Nordic Way” has never been stronger. As Nordic countries forge ahead with these digital transitions, it will be crucial to consider their impacts through the lens of the Nordic welfare values of equal access, universal health coverage and social trust. This could serve as a model for other regions seeking to uphold similar values. This paper will discuss some of this work taking place in the region. The Digital Health Revolution (DHR) project, launched in Finland in 2014, proposes a person centric data management model that empowers individuals to control the use, exchange and management of their personal health data². The foundations of DHR is built on principles of MyData, which are:

1. Human centric control and privacy
2. Usable data
3. Open business environment

The condensed version of the white paper was produced as part of the Digital Health Revolution project funded by Tekes, the Finnish Funding Agency for Technology and Innovation. The development of the paper benefited significantly from generous input and support provided by our outstanding sponsor and reviewers, reflecting a balance of corporate, NGO, government and academic institutions. The study was conducted with the close collaboration with the University of Oulu, which has been initiating and leading the DHR project. While MyData is not the only way to work with the emerging opportunities and challenges of health data, it does set a cohesive frame and is possibly the most development frame to work with person centric data management.

Global Megatrends

The pressure for a digital health agenda can also be considered in the context of global megatrends. This term refers to synthetic, complex aggregations of trends that exert a forceful impact on businesses, societies, economies, cultures and personal lives. The Copenhagen Institute for Futures Studies works with fourteen megatrends shown in the diagram below.

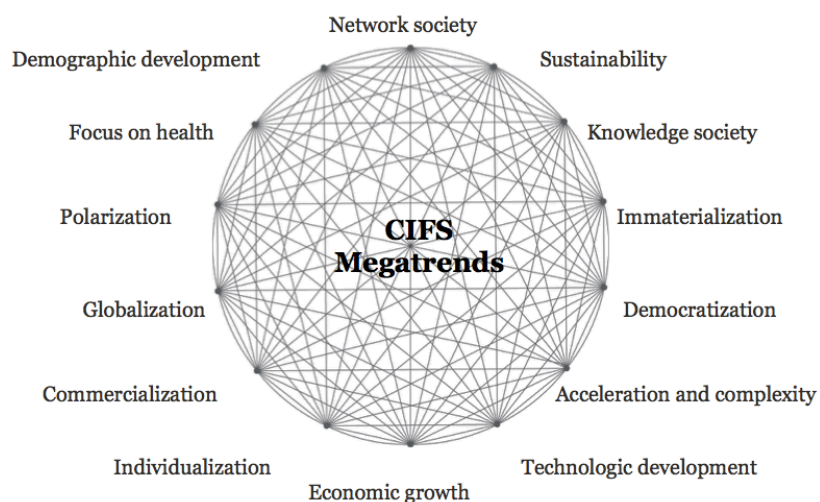


Figure 1: Global megatrends utilized by CIFS

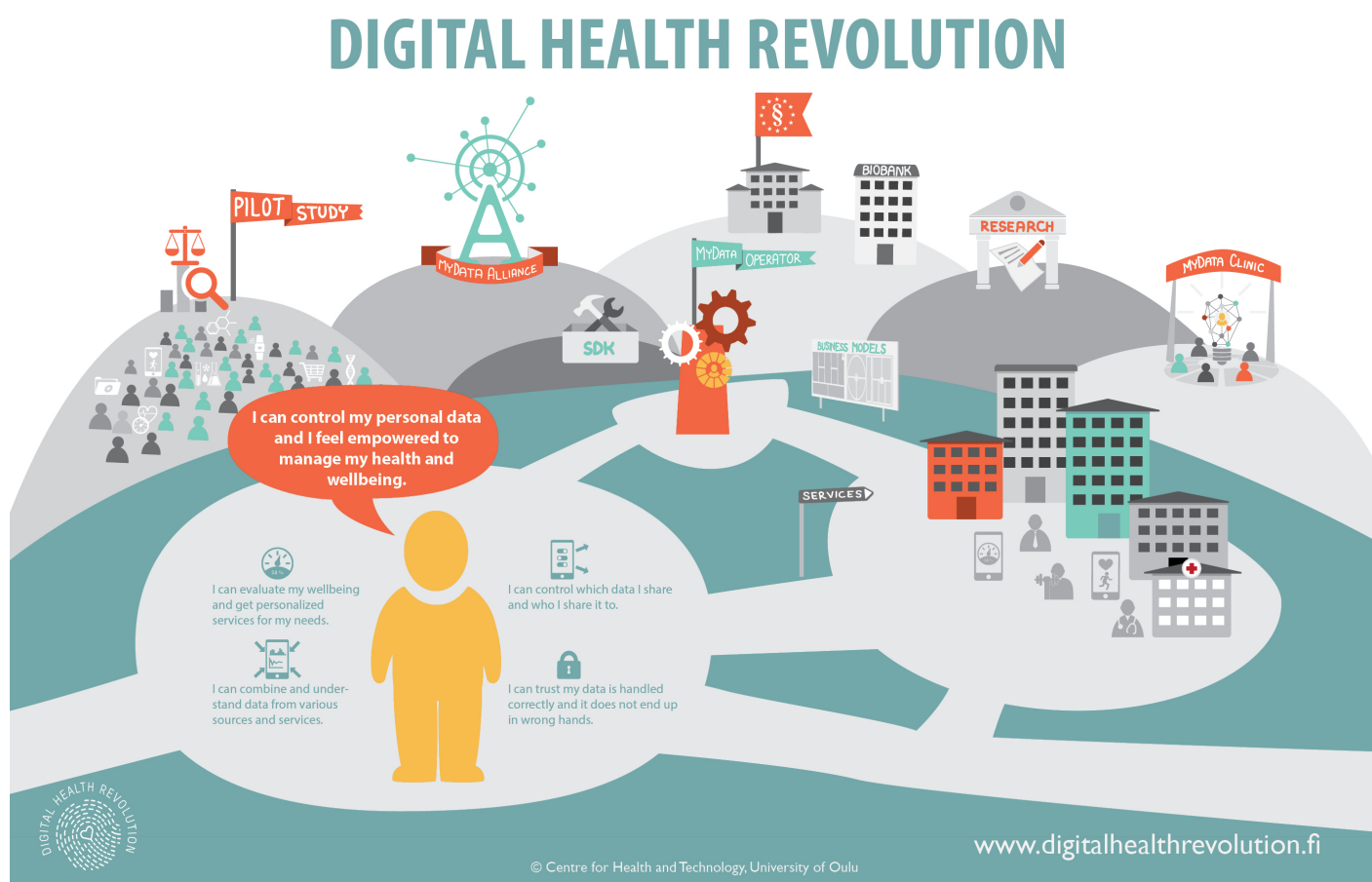
Demographic development, technological development, knowledge society and individualization are some of the strongest megatrends behind the digital health agenda. Commercialization, acceleration and polarization are also important considerations when planning the future health data infrastructure and management models in the Nordic setting. Naturally, these megatrends will also interact with the contextual environment. For example, Nordic social trust³ and baseline digital literacy will play a significant role in public acceptance of new technology. Nevertheless, social trust is a dynamic concept and cannot be taken for granted.

As the Nordic countries forge ahead during these digital transitions, it will be crucial to ensure that health data is interoperable, portable and secure. This white paper will explore the merits of developing a person centric health data management model in order to fulfil these aims.

The condensed version of the white paper will be presented in 5 sections:

- **Section 1** – Discusses personal data, health data, health-related data and the introduction of GDPR in Europe. It also discusses how Nordic citizens access their health data today.
- **Section 2** – Introduces person centric health data management through the Digital Health Revolution project and MyData principles.
- **Section 3** – Addresses the opportunities available to Nordic citizens, societies and businesses from a person centric model of health data management. It will also touch on some ethical challenges.
- **Section 4** – Highlights some future game changers to consider when planning the future health IT infrastructure in the Nordic region.
- **Section 5** – Concludes the white paper with some recommendations and a roadmap for the coming years.

The long version of the white paper can be downloaded on the websites of Copenhagen Institute for Futures Studies [here](#) and Oulu University [here](#).



Section 1 – Your Digital Self

Personal Data

As technology integrates deeper into our daily lives, more personal data is collected, stored and utilised. The EU GDPR regulation recognizes the diversity in personal data, anything from a ‘name, a photo, an email address, bank details, posts on social networking websites, medical information, or a computer IP address’⁴. One of the reasons aggregated data holds such value is because it is “greater than the sum of its parts”. It is no wonder that in 2016, The Economist declared data, and not oil, as the world’s most valuable resource of the 21st century⁵. Figure 2 depicts the various types of personal data and how they can intersect.

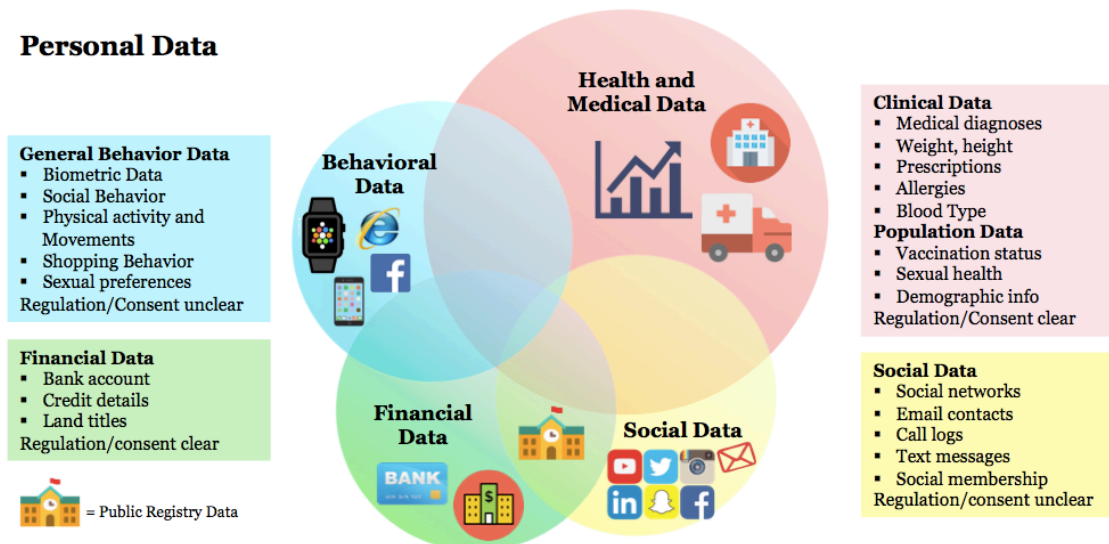


Figure 2: Types of personal data and how they intersect with health data

Many of us are familiar with our health data being collected through formal channels such as hospitals. Although the portability and interoperability of this health data is often poor, consent is usually strictly regulated. In more recent years, the amount of behavioural data collected on individuals has grown. Personal devices such as mobile phones⁶, computers, wearables⁷, customer loyalty cards and social media⁸ have facilitated a new form of personal data collection. Some of this behavioural data may be considered health-relevant, for example what food you eat or how far you walk per day. Behavioural data is fast becoming the new game changer in the digital healthcare landscape⁹. As governments struggle to keep pace with the acceleration of technology, industries have stepped in the market with little or unclear regulation.

General Data Protection Regulation (GDPR)

Beginning 25 May 2018, the new European General Data Protection Regulation (GDPR) will be enforced¹⁰. This has followed several years of discussion on how new protections should be updated to reflect the emerging digital landscape of data processing and data controlling. In particular, healthcare data will be afforded a special status¹¹. This includes data concerning health, genetic data and biometric data, the definitions of which can be found on the longer version of this white paper. Processing of this healthcare data will require explicit consent, or evidence that processing is necessary for preventative or occupational medicine or for reasons of public interest. Nevertheless, GDPR will be enforced in a data ecosystem in which data aggregators, and not citizens, are at the centre. While data protections will be strengthened, the ease with which citizens can access, transfer and use their own data remain a challenge.

Nordic Registries – theoretical goldmine, barriers in practice

Since birth, Nordic citizens have their individual health data collected and stored in national quality registries¹², summarized in Figure A in Appendix A (pg 10). The number, governance and structure of these registries vary by country, for example Sweden has 108 national quality registries compared to 54 in Norway. Although the comprehensive registries make it theoretically possible to combine data to form a Nordic cohort, there are many practical obstacles¹². Coding systems differ between countries, experience in retrieving data is variable, and data sets need to be realigned to be interoperable. Alongside differing laws and ethical clearances, such barriers make it hard to establish Nordic collaborations in practice today¹³.

Meanwhile, Nordic citizens access their own medical and health data through their respective Health Information Portals, which differ between each country. Sweden uses 1177.se¹⁴, while in Norway it is helsenorge.no¹⁵, kanta.fi¹⁶ in Finland and sundhed.dk¹⁷ in Denmark. These are summarized in Table A in Appendix A (pg 11). However, data in these portals are not interoperable between Nordic nations. Furthermore, to date it is not possible to integrate health-related behavioural data generated by citizens through personal devices, onto these health portals.

Section 2 – Introducing Person Centric Health Data Management

In the current state of personal data management, key data aggregators have emerged. Some of these are sector specific to health, while other household names such Google, Facebook, Apple and Microsoft span multiple sectors. Moreover, as new business strategies emerge the distinctions between sector specific aggregators are increasingly blurred. While these companies have provided many societal benefits and conveniences, several disadvantages arise from this model of personal data management¹⁸.

- First, there is no incentive for data interoperability (and portability) as it disables users from taking their data to a competing service. This hoarding suppresses innovation and research.
- Another drawback is that privacy and transparency become a secondary concern. This secrecy erodes public trust, which is further undermined by privacy breaches that circulate the media¹⁹.

MyData

As healthcare systems become increasingly digitalised and transition from reactive towards more proactive models of care, new opportunities arise to establish a person centric approach to health data management. In this domain, the MyData movement originating from Finland has made significant progress. Fundamentally, MyData refers to a new approach to personal data management and processing¹⁸.

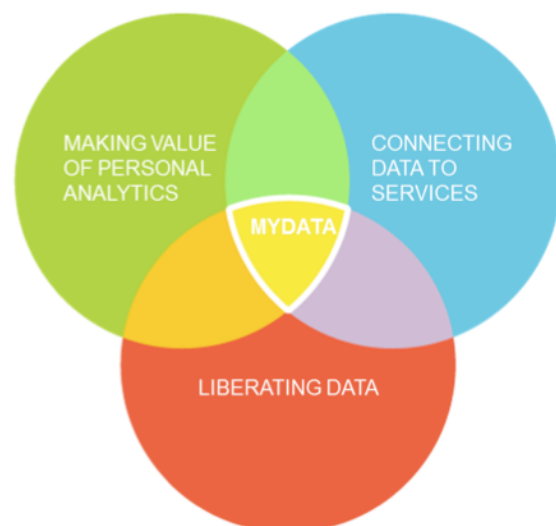


The three guiding principles of MyData¹⁸ are:

1. **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.
2. **Usable data:** It is essential that personal data is technically easy to access and use - in machine readable formats via secure, standardised APIs (Application Programming Interfaces).
3. **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.

In light of GDPR, a MyData-based ecosystem of health data management can be considered complementary, and not mutually exclusive to GDPR. This person centric approach to data inherently structures consent in the flow of data. By design, it addresses the right to data portability, right to access and right to have data forgotten. Furthermore, it promotes the right to privacy by design.

In 2014, the Digital Health Revolution (DHR) project was launched to investigate how a MyData-based service ecosystem could function in the healthcare setting²⁰. In particular, it has focused on the technological, regulatory and ethical requirements, as well as service transformation and business model opportunities to implement such a model in the healthcare setting.



Digital Health Revolution Project principles

To date, the DHR project has developed a series of concrete outcomes. A MyData infrastructure has been developed based on Creative Commons licenses, to liberate the potential of personal data and to facilitate its flow from multiple data sources to applications and services via a standard and interoperable consent management framework. The architecture has been defined against the MyData principles to meet and surpass the new privacy related juridical requirements that will be enforced EU-wide, also to ensure standardisation and interoperability. The infrastructure is currently undergoing testing in several pilot studies. However, many challenges remain to be overcome or even fully articulated.

Figure 3: Digital Health Revolution project principles

Section 3 – Opportunities and Ethical challenges

This white paper will now present a future scenario using a model case called the **My Nordic Health Record Card (NHRC)**. The purpose of this model is to serve as aspiration for Nordic stakeholders. The common goal is a human centric data management model that benefits Nordic citizens, societies and businesses. The opportunities and benefits for these three stakeholders are presented below.

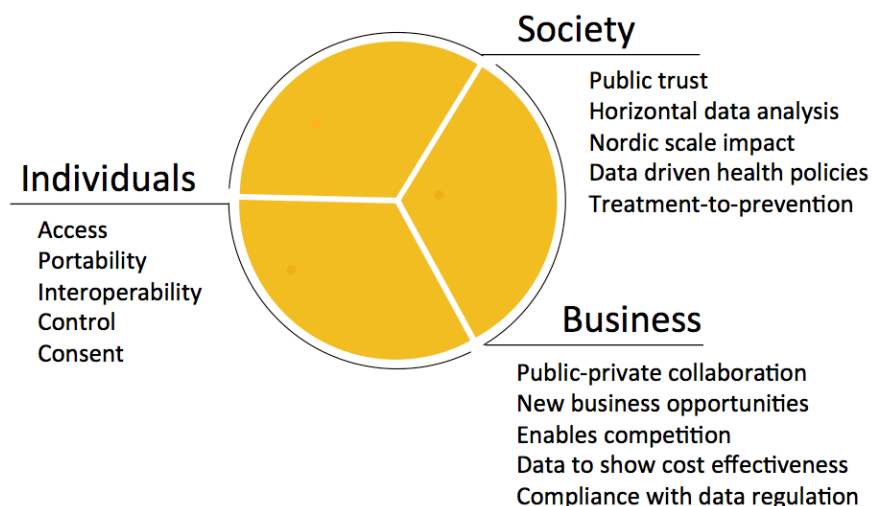
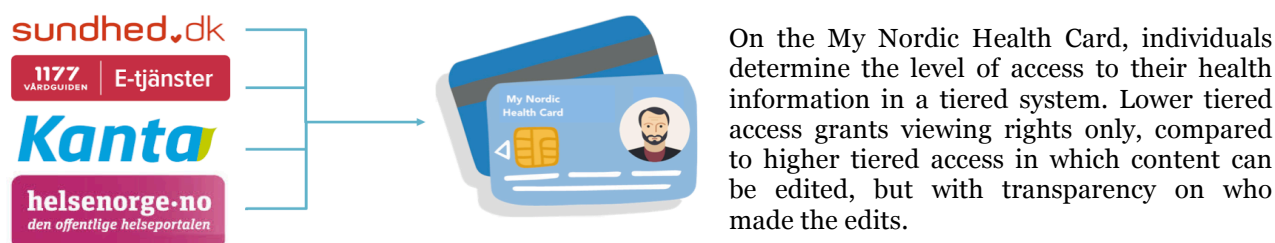


Figure 4: Opportunities for individuals, society and businesses in a model of person centric health data management

Nordic Individuals

Imagine a future where Nordic citizens access their health data through a My Nordic Health Card. It is linked to an online platform where medical reports, emergency contact, organ donation directives, allergies, and blood type are stored in a digitally interoperable format. With the individual's permission, or in the event of an emergency, this information is accessible to all hospitals and healthcare professionals in the Nordic countries. For the individual, their health data is both portable and interoperable.



Dynamic consent²¹ is one of the central features in this online portal. Private companies must seek explicit consent from individuals, through clear procedures and with the provision of user-friendly documents that explain the scope of use of health data. If the scope expands or changes, patients can be updated real-time with new consent solicited through the portal. Patients can dynamically approve or withdraw consent.

Nordic Societies

Today digital health sits high on the Nordic societal and political agenda. Telemedicine and ePrescriptions are slated to provide remote solutions to rural communities, fulfilling the Nordic Council's goal of creating more inclusive and innovative societies²². Alongside high levels of social trust, a window of opportunity has emerged for Nordic countries. It is now possible to imagine the formation of this interoperable, unified Nordic health record that places Nordic citizens in control of their own healthcare data.

Individually, the Nordic countries are small and this raises doubts about the scalability of technological solutions. Therefore, combined regional expertise would solidify the Nordic's position as a thought leader at the intersection of health and data science. Comparative analysis of health data sets between municipalities, regions, and between nations, adds value by making data interoperable for cross-disciplinary research.

Moving from a treatment-focused health paradigm to one of prevention and early detection also brings economic benefits to Nordic societies. Less healthcare expenditure is spent on hospitalisation, recurrent treatment of chronic diseases, as well as quality adjusted years of life (QALY) lost from the workforce²³⁻²⁴.

Nordic Businesses

Transitioning to a MyData-based infrastructure can bring many benefits to businesses in the Nordic region. The first point to highlight is that transparency of data flow is necessary for open collaboration. Businesses, including pharmaceutical companies, increasingly need to adjust their business models to changing consumer patterns, growing knowledge complexity and the hyperspecialisation of medicine. It is no longer possible to undertake all activities 'in-house', therefore collaboration with academic institutions and crowd-sourcing knowledge becomes vital. In particular, the demand for efficacy and cost-effectiveness data of new digital interventions will likely pressure private healthcare companies to collaborate with health professionals.

Another opportunity for industry in the Nordic region will be the rise of new services in response to healthcare digitalisation. Infrastructure maintenance including technical assistance, cyber-security, data protection, processors and compliance officers will provide scope for new business opportunities in the Nordics. Furthermore, the current gap in baseline digital literacy will mean new opportunities for data counselling could emerge.

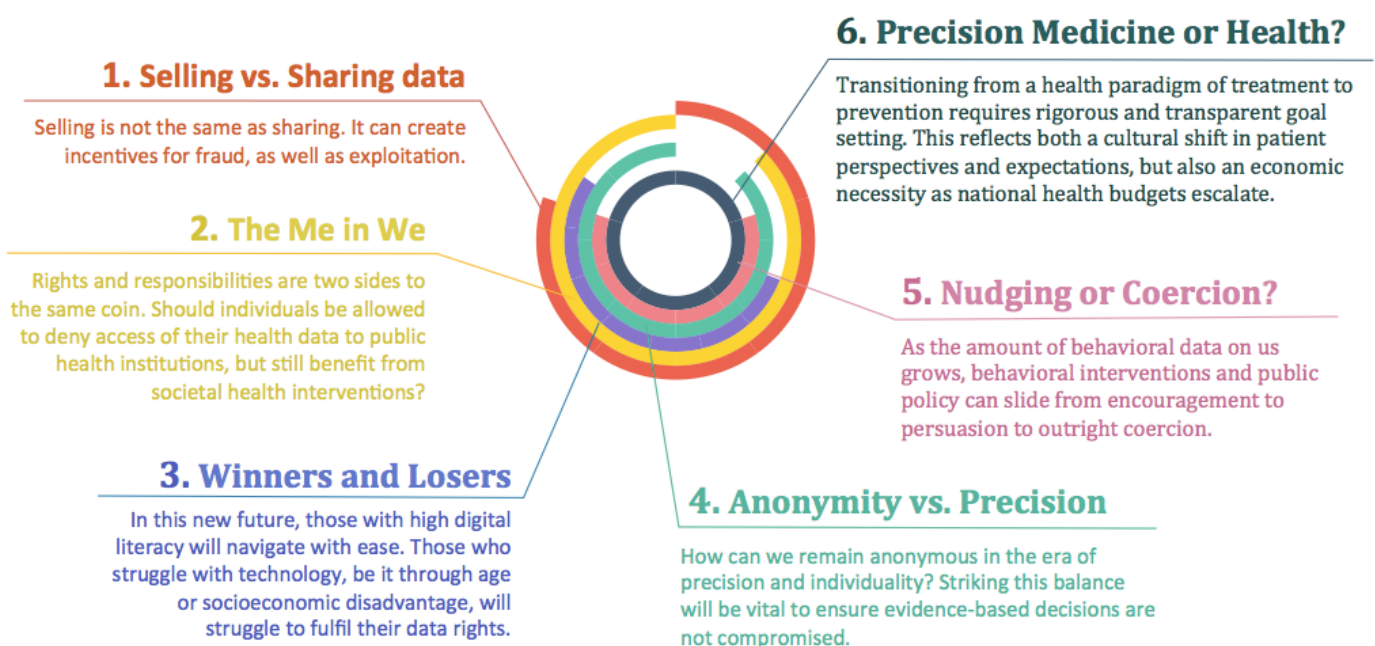
Today, big companies have monopolies on huge data sets, which locks out other businesses from entering the market. By having a person centric, interoperable model of health data management, *small businesses* will have the opportunity to compete to integrate various types of health data. This will generate evidence to drive change in practice and policy that favours their product or service.

Finally, the emergence of *public-private-crowd partnerships* will demand a new framework for interaction between these stakeholders. Research has shown that public health practitioners are increasingly aware that they cannot act alone in tackling the commercial determinants of health²⁵.

With significant growth in the amount of health data collected and shared, several new uses of data can be expected in the form of new services, solutions or treatments. In a context where the individual primarily or completely holds the rights to share their health data, as suggested by the MyData movement, the responsibility also falls back on the individual; individuals who actively share their data are more likely to receive a solution to their health demands. With this in mind, a potential role to emerge is a **digital health navigator**. The role could assist citizens with the usage and sharing of their digital health data with relevant actors. This provides opportunities for both private businesses, as well as municipalities, to step in.

Ethical Challenges

In a person centric model of health data management, new consequences and ethical challenges would arise. This paper identifies some broader ethical dilemmas emerging from a MyData ecosystem.



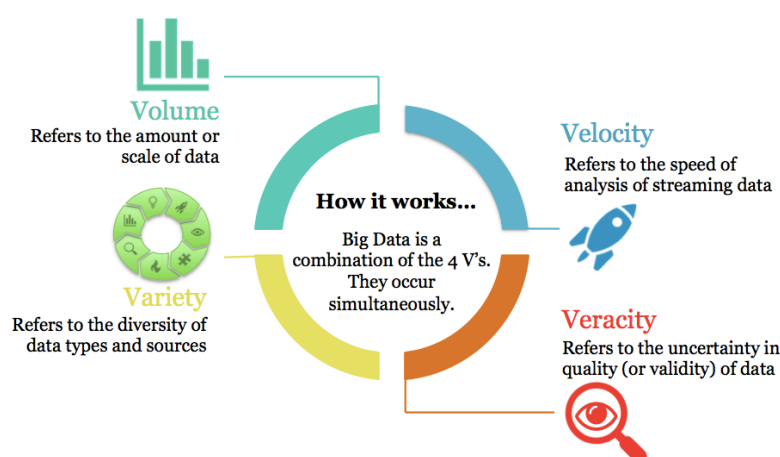
Section 4 - Future Game Changers

1. Ledger Technology (e.g. Blockchain)

- Current technologies are unable to consistently deliver a trustworthy ledger that accurately records previous episodes of access of health data. Data security is also a significant concern.
- A promising area of development is in Blockchain technology²⁶ and similar derivatives. As an open, distributed ledger, it records transactions between two separate parties in a manner that is both permanent and verifiable. The ability of Blockchain technology to embed transactions in digital code, protected from unauthorised tampering, deletion and editing, fosters transparency. It also raises the possibility of minimising intermediaries such as lawyers and brokers.
- Despite this, current Blockchain technology will struggle to sustain a MyData-based infrastructure primarily due to three reasons: energy requirements, micropayments and the time required to authenticate each transaction.
- Next generation Blockchain such as IOTA²⁷, which uses a Tangle ledger, may be promising.

2. Big Data during the era of Artificial Intelligence

- In recent years, the term 'big data' has infiltrated the lexicon of almost every field. Among its proponents in healthcare, the opportunities from big data analytics range from predictive modelling and clinical decision support to public health surveillance and research. Generally when people talk about big data, they refer to the well described 4 V's²⁸, which are:



- As healthcare data management models evolve, it will be possible to link data from national health registries, electronic health records from various institutions, and integrate health-related data from medical devices, wearable devices and sensors based on virtual reality. The ability to analyse health trends from non-traditional data sources, such as social media, has also been demonstrated from the use of Twitter as an early warning tool during the 2009 swine flu pandemic²⁹.

3. International Health Account Number (IHAN)

- Initiated and in development by SITRA in Finland, IHAN³⁰ builds on the new digital reality with GDPR and uses decentralized MyData concepts as its vision. The IHAN model recognizes each person in relation to his/her personal data just as IBAN recognizes each bank account.
- IHAN and similar concepts build on existing frameworks such as X-road, which is the data exchange standard in public sectors of Estonia³¹. The key value behind X-road is interoperability, which enables the integration of data from different public and private organizations and information systems.

Conclusion

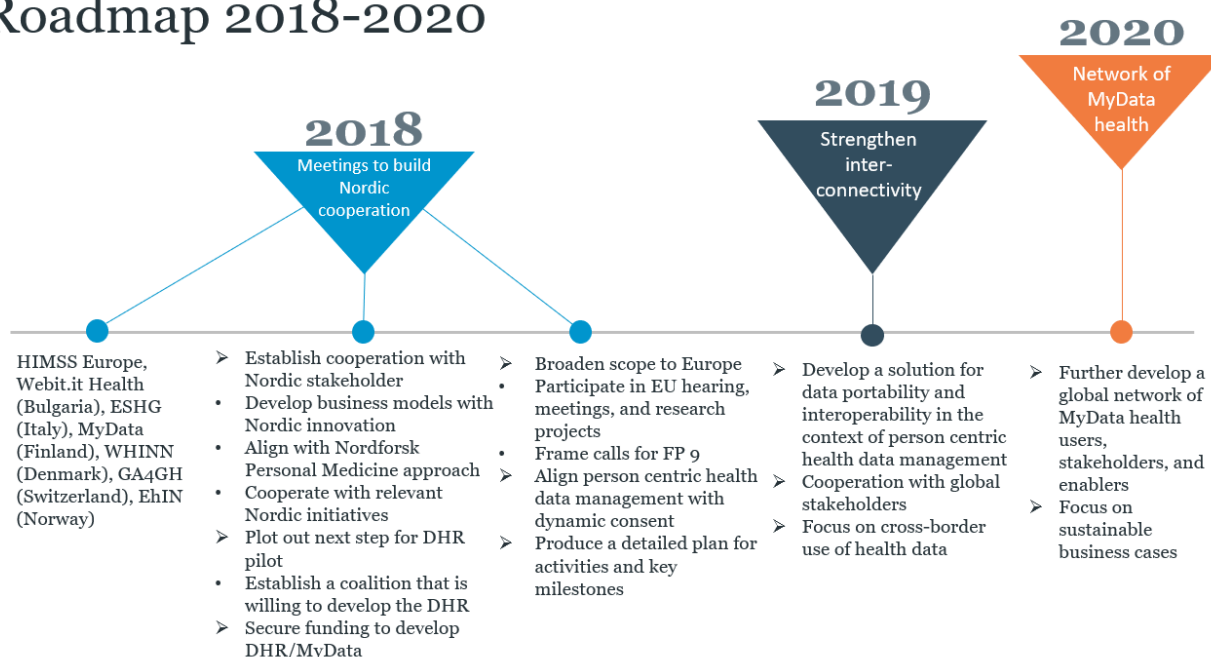
The future of health and medicine will undoubtedly merge with digitalisation and data. During these large-scale transitions, Nordic countries have the advantage of high social trust, a collective mindset of public good, and pre-existing digital infrastructure from longstanding population registries. Meanwhile, citizens increasingly recognise the need for more transparency, and this is mirrored by upcoming GDPR regulations to sweep across Europe. Early investment in person centric health data management today will provide benefits to Nordic individuals, societies and businesses in the region.

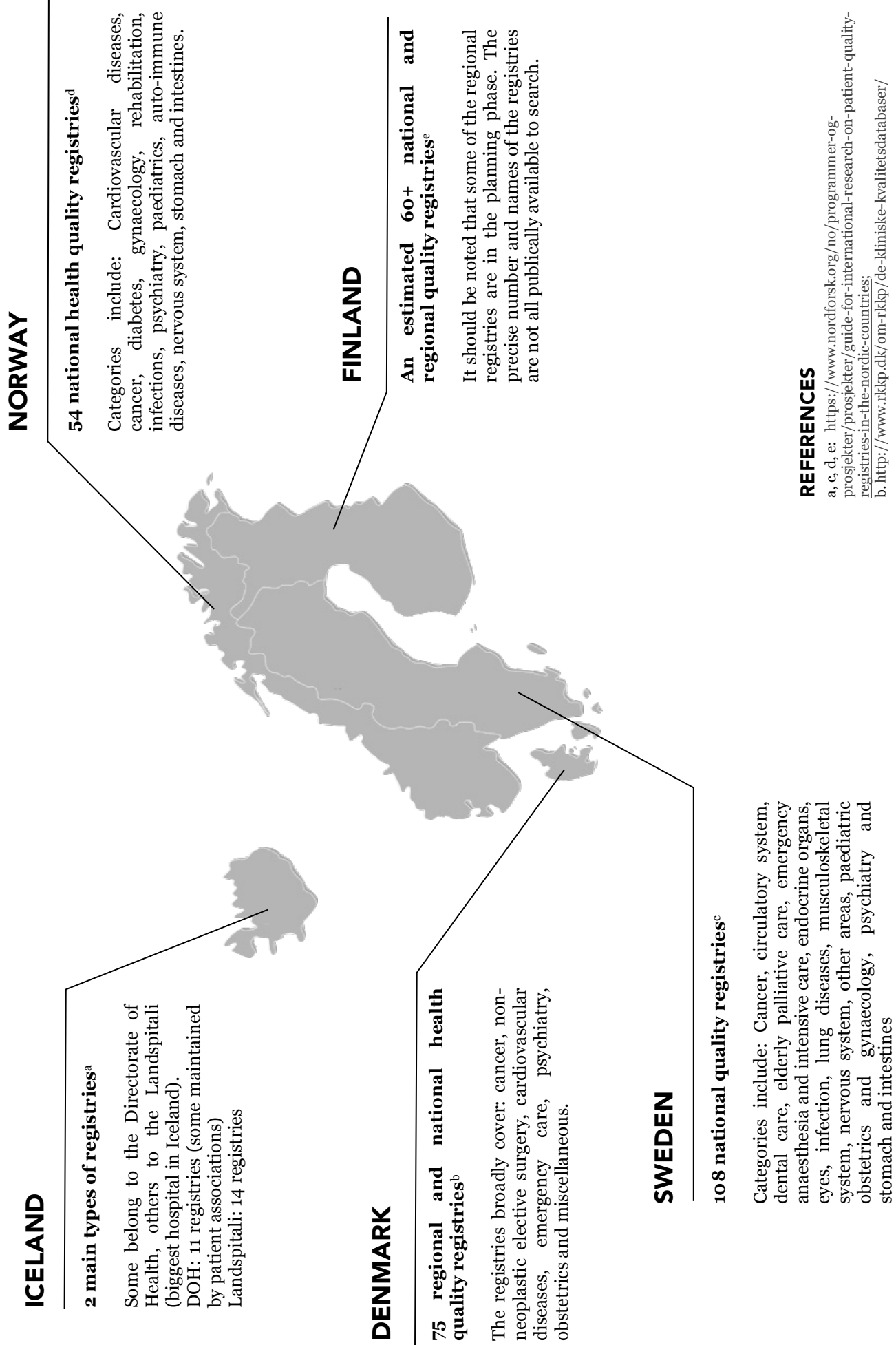
Moving forward, it is necessary for political, economic, societal and institutional agendas to align. As the Nordic Council of Ministers converge to discuss strategies for the future of the region, it can begin by exploring the merits of person centric health data management. Failure to capitalise on this opportunity and Nordic countries may soon be eclipsed by private data aggregators, or other nations, who dictate data priorities for Nordic citizens. With the arrival of GDPR, MyData begins to construct a frame to handle the new digital reality, in order to create more value from data by setting it free.

Section 5 – Recommendations and Roadmap

1. Conduct an in-depth comparative analysis of the differences in Health Information Portals in the Nordic countries today, including an analysis of governance structures within the health systems. Identify areas that need alignment.
 - i. Define the role of public sector health data aggregation, and how this will be enforced following the decentralizing of health data.
2. Define good data practices for data access and data sharing, including the status today.
 - i. Identify the most appropriate measures, indicators and assessment tools for efficient and trusted data sharing principles, to develop a mature model for data practice in the Nordics.
3. Exploit enabling technologies
 - i. Define the dynamics between individual, secondary and third party use of health data.
 - ii. Investigate novel data management possibilities, including dynamic consent.
 - iii. Explore the potential benefits of Blockchain-like technology (distributed ledgers) in the implementation of person centric health data management.
4. Provide a more detailed analysis of key ethical challenges regarding data management in the future.
5. Establish a co-operation: Identify and engage key stakeholders in the digital health revolution.
 - i. Conduct public forums in key Nordic cities.
 - ii. Align the Nordic regional ambitions with the EU agenda, especially the upcoming GDPR regulations, Digital Single Market and eHealth strategy.
 - iii. Ensure political alignment among Nordic countries when specifying a strategic agenda towards a person centric model of health data management, based on MyData principles. The MyData Local Hubs should be used, as well as meetings and conferences.
6. Business potential: Articulate business opportunities that arise from a person centric model of health data management. Engage with private companies to determine their needs and facilitate the development of sustainable business models.
7. Learning points:
 - i. Explore the potential learning points from the Estonian-Finnish experience with implementing X-road.
 - ii. Explore IHAN as a component of person centric data management, with regards to integrating health and health relevant data.

Roadmap 2018-2020





Appendix Figure A: Overview of population health and quality registries in the Nordic countries today

	Sweden			Denmark		Norway	Finland		Iceland
Name	1177 and Läkemedelskollen ^a	Sundhed.dk and Medicinkortet ^b	Helsenorge ^c	Kanta ^d	VERA (integrated part of EHR) and Digi.me ^e				
Responsible institutions	1177 owned by 20 Swedish Regions, Läkemedelskollen by eHealth Authority	Danish Health Data Authority	Directory of eHealth	Kela, THL, Ministry of Social Affairs and Health and others		Embætti landlæknis (The Directorate of Health)			
Structure	State, regions	State, regions, municipalities	State	State		Vera: State, Digi.me: Private			
Content/scope	1177 gives the individual the right to hide some data from the portal and can also block data from certain or all health professionals. In reality, the individual decides what information is stored and with whom it is shared Läkemedelskollen: Information on prescriptions, purchased drugs, high-cost protection, personal drug records kept in registries	State, regions, municipalities Sundhed.dk: Contains record and the context in which it has been viewed by professionals, treatment plans, validated health information, database of practitioners, information on health offers in region/municipality. Medicinkortet: Information on prescriptions, contact to GP for renewal.	Citizens can view and add certain information to their journals as well as see in which context their records have been accessed by professionals. Helsenorge also allows for change of GP, information on prescriptions and renewal. The portal also contains validated health information on various topics, e.g. lifestyle. Parents can view information on their children until they reach the age of 16.	Kanta includes Patient Data Repository, Electronic prescriptions, My Kanta pages, Pharmaceutical database. Users can see in which context their information has been viewed. Parents can act on behalf of their children until age 10; afterwards they can only view information added before the child reached the age of 10.		Vera allows citizens to view health information and the context in which their records have been accessed by professionals. Vera also sends reminders to take medication and the possibility of eBooking. As a new initiative by digi.me, citizens can receive a digital copy off all their data with the aim of patient empowerment.			
Individual permissions	1177 gives the individual the right to hide some data from the portal and can also block data from certain or all health professionals. In reality, the individual decides what information is stored and with whom it is shared	Sundhed.dk: Each person can hide personal health info which will then be marked as hidden information for health staff. If a citizen wants to add information to their record, they must send the information to a physician applying for the information to be added. Medicinkortet: Parents can view information on their children until the age of 15 if born after 2004.	Citizens can control the access to and sharing of their health information in the context of patient treatment and research. Children age 12-16 can choose to hide specific information on their prescriptions from parents in agreement with their doctors.	Citizens examine their own health records via internet and choose what info is shared with health professionals. It is possible to request further details regarding the context in which personal health information has been viewed by professionals.		In spite of being able to receive a digital copy through digi.me of one's personal health data, citizens do not officially have the rights; the data belongs to the system.			
Collaboration externally (behavioral data)	Inera, that is owned by the municipalities and regions	Sundhed.dk plans to expand the amount of data linked to each person and addresses data from fitness, medical and support apps (2016-18)	Unknown/unavailable	Covers both public health sector and most of private sector		Dattaca Labs is working with the government and local private businesses to create new services.			
Data security	Information is secured with the Swedish encrypted e-ID	Personal access only, except for parents (see above). Authorization can be given to others. In case of an emergency, all hidden information accessible by a health professional. Information is secured with the Danish encrypted 'NemID'.	Personal access only, however, authorizations can be given to others. Access on behalf of others can vary depending on the authorization given. Information is secured with the Norwegian encrypted e-IDs, e.g. Bank ID.	Personal access only, (except for parents, see above) however, authorizations can be given to others. Data is secured with the Finnish encrypted e-ID.		Information is secured with the Icelandic encrypted eCard.			
Future plans	EHalsa, a new citizen centric platform that also includes self monitoring, reporting and behavioral data. Temporarily halted pending legislative process	Integration of more data sources (including patient generated data)	Currently, not all regions have access to all features. Will be expanded.	Dental healthcare being added, social services data, potential export of portal		Digi.me/Dattaca Labs is working on expanding to different sectors in Iceland			

Appendix Table A: Comparative overview of health information portals used by Nordic citizens in respective countries today

a. <https://www.1177.se/>
d. <http://www.kanta.fi/en>

b. <https://www.sundhed.dk/>
c. <https://helsenorge.no/>
e. <https://digi.me/>, <https://www.landlaeknir.is/english/>

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