Nordic Innovation

Business Case for sharing of Nordic health data

Assessing the economic effects of a realized program vision

Contents

Preface

The Vision for the Nordic cooperation is that The Nordic region is to become the most integrated and sustainable region by 2030. In following up on this, Nordic Innovation initiated in 2018 the program Health, Demography and Quality of Life. The program aims at advancing the Nordic countries to be the most sustainable and integrated health region in the world by 2030.

The Business Case builds on several other activities carried out in the program; the Scenario Process (2019), Bridging Nordic Data: Legal Overview (by Deloitte, 2020) and a Use-Case focusing on simulating the effects on Nordic businesses (by Green Innovation Group et al., 2022).

The findings in this report underlines that there is a large economic potential to be gained if industries get access to Nordic health data and this is shared across the region. Our goal is that the findings will inspire decision makers to do the suggested changes in order to achieve the potential results which are identified in this report.

Disclaimer: This report is part of the program Health, Demography and Quality of Life by Nordic Innovation. Ernst & Young is responsible for all its content.

Oslo, November, 2022

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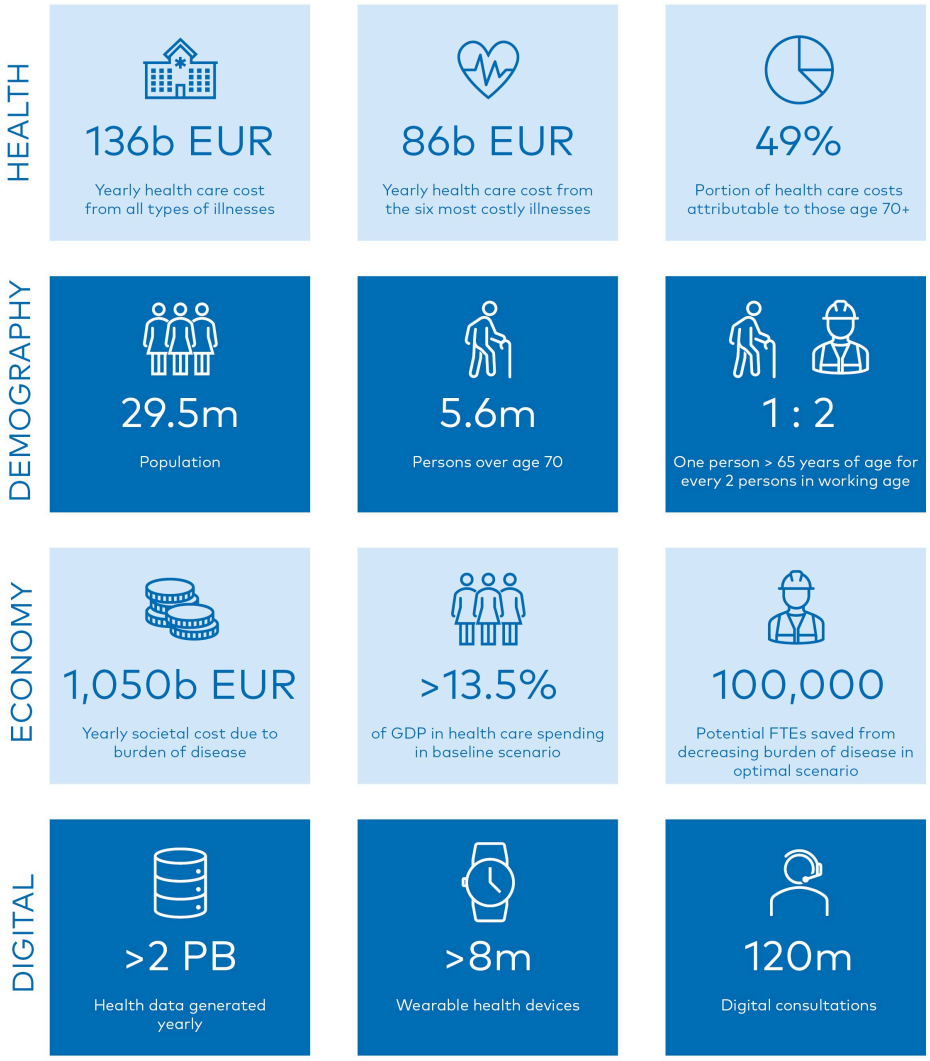
Managing Director, Nordic Innovation

SUMMARY

THE NORDICS IN 2040 WITH CURRENT TRENDS (not all of these will be affected by the 2030 vision)



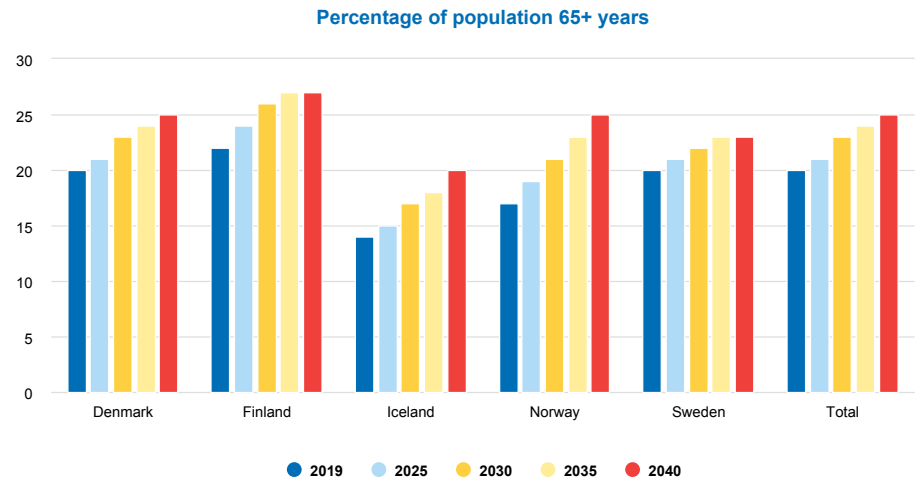
THE NORDIC REGION AND THE VISION FOR 2030

Today, the Nordic region comprises over 27 million people and is the 10th largest economy in the world by GDP. The individual countries are ranked high on digitalization and characterized by high productivity. A common trend across Nordic countries is rising healthcare expenditure linked with an aging population and increasing amounts of chronic illnesses and mental health issues. Besides the large annual toll and productivity loss because of diseases, the Nordic region spent over

160 billion EUR on healthcare in 2020. To accommodate the radical changes in demography, Nordic Innovation has set a vision that the Nordic region will be "the most sustainable and integrated health region in the world, providing the best possible personalized health care for all its citizens" by 2030. In this report, we examine the opportunities for the Nordic region to leverage health data to realize this vision and attempt to evaluate the potential economic effects of the realized vision. Even if we achieve the vision by 2030, we do not foresee the immediate realization of the full value potential of health data. Rather, our analysis and modeling show we can expect a time lag of a few years before the value realization will have a significant effect on the Nordic economies. Because of this, the estimated economic benefits in this report present the values for the year 2040, but it is worth stressing that to see these effects as outlined in this report, there is a need to implement changes as soon as possible, before 2030. Some effects will materialize earlier than 2040, assuming that the implementation is done by 2030.

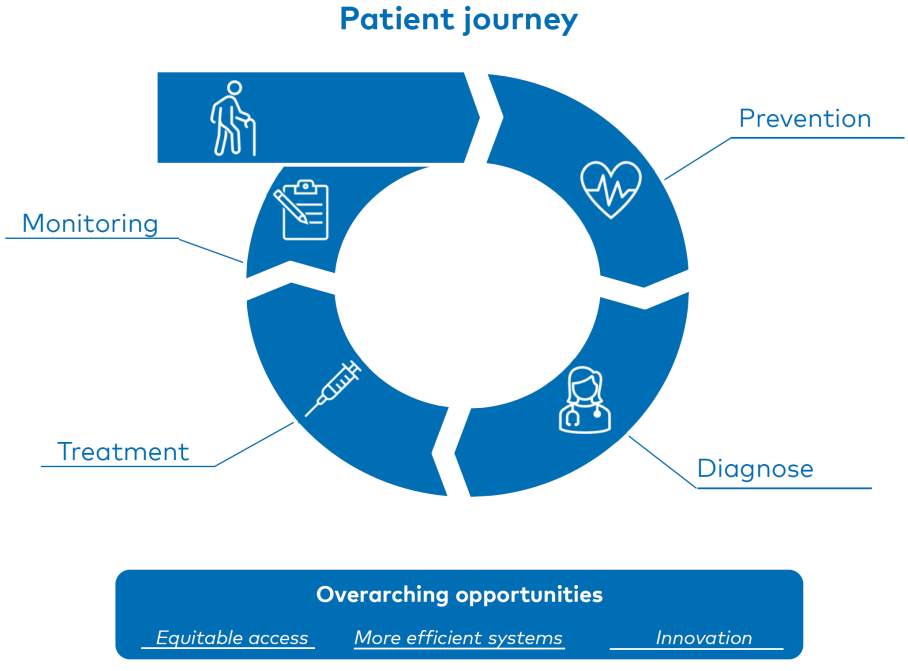
THE CHALLENGE FOR THE NORDIC REGION TOWARDS 2040

By 2040, there will be over 29.5 million people in the Nordic region, which comprises five countries and three self-governing areas, of which some are in the EU, two are in EEA, and some are outside the EU regulatory framework. We project that the rapidly changing demography will cause the annual cost of healthcare to rise by 23.5 billion EUR, which is more than 70% of the annual cost of all inpatient healthcare in the entire Nordics in 2019. The proportion of the population in non-working age to working age will rapidly increase so that in the coming years there are fewer people to support the Nordic welfare system. In addition, 900 000 full-time employees of productivity will be lost each year because of illnesses. In chapter 3 of this report, we assess the demographic transformation and economic effects this has on the Nordic region. We show that if we do not disrupt the current path, where the rising healthcare costs are exceeding the growth in GDP, an unsustainable share of the Nordic economy will go towards providing care. However, we are already seeing difficulties in recruiting the necessary personnel for the healthcare sector and our estimates suggest that we will need ~140 000 more personnel just to cover the five largest disease groups. Achieving economic sustainability and avoiding serious deterioration of the Nordic welfare system, therefore, calls for considerable advances in public health and the development of new health industry.



THE OPPORTUNITIES

Succeeding in an integrated, cross-border sharing of Nordic health data is likely to result in a significant positive economic impact and can help slow the growth in healthcare expenditure through increased efficiency, improving the population health, and at the same time, cause an expansion of the Nordic healthcare industry. Sharing health data may enhance the early detection of diseases, reduce the risk of medical error, and improve patient outcomes. The results will be that we can have more people in jobs and improve the inclusiveness of both healthcare series and industry in rural areas.



In chapter 4 of this report, we outline various opportunities that emerge throughout the patient journey because of access to Nordic health data. The geography of the Nordic region with approximately 30% of the population living in rural areas is a driver for new technology and innovations that facilitate equitable healthcare. We see that, for example, by shifting the focus from curing illnesses to preventing them, the health ecosystems will be able to deliver healthcare services to the inhabitants more efficiently and at a lower cost. More open systems may also cause improved collaboration and communication between professionals from different countries. Through improved monitoring, a larger proportion of the population may stay home longer. This will lead to lowering health care costs, improved quality of life, and increased productivity, which directly affects the Nordic national budgets. In addition to identifying the opportunities presented by Nordic health data, our business case reveals the magnitude of economic benefits to the Nordic region.

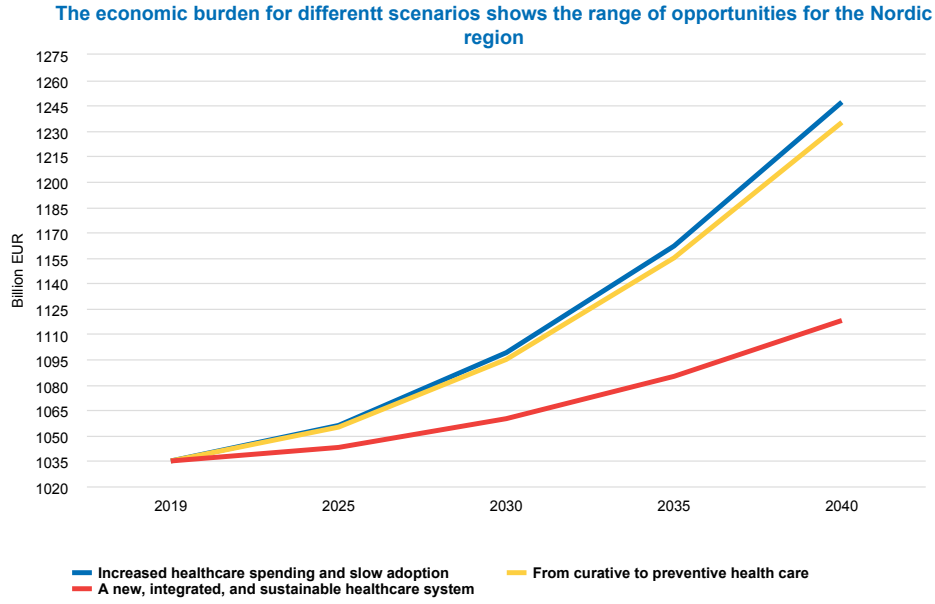
Baseline situation in 2040 if we do not meet the vision for the Nordic region

Improvements on baseline in 2040 if we achieve the vision

SCENARIOS

The path leading to the Nordic 2030 vision of being the most integrated and sustainable health region is not linear and will require disruptive thinking, systemic change, and increased collaboration between private and public actors. Sharing health data across the Nordic boarders is a key to better use of the workforce, enhanced transparency within the healthcare sector, improved collaboration, and interaction between private and public actors. To better understand the opportunity space, we developed scenarios that illustrate the gap between the expected evolution of health care and a more desirable future. The economic effects in our models arise because of improvements in the major disease groups where health

data will be able to affect the outcome, and the way of providing care or creating new business opportunities. In the baseline scenario, which has the costliest economic burden by 2040, we combine data on the forecasted population growth together with the assumption that illnesses per capita within different age groups will remain static across time. In the second scenario, with a slightly improved cost level, our assumption is that the sharing of health data has supported a slight shift towards more preventive health care, leading to a conservative 1-2% decrease in the per capita occurrence of the costliest illnesses. Finally, in the third and optimal scenario, we forecast the economic burden based upon a future where health data enables a new, integrated, and sustainable healthcare system. In this scenario, a greater per capita reduction in occurrence of between 10-20% is forecasted for the costliest illnesses.



THE VALUE POTENTIAL

Through the scenarios and economic models, we have identified a significant potential for reduction in health care costs, thriving innovation ecosystems, and an increase in the quality of life across the Nordic region. In our most optimistic scenario, we estimate yearly savings of 120 billion EUR from improved quality of life and a lowered cost of providing health care. At the same time, the reduction in illnesses may enable the addition of over 100 000 full-time employees to the economy. The effect of each new contribution that arises from sharing of Nordic health data may be variable, but accumulated, the impact they will have on the Nordic region is massive. Although the estimated potential is huge, our analysis shows that it will require substantial improvements to enable the flow of data, and distribution of information across borders, to enable a more efficient and cost-effective healthcare system. If the health tech industry retrieves 10% of the gain from reduced health care costs and increased productivity by selling services and products, this will increase the health tech market's annual turnover by 3 billion

euros. Our findings suggest that a 10-year timescale is expected before the economic effects of the 2030 vision may be fully realized. To reach its full potential, it is therefore critical that the central elements of the identified opportunities are implemented at a rapid pace.

Recommendations

Realizing the economic benefits of sharing Nordic health data will require substantial effort and change in both regulatory and health care environments. Through our interviews and literature review, we have seen that the transition towards cross-border data sharing is not primarily hampered by technology. Instead, the fundamental barriers relate to governance, local regulations and legal challenges, internal communication, and different perspectives on how innovative technology should be used and implemented. This has led us to propose the following list of recommendations that will help the Nordics to succeed with unlocking the value potential within data and data-sharing.

1. **Building the data sharing strategy and related action plan for the Nordics**
2. **Communicating the strategy and the potential benefits**
3. **Founding of clear leadership in each country**
4. **Finding and succeeding with easy wins**
5. **Establishing national Nordic data sharing bodies**
6. **Upkeeping an overview of the ecosystem**
7. **Harmonizing Nordic legislations**
8. **Agreements on open standards and terminologies**
9. **Launching Nordic initiatives for networked expertise**
10. **Aligning health care IT and digital health vendors behind an open ecosystem**

1. Introduction

1.1 Background

The Nordic healthcare sector is experiencing the convergence of several shifts in the population that are imposing increased costs and strains on the region. Especially concerning is the aging population, increase of chronic diseases, and higher rates of obesity. According to the Organization for Economic Cooperation and Development (OECD), the Nordics have some of the highest health care expenditures per capita in Europe[1]. This has put the region in 10th place in the world for health care costs, with 162.3 billion EUR per year. The growing challenges cannot be solved by increased public spending and employment of health care workers. The aging population in Nordic countries needs to be met by more efficient delivery of health care services, including adoption of health technology empowered by high-quality Nordic health data. If not, reduced quality and access to public health care are unavoidable. There will be too few hands to care and provide treatment to the elderly without technological disruption. The rapid demographic shift is highly visible in Figure 1 which shows the age-population ratio (also called the dependency ratio).

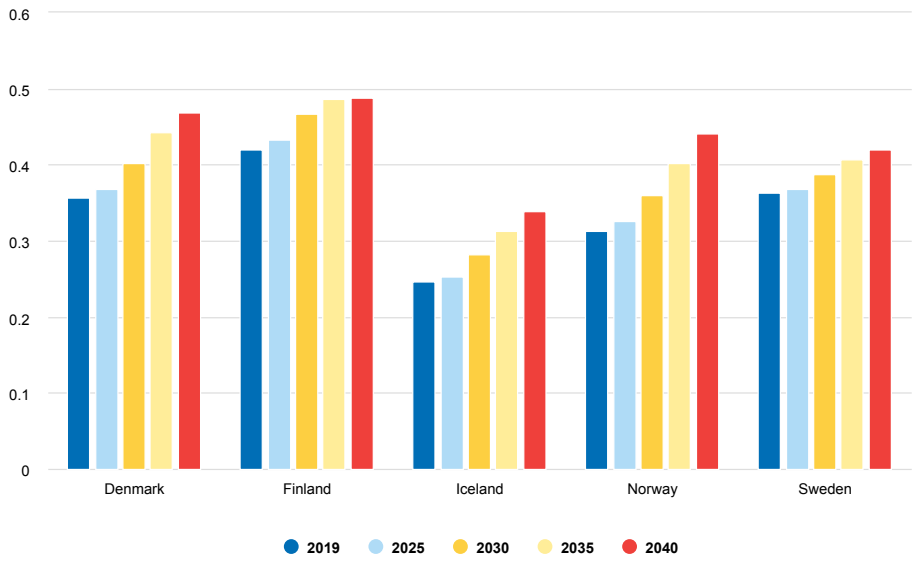


Figure 1: The ratio of old to young people in the Nordic countries is set to increase drastically by 2040. The ratio is based on the number of individuals aged 65 and over per 100 people of those aged between 20 and 64. In Denmark and Finland, there will be only 2 individuals in the working age (20 to 64) per individual of age 65 or older. Iceland has been the Nordic country with the youngest population, but towards 2040, their dependency ratio will increase as well.
Source: Nordic Statistics.

1. OECD Health Statistics 2021 (data refer to 2019, except Malta 2018)

Such a dramatic demographic change puts the sustainability of the Nordic welfare system at risk. The number of individuals needing care and treatment will increase, while the number of people ready to work, and to fund (with taxes) health care services, declines. Although the effect can be mitigated by improved health and labor market participation among those between the age of 65 and 70, we also see a sharp increase in the number of people of age 75 or more. This group has even greater needs for health care services and treatment.

> *There can be little doubt that these are very serious challenges and that the Nordic welfare states will have to adapt in order to cope with them. Whether in the process the very core of the Nordic welfare model will be lost or reinvented, is still an open question.*[2]

The challenge is not only about our ability to afford specialized care to patients with severe diagnoses. It is also about continual treatment as chronic illnesses are significantly more common among our most elderly citizens. Despite the unsustainable growth in health care expenditure, there are clear pathways to mitigate the costs, find innovative services and solutions, and improve the quality of life, which directly affects the local economies. A particular promising route forward involves improved utilization of data fueled by increased digitalization, collection of data, and cross-border sharing.

A Nordic welfare model at risk makes a robust business case for digital transformation of health care. Data-driven health transformation and productivity within our healthcare systems is one of the few options left for further developing the Nordic welfare states. A data-driven transformation will improve medical diagnosis and treatment decisions, facilitate digital self-management and person-centered care, as well as creating more evidence-based knowledge, skills, and competence for professionals to support health care.

In the aftermath of Covid-19, the healthcare sector in the Nordics has been making progress in the fields of digitalization and the use of data and data-sharing. Many new private actors have rapidly expanded to deliver various forms of digital care and services. At the same time, the sector is still far away from an optimal state of data-sharing, resulting in potential valuable improvements still being out of reach. Needless to say, we face immense challenges regarding sharing health data in terms of interoperability, legal grounds, and privacy. There is a delicate balance between the benefits of access to data and the risks for individuals and organizations. However, this report sets out to approach data and data-sharing in the Nordic healthcare sector from a perspective of the potential economic benefits that can be achieved from successfully reaching various forms of future states. By focusing on the potential, the aim is to identify promising areas for innovation and encourage transformative change to unlock the value.

2. *Quote by Axel West Pedersen and Stein Kuhnle, in Knutsen, Oddbjørn P. (ed.), The Nordic Models in Political Science: Challenged, but Still Viable? Bergen: Fagbokforlaget, 2017.*

1.2 Aim and Scope

The vision set forth by Nordic Innovation states that by 2030, the Nordics will be the most sustainable and integrated health region in the world, providing the best possible personalized health care for all its citizens. Sharing of Nordic health data is an enabler and prerequisite for the vision set forth by the Nordic Innovation program Health, Demography, and Quality of Life, allowing the region to improve equitable access, increase health status, and expand the health industry. The purpose of this project has been to investigate and estimate the potential economic effects of making the Nordic region the most sustainable and integrated health region in the world through the sharing of health data. Together with a study on the legal framework[3] and a use-case investigating the innovation landscape for health start-ups, this report aims to increase the understanding of the economic impacts of the access to and use of Nordic health data.

The business case is based on a combination of quantitative and qualitative approaches where we used in-depth interviews and questionnaires to identify areas where we might expect the most significant value realizations. To address the fundamental aspects of data bridging between the Nordic countries, we have organized the project around several opportunities centered on the patient journey. Through the qualitative approach, we have identified areas where we expect realization of economic effects from sharing of health data between the Nordic countries.

Health care and data are broad subjects, and the business case is based on many assumptions about the impact of data sharing and digital health, which is currently in its infancy. We start this report with a brief overview of health data and emerging technologies in the Nordic countries (chapter 3) followed by a description of how health data is transformed to value (chapter 4). We evaluate the economic effects of making the Nordic region the most sustainable and integrated health region in the world through three pillars:

I. Nordic data sharing may enhance the quality of life
II. Nordic data sharing can lead to a reduction in the costs of providing care
III. Nordic data sharing can lead to increased innovation, entrepreneurship, and expansion of the Nordic health industry

Following the economic assessment, we focus on an in-depth analysis of seven areas of potential value realization (chapter 5). By including use cases, success stories, and examples of value realization through sharing and use of health data we aim to illuminate some of the possibilities that lie in the intersection between data and health. Finally, we present a holistic business case where we evaluate the potential economic benefits and costs, together with a scenario analysis (chapter 6).

3. Nordic Innovation, *Bridging Nordic Data Legal Overview of Possibilities and Obstacles for Secondary Use of Health Data for Innovation and Development.*, 2020, http://norden.diva-portal.org/smash/get/diva2:1441471/FULLTEXT04.pdf.

1.3 The Nordic region and the potential for data sharing

Although the individual countries within the Nordic countries are small by themselves, with an estimated population of 27.6 million and a land area, excluding Greenland, covering 1.3 million km2, the Nordics as a region represent the 55th largest country by population and 20th in terms of land area. In terms of the estimated GDP of > 1,500 billion EUR, the region represents the 10th largest economy in the world and has the 10th highest expenditure on health care. At this scale, developing a framework for effective sharing of health data offers the potential to realize value in many areas.

The financing of health care is overall similar in the Nordic region with between 70-85% of all expenditures covered by the government[4]. While the welfare system has caused the Nordic countries to perform very well on wellbeing and happiness[5], detailed regional analyses show that there are inequalities related to demographic changes[6] expected to drive increased costs for the society. Specifically, we are facing an ageing population, areas with sparse populations, and forecasts that suggest we will have a shortage of qualified health care staff[7]. An aging population will not only need increased health care expenditure, but it will also reduce the portion of the working population, leading to fewer people supporting the elderly population. Because there is, on average, a significant net-cost to society for persons in young and old age there is a critical threshold to maintain to support the welfare system[8]. Considering these demographic changes, increased data sharing between the Nordic countries may directly lead to novel solutions that are accessible to a larger portion of the population independent of demographics.

From a Nordic perspective, health care is seen as one of the most important political challenges for the future. In Norway, 43 % of the respondents see health care as the most important challenge. In Sweden, this priority was shared with 34 % of the respondents[9]. Trust in government and the healthcare system is a clear advantage for the Nordic region. Within the EU (European Union), health care is a hotspot for corruption where nearly one out of three individuals rely on personal connections to get medical care and six percent paid a bribe for health care[10]. When it comes to adoption of innovative technology, the Nordic countries are known as quick adopters. The high trust in government also means that policy-making changes are highly effective. On the other hand, Nordics has an untapped potential within the health innovation space where we are considered slow innovators. Access to Nordic health data may enable an emerging technology industry fueled by access to Nordic health data.

4. Kristina Laugesen et al., "Nordic Health Registry-Based Research: A Review of Healthcare systems and Key Registries," *Clinical Epidemiology* Volume 13 (July 2021): 533–54, https://doi.org/10.2147/CLEP.S314959.
5. Helliwell, J. F., Layard, R., Sachs, J. D., De Neve, J.-E., Aknin, L. B., & Wang, S., *World Happiness Report 2022*, n.d., https://worldhappiness.report/.
6. Anna Lundgren, Linda Randall, and Gustaf Norlén, *State of the Nordic Region 2020 Wellbeing, Health and Digitalisation Edition*, 2020, http://norden.diva-portal.org/smash/get/diva2:1482486/FULLTEXT01.pdf.
7. Kristin Alsos and Jon Erik Dølvik, "The Future of Work in the Nordic Countries: Opportunities and Challenges for the Nordic Working Life Models," 2021.
8. Torben M. Andersen et al., *The Nordic Model. Embracing Globalization and Sharing Risks*, *ETLA B* (The Research Institute of the Finnish Economy, 2007), https://ideas.repec.org/b/rif/bbooks/232.html.
9. Aftenposten. 29. august 2022
10. "Global Corruption Barometer - European Union," Transparency.org, n.d., https://www.transparency.org/en/gcb/eu/european-union-2021.

2. Health data in the Nordics

2.1 The Nordic evolution of data and digitalization

The Nordic countries can in many ways be considered as forerunners in adopting digital health and moving towards more open digital health ecosystems. For example, we have been early adopters of electronic health and social care records, such as in Norway in 2006 when the first paperless hospital of the world was introduced. Other examples include various digital health services that have been developed for both professionals and citizens in the Nordic countries, such as virtual doctor visits that have been reimbursed in Finland for many years. Furthermore, Sweden and Denmark were among the first to implement electronic prescriptions in Europe, and the Nordic countries have been early adopters of telecommunication networks in health care. Lastly, Sweden set up the Sjunet network in 1997 which was developed to facilitate data sharing between counties and municipalities in a trusted and secure way.

These types of examples point to the value placed on cross-organizational data sharing that has historically been an important objective in all Nordic countries. Among the drivers for sharing data between the systems and organizations is the recognition that cross-organizational patient pathways need to benefit from shared data between the systems in various health care delivery entities. Other important drivers include the usage of telemedicine due to long distances and limited resource availability, as well as Nordic citizens typically being keen on participating in their own care and having a possibility to access their own data.

When it comes to data sharing infrastructure, several initiatives have arisen in the Nordic countries, such as Kanta in Finland and NPÖ in Sweden, where health care organizations were connected to national sharing infrastructures to enable the exchange of patient data with the patient's consent. Benefits from document-based sharing are limited, however, and document-based data is difficult to use for solutions such as AI and automation. This has led to the need for complementary structured data sharing which has more recently resulted in initiatives aimed at establishing open standards for data.

In more recent years, there has been increased pressure to adapt in the wake of demographic shifts and technological progress. From the demographic point of view, the Nordics are like most other nations who see a continually aging population and a steep rise in chronic illnesses. This has led to the demand for care outpacing the available supply. In addition, individuals and patients are demanding greater insights into their own health, requiring integrated health systems that place the individual at the center of the care model, thereby moving away from the siloes that have historically exemplified the system landscape. Finally, from a technological perspective, new devices, services, and solutions are making it possible to greatly improve how health care is provided, but they require the right data infrastructure to fully function.

Overall, the Nordic countries have historically performed well with regards to adopting digital health solutions, and the demographic and technological trends have further buttressed the need for continual improvement, but there are some important areas that are holding us back. One such example that is especially

relevant is the decentralized decision-making that has resulted in a fragmented system base in the Nordics. Due to this, the present state of cross-border data sharing is still limited in the Nordics.

BOX 1 – European Health Data Space

Announced in early 2020, the European Health Data Space is a legal, governance, data quality, and operability framework considered to be a key for stronger innovation and AI within the region. It aims to empower individuals across the EU to control their own health data, ensure proper use of individuals health data, and to foster economic growth through use of data.

While the present state of cross-border data sharing requires improvement, our interviews and research has identified some of the key drivers and trends that can facilitate cross-border data sharing. First, on a Nordic level, the economies of scale come into play in at least four different areas[11]. **Capacity**: depending on the available resource pool, the larger Nordic health care market can lead to better use of the resources. One example could be radiological marketplaces offering reading service to rural areas in the Nordics. **Competence**: a more integrated Nordic health care market provides an opportunity to establish professional networks for sharing knowledge and centers that attract a highly skilled and dedicated workforce. **Price:** providing care for specialized treatments may benefit areas with either scarce or excess capacity. Also, pooling of resources may be more cost-effective regarding investments in technology and specialized equipment. **Quality:** access to high quality datasets, such as the Nordic quality registers for various diseases, over larger geographic areas may result in better and more cost-effective treatment methods.

When comparing the Nordics with the EU, there are major differences in the degree of digital transformation. The Nordic countries are considered forerunners with a high degree of digital literacy and competency, scoring well above the EU-average[12]. Especially interesting is the high fraction of individuals (> 90%) that are interacting with the government using digital solutions compared with the EU-average (60%).

On a high-level, we can distinguish between primary and secondary use of health data. Primary use relates to use cases that directly affect the health care operations, such as supporting continuity of care. This type of data includes prescriptions, laboratory results, and genetic data, and is mainly accessible through electronic health records (EHR). Secondary use of data includes individual-level data with a much wider scope to support research, innovation, policy making, and personalized medicine. Relevant data for secondary use include socio-economic information and insurance history. Also, individuals are increasingly sharing data from wearables and smart appliances in the home, leading to a data pool that gives grounds for personalized health care. The ability to capture and access health data in near real-time represents a leap forward in understanding the health response to medications, external factors such as weather, noise, air quality, demographics, and geography.

11. Oxford Research, "Nordic Collaboration in Health Services," 2009, https://oxfordresearch.se/wp-content/uploads/2017/10/nordic_collaboration_in_health.pdf.
12. "The Digital Economy and Society Index (DESI) Shaping Europe's Digital Future," n.d., https://digital-strategy.ec.europa.eu/en/policies/desi.

BOX 2 – Health data and data sharing

Defining health data is a complex task. On a high-level health data is all data that touches upon the health of the population in some way or another. This involves weather, noise, socioeconomics, etc. In this business case, we use the definition that health data is any data that may be used to improve the health of individuals, drive innovations and economic growth from the perspective of health care.

By sharing of data, we mean that health data is accessible and in a usable format for those who need it. The goal of using and sharing health data is to provide better insights and solutions than we could without these data. While earlier work focused on the quality of the datasets, such as completeness and readability, current progress is aimed at improving contextualization, interoperability, access, and integration across different levels within the health space.

2.2 Technology and innovations in health data

Collection and accessing health data

The first stage of any data driven development is the collection of high-quality data and information. A particular strength of the Nordic countries has been collecting data on the personal numbers of people for many years, meaning that health data can be associated with a specific set of information, such as age and gender. This means that there is high quality biobanks and comprehensive health register data available for the whole Nordic region[13]. This means that there already exists an extensive pool of data that, once shared, may cause rapid benefits.

There is also an abundance of opportunities where new data may be collected and recorded. Data may be come from either a traditional care setting (e.g., hospital or GP), or through patient-generated health data[14] such as sensors and wearables. For example, smart phones have a wealth of sensors that may be used to passively record physical activity, evaluate lung conditions[15], and record the heartbeat[16]. In addition, smartphones allow for ecological momentary assessments that allows insights into people's thoughts and behavior in a normal environment[17]. Wearables, such as smart watches and rings, can continuously monitoring of heart rate and electrical signals, provide additional data on personal motion, and cardiac information[18]. Emerging technologies for the collection of novel data is wearable sensor patches, radiofrequency sensors, smart fabrics and textiles, and ingestible

13. Joint Committee of the Nordic Medical Research Councils, *Personalised Medicine in the Nordic Countries*, 2019, http://norden.diva- portal.org/smash/get/diva2:1347257/FULLTEXT01.pdf.
14. Heather S. L. Jim et al., "Innovations in Research and Clinical Care Using Patient-generated Health Data," *CA: A Cancer Journal for Clinicians* 70, no. 3 (May 2020): 182–99, https://doi.org/10.3322/caac.21608.
15. Eric C. Larson et al., "SpiroSmart: Using a Microphone to Measure Lung Function on a Mobile Phone," in *Proceedings of the 2012 ACM Conference on Ubiquitous Computing - UbiComp '12* (the 2012 ACM Conference, Pittsburgh, Pennsylvania: ACM Press, 2012), 280, https://doi.org/10.1145/2370216.2370261.
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17. Saul Shiffman, Arthur A. Stone, and Michael R. Hufford, "Ecological Momentary Assessment," *Annual Review of Clinical Psychology* 4, no. 1 (April 1, 2008): 1–32, https://doi.org/10.1146/annurev.clinpsy.3.022806.091415.
18. Marco V. Perez et al., "Large-Scale Assessment of a Smartwatch to Identify Atrial Fibrillation," *New England Journal of Medicine* 381, no. 20 (November 14, 2019): 1909–17, https://doi.org/10.1056/NEJMoa1901183.

pills with sensors[19].

Information and health data exist in structured (organized), unstructured (unorganized), and mixed formats[20]. Traditional types of data that are collected in health care are related to biochemical analysis, scans and imaging, hand or computer written notes and prescriptions. However, the field is gravitating towards an increasing collection of semi-structured data from wearables, home sensors, and wireless devices. Smart electronic components and implantable computers that harvests energy from mechanical forces, vibrations, together with non-invasive measurements of glucose and blood concentrations is set out to reshape the availability of critical data. In the Nordic region, structured data such as electronic health care records (EHRs) are a dominant source of data for inhabitants.

While much of the data related to health may be anonymized, some patient health data may be difficult to protect. For instance, genomic data can be used to directly identify an individual, while traditional clinical data may more easily be encrypted to secure the patient's identification. It is therefore key, for any data sharing initiatives, to put in place regulations for when and how data should be shared. Also, we should note that for patients in small groups, such as in rare diseases, there will be a higher risk of being identified than in larger groups. By improving the interoperability of the data, disconnected systems in the healthcare sector may replace existing systems and allow secure access to data.

Data may be collected with or without consent. That is, the patient has agreed that the data is collected and used. In the case of data that is collected without consent, there may be difficulties in the use and implementation of algorithmic models. An emerging approach for accessing and linking data from health registries (data mostly collected without consent), is to access the data without moving it. This type of federated analysis is compatible with country specific analyses platforms.

BOX 3 – Findata

Findata is an independent health access body located in Finland which provides guidance and grant permits for the secondary use of social and health data. Instead of keeping data stored in different registers or hospitals, the agency facilitates, streamline, and secure the use of data which may be used for research, teaching and health planning. In doing so it both increases the access to data and reduces the cost of retrieving relevant data.

Findata has received over 740 applications for data of which approximately 75% have been positive.

Emerging technologies for analyzing data

In the second stage, data is transformed into a state that may be linked to other meaningful health care data and used for health benefit. Traditionally, much of the information available to the health care practitioners are "snapshots" or overviews (documents) and patient self-reports of the health at a single point in time. The

19. Ida Sim, "Mobile Devices and Health," *New England Journal of Medicine* 381, no. 10 (September 5, 2019): 956–68, https://doi.org/10.1056/NEJMra1806949.
20. Clemens Scott Kruse et al., "Challenges and Opportunities of Big Data in Health Care: A Systematic Review," *JMIR Medical Informatics* 4, no. 4 (November 21, 2016): e38, https://doi.org/10.2196/medinform.5359.

ever-evolving concept of digital and mobile health makes use of technology to better integrate continuous datasets from wearables and sensors, with the traditional data sources.

Transformation and analysis of health data benefit from the exponential increase in computing power, which allows for cheaper and more advanced computing at lower costs. With the new programming tools and automated machine learning (AutoML), predictive systems that would take months to years to develop now can be rapidly developed and optimized on real-world data. The fact that custom models consistently lead to better clinical outcomes than "off-the-shelf" predictive models, highlights the importance of local validation and optimization[21].

Although artificial intelligence and machine learning (see box) algorithms have the potential to both speed up the time and accuracy of identifying diseases like tumors[22] through capturing complex, and nonlinear relationships in the data, there are no algorithms that can output information that is not there. That means that predictions using clinical data alone, has relatively limited predictive power. However, incorporating data on the individual-level, such as demography, biomarker measurements, genomics, and clinical history, significantly increase the predictive ability of machine learning approaches and is critical to capture the value of data.

BOX 4 – What is AI and machine learning

Artificial intelligence (AI) is a field within computer science that aims to simulate human intelligence. The field encompass the subdivisions machine learning and deep learning.

AI has great potential in the health care space and will play a key role in transforming the way health care is being delivered. The importance of Nordic Health Data is for training, validation, and testing of machine learning models.

There is a growing number of use-cases where AI support image analysis, genetic analysis, pathology, and clinical decision-support.

How will we interact with the health care in the future?

Through implementing data-driven insights and services, the nature of health care is progressing farther towards evidence-based care than what has previously been possible. If we consider how usage of health data will affect the healthcare system, it becomes clear that there are mainly two actors that are affected. The first one is the health care workers, who may get better decision-making tools. The second is the end-users, or the patients. As patients get ownership to their own data and insights, the role of health care workers is gradually changing from an authoritative role to a guidance role where patients are expected to make their own decisions based on data and software tools. However, as the healthcare system gets better

21. Terrence C. Lee et al., "Clinical Implementation of Predictive Models Embedded within Electronic Health Record Systems: A Systematic Review," *Informatics* 7, no. 3 (September 2020): 25, https://doi.org/10.3390/informatics7030025.
22. Todd C. Hollon et al., "Near Real-Time Intraoperative Brain Tumor Diagnosis Using Stimulated Raman Histology and Deep Neural Networks," *Nature Medicine* 26, no. 1 (January 2020): 52–58, https://doi.org/10.1038/s41591-019-0715-9.

and powered by real-time contextualized information on individuals, there will be a shift in the expectations of the healthcare system to detect anomalies which may indicate acute medical conditions that needs to be handled by professionals. If applied correctly, the interplay between healthcare system and individuals can lead to improved health outcomes and increased wellbeing.

2.3 Barriers for adoption

While the purpose of this report is to lay out the business case for the sharing and utilization of health data on the Nordic level, it is worthwhile to briefly explore upon some of the common barriers that may hamper the development and implementation of a shared Nordic health data initiative[23]. Among the important topics are areas such as the regulatory environment, access to data and infrastructure, the governance and leadership model, as well as trust and transparency.

BOX 5 – Digital health

By digital health we mean the use of digital technologies to deliver health care services to either individuals or medical personnel. It is changing how the patients interact with the healthcare system and involves support for remote care, therapeutic decision-making, monitoring and diagnostics. Digital health is fueled by data coming from a range of sources such as electronic health records, wearables, and mobile health applications.

Because digital health enables improved models of care that are better suited to people and patients' needs, it represents one of the industries with the largest growth potential.

Legal: From the perspective of the regulatory environment, the main topics of conversation are whether, how and with whom personal data can be shared. From the EU level, the two most important regulations are General Data Protection Regulation (GDPR) and Schrems II. Together, these two regulations limit how personal data can be handled as well as which actors are allowed access to personal data. Notably, technology companies based in the US are especially impacted by the latter which has the consequence for Nordic health care organizations limiting their use of services from these companies. This may also affect the future of some current EHR implementations. Finally, each Nordic country also has their own data protection laws which follow the established European standards, but may vary in local implementations. There are variations in practices of patient consents and denials, for instance. When data is shared from one country to another there are things to check on the local access control layer concerning the professional attempting to view, the organization where the professional is working and the current patient consents and denials for cross-border access. Building of local access control layers taking into account the variation in laws is complex and may slow the development of data sharing across Nordics. Harmonization of the related legislation on the Nordic level is the preferred option in the long run.

23. Abboud, Authors Linda et al., "Summary of Results: Case Studies on Barriers to Cross-Border Sharing of Health Data for Secondary Use" (The EU's Joint Action Towards the European Health Data Space (TEHDAS) cooperation project, n.d.).

Due to the impact of the regulatory environment on businesses and innovation, this barrier and how to solve it is currently under investigation and analysis, such as in Sweden[24] and in Norway[25].

Data and infrastructure: There are a lack of technical interoperability in many cases which relates to the ability of systems and solutions to exchange data with each other. Many vendors use their own internal data models and there is reluctance to share data with others. This has resulted in silos of data and limited data exchange between different solutions. Many IT vendors are still not prioritizing the sharing of data with systems outside of their own ecosystems.

The other challenge is semantic interoperability. When data is shared, the context of the data needs to be preserved as well. For instance, there is a difference whether blood pressure has been measured in the calm of your home or in an emergency. When data is exchanged, we normally convert it into messages which represent a certain amount of data. Very often the context of the data is not preserved leading into misunderstandings and poor-quality data. Language is another semantic challenge to overcome in cross-border data sharing: we have 5 different national languages and many beyond in the Nordics. This needs to be addressed and structured data is the key here.

Governance and leadership model: There is a largely decentralized model in organizing health care in the Nordic countries, meaning that the responsibility of providing care is distributed to a total of 59 different regions within the 5 countries[26]. This makes the act of pursuing a joint effort in data and data sharing more difficult than if there were five national actors to coordinate. On the other hand, there is a national body responsible for document-based data sharing in each Nordic country. These bodies might take over the governance of cross-border data sharing as well.

Trust and transparency: Protection of personal data is not simply a regulatory question, but also a matter of public perception. This poses the challenge of ensuring that trust remains high amongst citizens that the companies and organizations that handle their data will do so responsibly. As health data becomes more of a talking point, this trust will continue to become more important, requiring actors that store and utilize the data to be transparent about how the data is meant to be used and also to provide legally determined logging of the data usage. The citizens own their data and manage the usage of it with consents and denials. Finally, the citizens must be able to follow the usage of their data, requiring that data sharing is done in a secure and trusted way.

In practical terms, low trust can create a blocker for data sharing when citizens are recognized as owning their personal data, including their health care data. This adds a layer of complexity to providing holistic care for patients in a cross-organizational setting with a selection of specialists. In addition, researchers and pharmaceutical companies may be particularly impacted as access to data that is not anonymized will require each participant to agree on the use of their data beforehand, potentially limiting some forms of research and innovation.

24. Säker och kostnadseffektiv it-drift - Regeringen.se
25. Cloud Computing strategy for Norway - regjeringen.no
26. Laugesen et al., "Nordic Health Registry-Based Research."

3. From health data to value

3.1 The current cost of health in the Nordic region

The total economic burden of diseases in Nordic countries in 2019 was around 1,000 billion EUR. The population aged 70 and older accounted for approx. 40 percent of total costs, while accounting for only 14 percent of the total population. Cancer and cardiovascular diseases are the two diseases that contribute the most to total burden of diseases. Mental and substance use disorders and musculoskeletal diseases affect the working-age population to a larger degree than the older population.

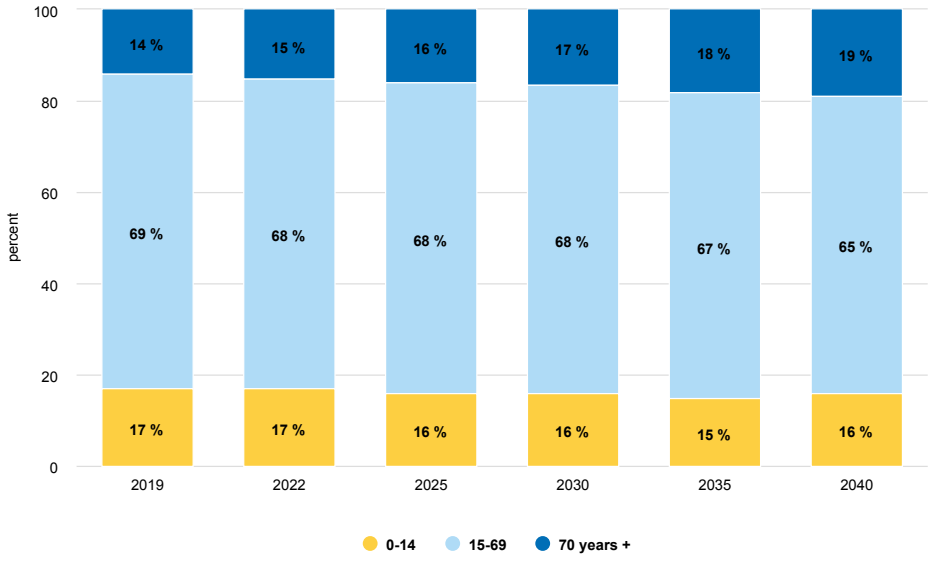


Figure 2: Population projections in all Nordic countries (2019-2040).

Table 2 shows total costs of all diseases and the 6 diseases that account for the largest share of total cost, sorted by age group and type of cost. The health sector costs, and lost productivity is a function of the burden of the disease and type of diagnosis. This means that each diagnosis effects the cost in a different way. As we can see, diseases of the digestive system are associated with higher healthcare sector costs, but do not cause particularly high productivity costs. On the other hand, we can see that diseases of the musculoskeletal system and connective tissue have high productivity costs, but smaller healthcare sector costs.

Table 1: Healthcare sector costs and value of decreased or lost productivity as a function of the burden of disease.
Source: Samfunnskostnader ved sykdom og ulykker 2015. Helsedirektoratet. Rapport IS-2839 and our own calculations.

ICD-10 Version 2019	DALY	Health sector cost	Value of decreased or lost productivity*
Certain infectious and parasitic diseases	1	0,061	0,018
Neoplasms	1	0,076	0,042
Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	1	0,161	0,009
Endocrine, nutritional, and metabolic diseases	1	0,159	0,082
Mental and behavioural disorders	1	0,191	0,248
Diseases of the nervous system	1	0,058	0,100
Diseases of the eye and of the ear	1	0,277	0,052
Diseases of the circulatory system	1	0,104	0,048
Diseases of the respiratory system	1	0,204	0,100
Diseases of the digestive system	1	0,315	0,153
Diseases of the skin and subcutaneous tissue	1	0,084	0,064
Diseases of the musculoskeletal system and connective tissue	1	0,093	0,260
Diseases of the genitourinary system	1	0,285	0,045
Pregnancy, childbirth, and the puerperium	1	0,378	0,324
Certain conditions originating in the perinatal period			
Congenital malformations, deformations, and chromosomal abnormalities	1	0,061	0,099
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified			
Injury, poisoning and external causes of morbidity and mortality	1	0,145	0,164
All other diseases	1	0,190	0,022
Not distributed			
In total	1	0,233	0,130

Note: *The age group 70 years and older has a productivity cost of 0

Table 2: Cost of the top 6 diseases and the total cost of all diseases - (All Nordic countries). In billion euros 2019 by age groups

ICD-10 Classification	Age	DALY	Health sector cost	Value of decreased or lost productivity	Total cost
Malignant neoplasms	0-14	1,11 €	0,08 €	0,05 €	1,24 €
	15-69	79,06 €	6,04 €	3,31 €	88,40 €
	70 +	85,41 €	6,53 €	0,00 €	91,94 €
	Tot	***165,58 €***	***12,65 €***	***3,35 €***	***181,59 €***
Cardiovascular diseases	0-14	0,26 €	0,03 €	0,01 €	0,30 €
	15-69	48,21 €	5,00 €	2,32 €	55,53 €
	70 +	98,50 €	10,21 €	0,00 €	108,71 €
	Tot	***146,97 €***	***15,24 €***	***2,33 €***	***164,54 €***
Mental and substance use disorders	0-14	5,02 €	0,96 €	1,25 €	7,23 €
	15-69	88,28 €	16,89 €	21,93 €	127,11 €
	70 +	11,94 €	2,28 €	0,00 €	14,22 €
	Tot	***105,24 €***	***20,14 €***	***23,18 €***	***148,56 €***
Neurological conditions	0-14	1,90 €	0,11 €	0,19 €	2,20 €
	15-69	29,92 €	1,75 €	2,99 €	34,66 €
	70 +	58,92 €	3,44 €	0,00 €	62,35 €
	Tot	***90,73 €***	***5,29 €***	***3,18 €***	***99,21 €***
Musculoskeletal diseases	0-14	0,76 €	0,07 €	0,20 €	1,03 €
	15-69	51,89 €	4,84 €	13,47 €	70,20 €
	70 +	21,00 €	1,96 €	0,00 €	22,96 €
	Tot	***73,65 €***	***6,87 €***	***13,67 €***	***94,19 €***
Respiratory diseases	0-14	1,48 €	0,30 €	0,15 €	1,93 €
	15-69	20,61 €	4,20 €	2,07 €	26,88 €
	70 +	31,55 €	6,43 €	0,00 €	37,99 €
	Tot	***53,64 €***	***10,94 €***	***2,22 €***	***66,80 €***
Total cost of all diseases	0-14	27,89 €	5,07 €	4,60 €	37,57 €
	15-69	439,41 €	62,65 €	56,36 €	558,42 €
	70 +	393,34 €	45,77 €	0,00 €	439,12 €
	Tot	***860,65 €***	***113,49 €***	***60,85 €***	***1034,99 €***

Table 3: Cost of the top 6 diseases and the total cost of all diseases - Per capita. All Nordic countries in billion euros 2019 by age groups.

ICD-10 Classification	Age	DALY	Health sector cost	Value of decreased or lost productivity	Total cost
Malignant neoplasms	0-14	40,6 €	3,1 €	1,7 €	45,4 €
	15-69	2 887,7 €	220,6 €	120,8 €	3 229,1 €
	70 +	3 120,0 €	238,4 €	0 €	3 358,4 €
Cardiovascular diseases	0-14	9,4 €	1,0 €	0,5 €	10,8 €
	15-69	1 761,1 €	182,6 €	84,7 €	2 028,4 €
	70 +	3 598,0 €	373,1 €	0	3 971, 0 €
Mental and substance use disorders	0-14	183,3 €	35,1 €	45,5 €	264,0 €
	15-69	3 224,8 €	617,1 €	801,2 €	4 643,2 €
	70 +	436,0 €	83,4 €	0 €	519, 4 €
Neurological conditions	0-14	69,4 €	4,0 €	6,9 €	80,4 €
	15-69	1 092,9 €	63,8 €	109,3 €	1 266,0 €
	70 +	2 152,0 €	125,5 €	0 €	2 277,6 €
Musculoskeletal diseases	0-14	27,8 €	2,6 €	7,2 €	37,6 €
	15-69	1 895,4 €	176,8 €	492,0 €	2 564,2 €
	70 +	767,1 €	71,6 €	0 €	838, 7 €
Respiratory diseases	0-14	53,9 €	11,0 €	5, 4 €	70,3 €
	15-69	752,95 €	153,51 €	75,54 €	982,0 €
	70 +	1 152,6 €	235,0 €	0 €	1 387,6 €
Total cost of all diseases	0-14	1 018,9 €	185,1 €	168,2 €	1 372,2 €
	15-69	16 050,7 €	2 288,5 €	2 054,6 €	20 393,8 €
	70 +	14 368,0 €	1 672,0 €	0 €	16 040, 0 €

Table 4: Cost of the top 6 diseases and total cost of all diseases - (All Nordic countries). In billion euros. 2040. By age groups. Report data

ICD-10 Classification	Age	DALY	Health sector cost	Value of decreased or lost productivity	Total cost	Estimated increase in costs 2019-2040
Malignant neoplasms	0-14	1,08 €	0,08 €	0,05 €	1,21 €	-0,03 €
	15-69	80,62 €	6,16 €	3,37 €	90,15 €	1,75 €
	70 +	124,41 €	9,50 €	0,00 €	133,92 €	41,98 €
	Tot	***206,12 €***	***15,75 €***	***3,42 €***	***225,28 €***	***43,70 €***
Cardiovascular diseases	0-14	0,25 €	0,03 €	0,01 €	0,29 €	-0,01 €
	15-69	49,20 €	5,10 €	2,37 €	56,67 €	1,13 €
	70 +	142,26 €	14,75 €	0,00 €	157,01 €	48,30 €
	Tot	***191,71 €***	***19,88 €***	***2,38 €***	***213,96 €***	***49,42 €***
Mental and substance use disorders	0-14	4,91 €	0,94 €	1,22 €	7,07 €	-0,16 €
	15-69	90,40 €	17,30 €	22,46 €	130,17 €	3,05 €
	70 +	17,30 €	3,31 €	0,00 €	20,61 €	6,39 €
	Tot	***112,61 €***	***21,55 €***	***23,68 €***	***157,84 €***	***9,28 €***
Neurological conditions	0-14	1,85 €	0,11 €	0,19 €	2,15 €	-0,05 €
	15-69	30,62 €	1,79 €	3,06 €	35,47 €	0,81 €
	70 +	85,64 €	5,00 €	0,00 €	90,63 €	28,28 €
	Tot	***118,11 €***	***6,89 €***	***3,25 €***	***128,25 €***	***29,04 €***
Musculoskeletal diseases	0-14	0,75 €	0,07 €	0,19 €	1,02 €	-0,01 €
	15-69	53,04 €	4,95 €	13,77 €	71,75 €	1,55 €
	70 +	30,56 €	2,85 €	0,00 €	33,42 €	10,46 €
	Tot	***84,35 €***	***7,87 €***	***13,96 €***	***106,18 €***	***11,99 €***
Respiratory diseases	0-14	1,45 €	0,29 €	0,14 €	1,88 €	-0,04 €
	15-69	21,08 €	4,30 €	2,11 €	27,49 €	0,61 €
	70 +	46,13 €	9,40 €	0,00 €	55,53 €	17,54 €
	Tot	***68,65 €***	***14,00 €***	***2,26 €***	***84,91 €***	***18,11 €***
Total cost of all diseases	0-14	27,48 €	5,03 €	4,56 €	37,08 €	-0,49 €
	15-69	449,48 €	64,07 €	57,54 €	571,10 €	12,79 €
	70 +	572,07 €	66,63 €	0,00 €	638,70 €	199,59 €
	Tot	***1049,04 €***	***135,73 €***	***62,11 €***	***1246,88 €***	***211,89 €***

3.2 Transforming health data to value

We have seen that there is a high cost in many areas of the healthcare system. By stimulating digital transformation of health care and health industries through cross-border sharing of health data, we expect to see vast benefits throughout the patient journey (see also chapter 5). Sharing and facilitating access to health data will enable and create economic benefits founded on the three pillars: improved health in the population, reduced costs, and expansion of a more productive and competitive Nordic health industry. In the following sections we investigate the individual pillars of economic value.

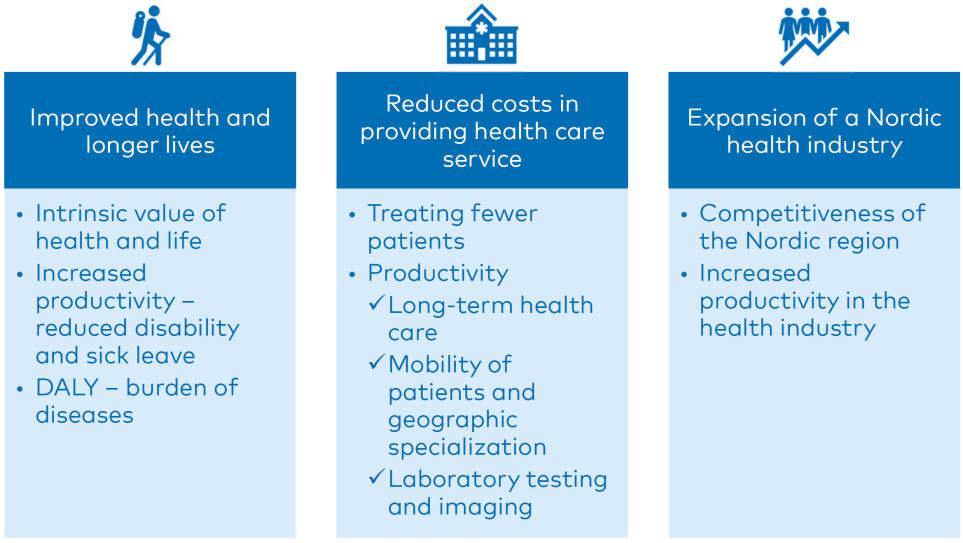


Figure 3: Three pillars of economic value

Pillar 1: Improved health and longer lives

What is the economic value of healthy lives? Improved health and longer lives have an intrinsic value, and its monetary value can be learned directly by asking affected parties about their willingness to pay for various health improvements or revealed indirectly by observing actual behavior associated with health risk factors. Illnesses, disability, and premature mortality represent a loss to the individuals affected and a burden to society. Public health research offers insight into key risk factors associated with severe diseases such as cancer, diabetes, and heart and vascular conditions.

Disabilities reduce health, both by lowering health related quality of life for patients, and by causing premature death. The first is measured as "years of healthy life lost because of disability" (YLD), and the second is measured as "years of life lost" (YLL). The sum of these two equals DALY, represents the total burden of diseases to society (Figure). The metric called Disability-Adjusted Life Years (DALY), developed by WHO, has become an international standard for quantifying health and how many "healthy lives" are lost to disabilities, diseases, and injuries. The burden of disease is large, even in a well-developed region such as the Nordics, recognized for its quality-of-life societies and welfare states. The total number of disability-

adjusted life years lost to diseases in the Nordics amounted to around 7.2 million in 2019. Although this burden is less tangible than costs seen in public budgets or in private companies' income statements, it represents, nevertheless, a real cost to society.

Figure 4: Disability-Adjusted Life Years (DALY) is a measure of the overall burden of disease.
Image source: Wikipedia.

Many of these risk factors are affected by lifestyle choices, including smoking, exercises, and diet and can thus be reduced through prevention. Improving prevention can be achieved with two approaches: the population-based and the individual high-risk approaches both of which can benefit from digital health and health data[27]. The individual high-risk approach aimed at firstly identifying individuals with high risk for developing diseases or negative outcomes and then targeting this specific population with ad hoc preventive interventions. This kind of prevention strategies focuses especially on individuals with high level of known risk factor for chronic diseases or people that show premorbid signs prior to the onset of illness.

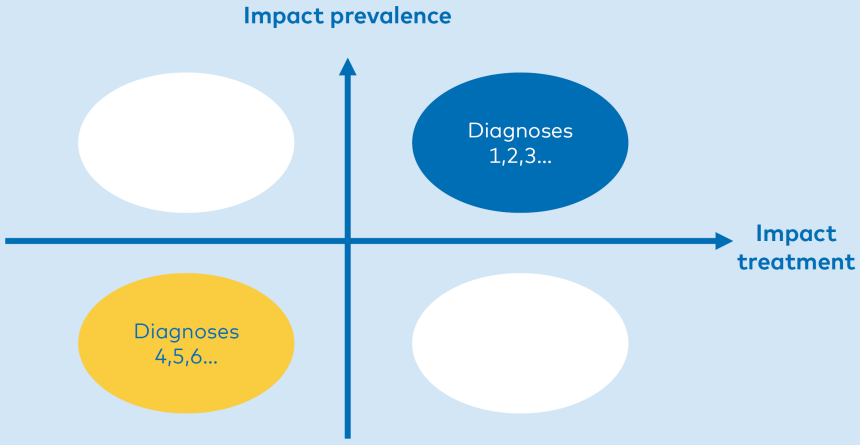
27. Rose, G. (1995). The strategy of preventive medicine. New York: Oxford University Press

Economic benefits through better public health

Our hypotheses explore how vision 2030 for sharing health data in Nordic countries will improve health through better prevention and treatment. This will lower the burden of diseases in Nordic countries. The total burden of diseases in the future depends on the following key public health parameters:

Prevalence is the number of people in the population with a specific disease, that is determined both by the number of new cases each year, and by how long people tend to live with the disease. Data-driven improvement of health care can have conflicting impact on prevalence; improved prevention reduces prevalence, while improved treatment of severe diseases increases prevalence since people live longer, without being fully recovered.

Treatment and care of patients affect both how long people live with a disease. For severe, life-threatening diseases, improved treatment may reduce morality, and for less severe diseases, improved treatment may cure or lower the health loss associated with a diagnosis.



The figure shows how different diseases can be affected

There will be minor differences between the Nordic countries to the exact value attached to healthy lives. But for the purpose of this study, we have chosen 132 000 EUR as the economic value of a DALY based upon the statistical value of a life[28].

The estimates show that total economic burden of diseases in Nordic countries will be around 1,250 billion EUR in 2040. This is an increase of 200 billion EUR from 2019. Cardiovascular diseases, malignant neoplasms and neurological conditions are the three diseases that contribute the most to the total burden. Neurological conditions (71 percent) and cardiovascular diseases (73 percent) are diagnoses that typically occur with the older population, while the malignant neoplasms also affect the younger population. To establish a baseline for evaluating the benefits of Nordic health data, we have estimated the current cost base towards 2040. Our baseline projection takes into account the demographic changes we see in Nordic countries. The demographic projection which is used is shown in Figure 2. The proportion of the population older than 70 years in the Nordic countries will increase from 14 percent to 19 percent from 2019 to 2040. This will significantly affect the burden of diseases and healthcare sector costs.

Pillar 2: Reduced costs in providing health care

The Nordic countries spent over 160 billion EUR on health care in 2019. These costs are distributed on several major areas (Figure). The healthcare sector costs of diseases are estimated to around 113 billion EUR in 2019 (Table 2) where mental and substance use disorders and cardiovascular diseases contribute most to the total costs with 20 and 15 billion EUR, respectively. These costs reflect the current level of productivity in diagnostics, treating, and caring in our healthcare system. In 2030, we expect the healthcare sector cost to increase by 13.3 billion EUR to a total of 126.7 billion EUR (Table). By 2040, the health sector cost is estimated rise to 135.7 billion EUR. The increase is mainly due to an aging population. This is evident as the healthcare sector cost of cardiovascular diseases increase the most. But malignant neoplasms, respiratory diseases and neurological conditions also have a significant increase in the healthcare sector costs. Although the complexity of health care does invite simple solutions to improve productivity, a digital transformation has a proven potential for succeeding – both by better prevention and by high precision tailoring treatments to individual patients.

28. Source: Samfunnskostnader ved sykdom og ulykker 2015. Helsedirektoratet. Rapport IS-2839

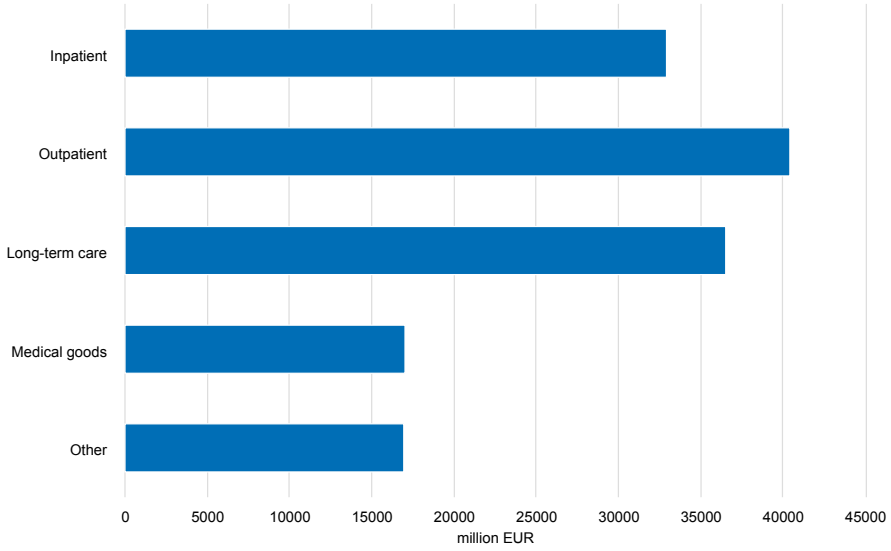


Figure 5: The distribution of health care expenditure in the Nordic countries in 2019. *Data from OECD.*

Projection of the current welfare system, only taking into account demographic changes as described in the preceding chapters, will most likely underestimate the increased burden on public budget. We also expect increased costs per health care worker due to the so-called Baumol's cost disease. According to the Baumol-effect, we need to pay public health care workers more in the future. Not necessarily because they have become more productive than before, but to be able to recruit health care workers, who increasingly see higher-pay career options elsewhere when entering higher education.

In addition, demand for welfare services is increasing since these services tend to be valued more highly when material well-being increases (Wagner's law) and because new treatment options become available. As pointed out by the Danish economist Torben Andersen:[29]

> *Providing welfare services of contemporaneous standards meeting the reasonable needs of most people is thus a moving target. At the same time improving material living standards may tend to increase the demand for leisure (shorter working hours, longer vacations etc.) with the implication that tax bases and thus tax revenues decrease.*

Since public spending and employment alone cannot solve the problem for Nordic countries, we need to rely on better prevention of costly diseases, and on increased productivity in delivering health care services.
A significant cost for the public healthcare system will be increases in age related expenditures such as for chronic illnesses. The total population aged 70 or older in the Nordic countries amounted to 4.1 million in 2022. By 2030 the number will rise to 4.8 million, and by 2040 we expect this to increase to 5.6 million. This increase in the size of the elderly population will have a significant impact on our resources and will therefore require us to review how we allocate health care. However, it will also

29. Andersen, T. M. (2015) The Nordic Welfare Model and Welfare Services – Can we maintain acceptable standards? Research on Finnish Society, Vol. 8, pp. 85–96.

increase the societies' rate of return on investment in prevention and efficient treatment, and access to health data will be key prerequisite to succeed with those investments.

There are large variations in the need for personal care and help among the elderly between the different countries.[30] In Finland, 70% of respondents above 65 reported that they do not need help. In Iceland 40% reported no need for help. The response in Sweden, Denmark and Norway was more similar - between 50 to 60%. Leveraging health data and health tech may lead to higher quality digital solutions that may reduce the proportion of elderly that requires personally performed care.

While the health effect (DALY) to society is unambiguously positive, the effect of digital transformation on costs are less clear cut. Because of the difficulties and high degree of uncertainty on estimating the direct benefits to savings in the health care we estimate the impact of different variables that arises:

Baumol's disease in health care

An economy will have sectors with varying potential for technological change and increased labor productivity. Industries with more high-tech capital will substitute capital for labor be replaced by capital, and see remaining workers become much more productive. Higher labor productivity is associated with higher wages since companies compete in attracting workers. In his novel analysis, Baumol (1967) pointed out that technology-induced increase of wages in *progressive* industries is contagious – causing pay rise also in *non-progressive* (less capital-intensive) sectors, such as education and parts of the healthcare sector. Pay rise becomes necessary to attract workers in the future. Since higher wages in the non-progressive industries are not matched with increases in productivity, the costs of providing these services are driven up over time.

According to this hypothesis, it will be more costly to recruit and retain nurses and doctors in Nordic healthcare sectors in the years to come.

30. "Disability Statistics - Elderly Needs for Help or Assistance," n.d., https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Disability_statistics_-_elderly_needs_for_help_or_assistance.

Table 5: Correlation between effect type and health care cost

Effect type	Its effect on health care costs	
Fewer patient and improved health due to better prevention	Strong decrease	+++
Less time per consultation and contact with health personal and doctors	Moderate decrease	--
Increased demand for health care services due to better access to health care	Small increase	+
Patients with diseases and conditions currently lacking efficient treatment will be treated	Moderate increase in specialized treatment (hospitals)	++
	Moderate decrease in chronic health care	--
Innovation of more advanced and expensive therapies	Moderate increase	+
The longer people live, the more health care services they will utilize	Strong increase	+++

Example: Improved access to general practitioners

Through the adoption of new technologies, innovative digital health prevention interventions can be delivered to a wider audience in the population than with traditional approaches. A study published by the European Commission[31] shows that 1) the average cost of telemedicine is ~15% of traditional medicine, and 2) time spent on telemedicine (20 minutes average) is roughly half of that of traditional medicine (40 minutes average). The high degree of digitalization in the Nordic region and a population with high digital competency means that the deployment of telemedicine solutions should be relatively easy and require rather small investments.

By combining information about the number of general practitioners in Nordic countries, as reported by Eurostat, and a Nordic study[32] of average number of visits per day, and average length of visits, we calculated the number of consultation hours spent by doctors and patients, and patients' travelling time. By using population forecasts, we establish a baseline scenario for 2040. This will be time spent on consultations and travelling in 2040 if telemedicine is not adopted.

Available information does not allow us to develop these forecasts for different age groups, but since the doctor visits are more frequent among elderly, we will be underestimating the increase in these hours in 2040. Approximately 200 million consultation hours in Nordic countries in 2040, therefore, is most likely a conservative estimate.

31. European Commission, "Market Study on Telemedicine," 2018, https://health.ec.europa.eu/system/files/2019-08/2018_provision_marketstudy_telemedicine_en_0.pdf.
32. Torunn Bjerve Eide, Jørund Straand, Cecilia Björkelund, Elise Kosunen, Ofeigur Thorgeirsson, Peter Vedsted & Elin Olaug Rosvold (2017) Differences in medical services in Nordic general practice: a comparative survey from the QUALICOPC study, Scandinavian Journal of Primary Health Care, 35:2, 153-161,

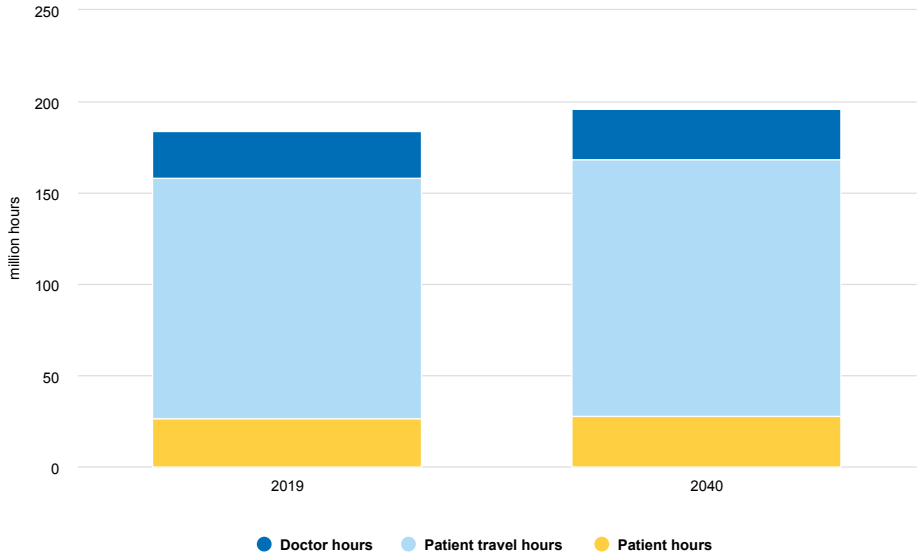


Figure 6: In 2019 patients in Nordic countries spent in total 130 million hours to see their doctor. In a baseline case, when only demographic changes are playing a role, this will increase to 140 million hours. This means that time spent travelling to doctors in the Nordic region cost the society 1,4 billion Euro 2040.

Although costs can be reduced by telemedicine, there is also a risk that improved access will increase demand. With a free health care service, prices are not rationing demand. Making access easier by adopting telemedicine is nevertheless representing an economic benefit. But we need to find robust mechanism to translate these benefits into alternative good use of doctors and patients' time.

Pillar 3: Health industry and productivity

In addition to the intrinsic value of quality of life, there is also a wider economic benefit to society of reduced of improved health and longevity. Healthy people stay in the working force longer and are more productive during their working years. Although the productivity effect of improved health is a well-documented fact, it is more controversial to include productivity effect in health economic evaluations of policies.

Including the value of productivity in economic valuation, favors policies targeting younger people. Policies that improve health of the elderly, will not include productivity effect since they have left the working force. Since politicians do not want to discriminate on the basis of age when prioritizing within a fixed healthcare budget, productivity is often left health economic evaluation of new treatments. Because the business case addressing health data is not about the best use of Nordic countries health care budgets, but rather an attempt to uncover the overall benefits to society from realizing the 2030 Vision for Nordic health data. Such a business case would be incomplete without including productivity effects.

The productivity loss due to sickness and diseases is estimated to approximately 61 billion EUR in 2019, although far less than the cost of lost healthy lives and healthcare sector cost, it still represents a significant loss in the economies. Mental

and substance use disorders caused a productivity loss of approximately 23 billion EUR in 2019, or approximately 30 percent of the total productivity loss. This is because many young people (aged between 15-69) have this diagnosis. In the period from 2019 to 2030, we estimate a rise in productivity loss of 1.4 billion EUR. From 2030 to 2040, we expect a decrease of 38,000 individuals in the age group between 15 to 69, leading to an expected loss of productivity will decrease by 0.1 billion EUR. The productivity loss is due to an increase in mental and substance use disorders and musculoskeletal diseases. Note that the productivity loss estimated doesn't describe the loss in productivity due to an increasing old population, but the loss due to diagnosis in the working population.

Quantified total costs and burden of diseases in Nordic countries mirror a huge potential for innovation and product development in health technology. To reduce these costs, Nordic countries need to improve prevention of diseases and to increase productivity in curative health care. A key finding from our work with the business case is that access to and sharing of Nordic health data can stimulate innovation in both areas.

We can only succeed with a new, integrated, and sustainable healthcare system if a Nordic health tech industry, broadly defined, is able to respond to the opportunities created by Nordic health data. *Stated differently, a prospering Nordic health tech industry that takes advantage of Nordic health data is a prerequisite for successful transition.*

This is important for our understanding of the economic value to society of stimulating growth in the Nordic health tech industry. The expected return on investment in health teach projects rely on their ability to create value to customers that are translated into willingness to pay. Since our healthcare sectors to a large extent are funded by the governments, well-functioning public-private partnerships are crucial for identifying promising areas of data-driven improvements and for establishing a market (demand) for health tech companies. A large fraction of income generated in Nordic health tech companies will stem from government funded sources – either from domestic payers or from export with the Nordic region.

Profitable data-driven innovations, therefore, needs to appropriate part of the economic value of improved prevention, better treatment, and higher productivity. Value-creation in the health tech industry does not add to the economic value to society already quantified – it reflects a much-needed transfer of value to companies and entrepreneurs that succeed.

A successful health tech industry that takes full advantage of Nordic health data will be characterized by competition. Health authorities as procurers of services and products, together with the governments' industry and innovation policy, will be key in creating a competitive health tech industry in the Nordic region. Competitive health tech markets lower prices and stimulate innovation. The health tech market become larger, and the full value of health data can be realized.

An innovative Nordic industry that can leverage Nordic data will not only serve the Nordic market, but there is also large potential for export to the European region and elsewhere. To the extent that this happens, it will add directly to the total economic benefit. Health data increases stimulate innovation and increases productivity, and the economic value of increased export is another way of harvesting transforming data to value.

To realize the potential, we need extensive sharing of health data, including easy access to these for research, business development, and service providers, and a competitive health tech industry that attracts investors. According to HealthTech Nordic[33] [34] the health tech industry is already booming and puts the Nordic region on the world map, and five main factors are contributing:

- The Nordic governments as well as regions, municipalities and other authorities work purposefully towards a digitized healthcare system
- The region features world-class medical care and research institutions
- The region features world-class research and development in new technology
- The availability of highly skilled workforce in software and hardware development is good
- It is relatively easy to start up new businesses and there is a well-developed system to support new businesses and entrepreneurs

Combined with an increasing global demand for high quality modern health care, this makes the future for Nordic health tech industry look very promising.[35] Realizing the vision of sharing Nordic health data will reinforce all five factors. If the growth of the Nordic health tech industry creates new jobs, this does not add to the estimated economic benefit of sharing health data. New jobs follow from health tech ability to improve health care services and prevention of diseases, by making health care more accessible for patients and giving health care professionals access to improved tools enabling them to better aid more patients.

Health technology in Finland

According to the US International Trade Organization, Finland is one of the few countries in the world that exports more health technology than it imports. The United States was the most important destination for export in 2019 getting 38.5 percent of the total value. The value of Finland's exports of health technology products rose to $2.74 billion in 2019, an increase of 5.7 percent over 2019. Imports of health technology products rose 4 percent to $1.48 billion. The sector employs over 13 000 people.

More than 50 % of health tech companies in Finland have less than 25 employees. Consequently, a survey of the Norwegian health industry confirms that small health tech companies rely on the Nordic market.[36]

33. "Health Tech Startups Creates New Jobs Shows New Statistics," Nordic Life Science – the Leading Nordic Life Science News Service (blog), June 16, 2018, https://nordiclifescience.org/health-tech-startups-creates-newjobs-shows-new-statistics/.
34. "Despite the Pandemic – Healthtech Companies Continue to Grow Rapidly, Creating Better Health and New Jobs - HealthTech Nordic," April 14, 2021, https://healthtechnordic.com/survey2020/.
35. https://nordiclifescience.org/health-tech-startups-creates-new-jobs-shows-new-statistics/
36. Menon Economics. Helsenæringens verdi 2022.

4. Opportunities for the Nordic region

To determine the potential economic benefits associated with health care improvements resulting from data and data sharing across the Nordic countries, we first review opportunities in the context of the patient journey. Within this framework, there are seven distinct areas where data-sharing may affect either the healthcare system or the patients. In this chapter, we use the insights from health care experts across the Nordic region and the rest of the world to evaluate various opportunities within each of these areas.

4.1 Opportunity 1 - Equitable access

What is equitable access?

Every Nordic inhabitant should have equitable access to health care. This is partially present today, but it is important to note that equity differs from equality. Equality is often what we refer to when speaking about health care, but that focuses solely on everyone having access to the same level of care. Equity, on the other hand, is about the outcome of the care provided. This adds an important layer of complexity as it requires the health care ecosystem to work with patients and individuals to not simply make care available, but also to ensure that it is allocated and utilized according to needs. The effect of this perspective is that more care can be given to sicker patients and that providers need to find ways to attract individuals who may be hesitant to seek medical care, even when necessary.

Who does it affect?

Although the Nordic countries have been one of the leading regions in the world regarding equality, there are still significant shortcomings regarding equity which, when resolved, will raise the base level of quality of life in the region. An example of a recent shortcoming is related to COVID-19. During its outbreak, the Nordic region saw that immigrants and minority groups had significantly higher risks of infection, hospital admission and death[37]. Unfortunately, similar findings relate to other health risks as well, highlighting the need for further improvements[38]. Other challenges related to equitable access are language skills, level of education and knowledge, digital competency, and familiarity with how the healthcare system works.

In Norway, for example, it has been shown that the level of education is a powerful indicator of health differences. For instance, those with the highest level of

37. Gunn Elisabeth Vist et al., *Incidence and Severe Outcomes from COVID-19 among Immigrant and Minority Ethnic Groups and among Groups of Different Socio-Economic Status: A Systematic Review* (Norwegian Institute of Public Health, Division for Health Services, 2021), https://fhi.brage.unit.no/fhi-xmlui/handle/11250/2754026.
38. Marte KR Kjøllesdal, Jennifer Gerwing, and Thor Indseth, "Health Risks among Long-Term Immigrants in Norway with Poor Norwegian Language Proficiency," *Scandinavian Journal of Public Health*, 2022, 14034948221085400.

education live five to six years longer and have better health than those with the lowest level of education[39]. This is not only because higher education historically has led to better jobs with better work conditions, but also because the higher knowledge about the various health risks and ability to act on the information[40].

What are the technologies and data involved?

With increased digitalization and implementation of innovative technologies, there is the potential to move away from physical care to a more digital form of health care where health data may also involve and be coupled to socioeconomic information, genetics, ethnicity, education, and language skills. Because of the various challenges, a key part of enabling equitable access and to secure inhabitant follow-up is tailored messaging technology.

What is the economic potential?

Research shows that the health of a nation's population has a significant effect on the overall economic prosperity[41]. This is because of the impact that quality of life has on individuals' ability to work and contribute to society. In addition, an increase in quality of life also leads to a reduction in the pressure on healthcare systems, enabling a greater focus on those who need care the most. Looking at Sweden as an example, we know that the number of the foreign-born people has increased over the past several years and that there are nearly 2.1 million people who are now foreign born[42]. Considering that this group has, amongst others, higher rates of long-term illness and poorer mental health[43], these health inequities affect the economic prosperity of the country and the Nordic region. Taken together, there is enormous potential in the Nordics to increase the quality-of-life baseline through equitable health care, which will support the region in raising economic prosperity.

Vision

Nordic data enables detailed analyses of demographical segments to better understand where health care equity has not yet been reached and thereafter use the information to pursue targeted efforts at raising the quality-of-life baseline through more equitable access to health care.

39. Astri Syse et al., "Social Inequalities in Health," Norwegian Institute of Public Health, n.d., https://www.fhi.no/en/op/hin/population/social-inequalities/.
40. Bruce G. Link and Jo Phelan, "Social Conditions as Fundamental Causes of Disease," *Journal of Health and Social Behavior*, 1995, 80–94.
41. Robert Stefko et al., "Gender Inequalities in Health and Their Effect on the Economic Prosperity Represented by the GDP of Selected Developed Countries—Empirical Study," *International Journal of Environmental Research and Public Health* 17, no. 10 (2020): 3555.
42. "Summary of Population Statistics 1960–2021," Statistiska Centralbyrån, n.d., https://www.scb.se/en/finding-statistics/statistics-by-subject-area/population/population-composition/population-statistics/pong/tables-and-graphs/yearly-statistics--the-whole-country/summary-of-population-statistics/.
43. Anna Brydsten, Mikael Rostila, and Andrea Dunlavy, "Social Integration and Mental Health - a Decomposition Approach to Mental Health Inequalities between the Foreign-Born and Native-Born in Sweden," *International Journal for Equity in Health* 18, no. 1 (April 3, 2019): 48, https://doi.org/10.1186/s12939-019-0950-1.

Opportunity in equitable access

Combining information on socioeconomic status, ethnicity, and primary language with health data can help increase health equity by providing a more complete picture of an individual's overall health and well-being. This information can be used to identify and address health disparities that may exist among different populations and to develop targeted interventions and programs that are tailored to the specific needs of these populations. For example, if a particular group has higher rates of chronic illness, such as diabetes, compared to the general population, this information can be used to develop targeted public health campaigns or outreach programs that aim to educate and support members of this group in managing their health conditions. 90% of heart diseases can be prevented through changes in diet, physical activity, and smoking habits (WHO). Additionally, by incorporating information on socioeconomic status and language, healthcare providers can better understand and address the barriers that may prevent individuals from accessing care, such as lack of insurance or transportation, and work to improve health equity for all members of the community.

Source: WHO (https://apps.who.int/gb/archive/pdf_files/WHA55/ea5516.pdf)

4.2 Opportunity 2 – More efficient systems

What do we mean by more efficient systems?

A striking feature when we compare the world's healthcare systems is that the average life expectancy increases with increased spending until a certain point, after which it flattens out[44]. This means that the act of putting more capital into health care at this point appears to no longer increase the estimated life expectancy of the population. From the perspective of nations trying to keep up with costs, this finding is not all bad news as it means that more focus can go towards efficiency improvements rather than towards increased spending [Anchor] . And as has been seen in practically all other sectors, data and data sharing are excellent tools for improving efficiency.

In the Nordics, nearly 4% of the total population is employed as health care professionals[45], making up roughly half of the overall health care expenditures. As the pressure on the healthcare system increases, more efficient systems is one of the keys to achieving Nordic health goals in the future. At a high level, the healthcare system can be more effective through improving the resource allocation, reducing the waste, and improving the quality of care. Considering that approximately 20-30% of health care spending in Europe is waste (i.e., not producing any value) mainly from overtreatment, inefficiency, and preventable harms[46]. According to OECD research[47], around 10% of patients are unnecessarily harmed during care,

44. The Most Efficient Health Care Systems - Vantage Technologies (vantage-technologies.co.uk)
45. Database - Health - Eurostat," accessed August 10, 2022, https://ec.europa.eu/eurostat/web/health/data/database
46. Stephen J. Swensen et al., "The Business Case for Health-Care Quality Improvement," *Journal of Patient Safety* 9, no. 1 (March 2013): 44–52, https://doi.org/10.1097/PTS.0b013e3182753e33.
47. "Empowering the Health Workforce to Make the Most of the Digital Revolution En OECD," accessed August 10, 2022, https://www.oecd.org/publications/empowering-the-health-workforce-to-make-the-most-of-the-digital-revolution-37ff0eaa-en.htm.

mostly due to lack of access to information. With more efficient systems, we therefore focus on a health ecosystem allowing the best possible resource allocation at the highest quality of care and handling of patients.

Many of the health data registers that exists today that can be used for research and innovation, are fragmented, and apply different standards. Without improvements in the current health systems and data flows, necessary data and information will continue to be siloed, hindering novel insights and large-scale improvements.

Case: X-eHealth

X-eHealth is a common framework for exchange of electronic health records. The project aims to advance the integration of eHealth services, contribute to standardization and defragmentation of health data, and facilitate interaction between health care providers.

https://www.x-ehealth.eu/

Who does it affect?

Digital transformation and implementation of new technical solutions in healthcare systems causes a reduces in manual routine tasks and more efficient use of health care workers. This upgraded occupational structure has direct economic consequences. The delivery of the right information to the right people at the right time may significantly benefit health care providers and health care staff. Through increased data sharing and digitalization, patients benefit from lower costs because of reductions in administrative tasks and unnecessary costs.

What is the economic potential?

From a business perspective, there are clear financial benefits from reducing health care that is considered overuse, inefficient, defective and/or under-use[48]. This includes a reduction in overlapping examinations, as well as lowering health care expenditures from elimination of waste and a reduction in hospitalization and the length of stays. Additionally, clinical quality improvements in patient centric care, which is supported by the re-use of patient data, is one of the enablers that will allow the realization of these economic benefits.

48. Swensen et al., "The Business Case for Health-Care Quality Improvement."

Opportunity in more efficient systems – home treatment for cancer patients

Transitioning to more home treatment has been demonstrated to lead to increased cost-effectiveness and a reduction in the risk of hospitalization for cancer patients. Communication and access to real-time health data is a prerequisite for many of the home treatment options. At home there is less chance of being infected by other diseases, and the patient is in a safe and known environment. In one study involving cancer patients, the patient centered medical homes caused:

- 55% less unplanned hospitalizations
- 47% lower cost - mean cost reduced from $9180 to $4399

References:
https://ascopubs.org/doi/full/10.1200/JCO.20.03609
https://www.medpagetoday.com/hematologyoncology/othercancers/92808

Vision

The systems and solutions underpinning the health care data infrastructure function as enablers of the utilization of data and its sharing across the Nordics. In turn, the Nordic health care ecosystem is able to understand and triangulate inefficiencies, opening up opportunities for decreased costs and increased innovation.

4.3 Opportunity 3 – Preventive health care

What do we mean by preventive health care?

Preventive health care has been a key talking point and goal among the Nordic countries because of its clear connection to cost reductions, especially for costs associated with chronic illnesses and lifestyle diseases, such as obesity and cardiovascular diseases, which have been on the rise in Nordic countries for decades. However, the ambitious goals are not consistent with the actions. While curative health care spending accounts for approximately 10% of GDP while preventive health care represents less than 0.3% of GDP. Although preventative health care is often discussed from the perspective of entirely avoiding illnesses, there are also significant value realizations associated with preventing the need for additional health care services for those already living with illnesses as well as in preventing rapid health deterioration for those with more severe symptoms.

The ability to develop services and guidance tied to preventative health care is built on the ability to analyze large numbers of people and patients to find connections between actions taken and their impact on predicted future illnesses. To accomplish these goals, preventive health care sets out to identify health care risks and to support the establishing of new behaviors to improve or stabilize individuals' health. Through our interviews and surveys, we find that there is a general agreement that access to Nordic data will have a high to very high impact on preventive health care.

Who does it affect?

Not all diseases and health risks can be prevented[49], but many of the chronic illnesses that are becoming more prevalent in the Nordics are possible to prevent. Some of these include various forms of cancer, type 2 diabetes, and certain forms of heart disease. In addition, a plethora of less severe ailments can be prevented, ranging from hearing loss to backpain. This means that everyone has the potential to benefit from preventative care, but in particular, individuals at high risk for severe chronic illnesses can be the most positively affected in the short-to-medium term. An important aspect of preventive health care is that a lot of the responsibility lies on the individuals. There is no health care institutions and governmental entities that will force changes in lifestyle. However, these actors can, together with innovators, provide services that facilitate the change.

What are the technologies and data involved?

Many technologies and data sources, such as wearables, sensors, biomarkers, genomics, apps and software, professional health systems and registers, and machine learning, may be involved in preventive health care.

What is the economic potential?

Preventive health care is a critical part of personalized health care as it 1) increases the productivity, measured as the number of days available to take part in market activities, 2) reduces complications and hospitalization needs, and 3) reduces the mortality and improves the quality of life. From an economical perspective, prevention is one of the hypotheses with the greatest potential. For instance, an analysis found that health interventions such as preventive health care return an average of 14.3 EUR for every 1 EUR invested[50]. Despite the importance of preventive health care, our analysis suggests that the potential used in the Nordic region today is less than 20% and more than 10 years (Section 5.8) is estimated to be required to reach a best-case use of data in preventive health care. However, there are relatively simple ways to more quickly improve the utilization of preventive health care, such as through the gamification of health which we are already seeing in some apps and products sold today.

Vision

Data sharing across the Nordic countries allows for improved analyses and a deeper understanding of a variety of diseases, in turn enabling preventative actions to be taken by better informed doctors and patients. In addition, for the preventive methods that are already recognized, we have improved the success rate for stimulation of desired behaviors through a more concrete and personal connection between an individual's actions and their future state of health.

49. "Avoidable Mortality (Preventable and Treatable)," in *Health at a Glance 2019*, by OECD, Health at a Glance (OECD, 2019), https://doi.org/10.1787/3b4fdbf2-en.
50. Rebecca Masters et al., "Return on Investment of Public Health Interventions: A Systematic Review," *Journal of Epidemiology and Community Health* 71, no. 8 (August 1, 2017): 827, https://doi.org/10.1136/jech-2016-208141.

4.4 Opportunity 4 – Improved diagnostics

What do we mean by improved diagnostics?

Whereas preventive health care focuses on preventing a disease from developing, diagnostics refers to the ability to identify a disease correctly and quickly. Disease diagnostics and prediction is a critical function of the healthcare system but depends on the individual health care personnel to interpret often complex symptoms. If done correctly, Nordic health data may be an enabler for early detection, which is key to improve the medical outcome for patients. One field that holds significant potential is for diseases that rely on medical imaging for diagnostics, such as cancer, where there is an enormous potential to speed up and improve the accuracy and outcomes.

What are the technologies and data involved?

Today, much of the diagnostics works as a one-off diagnostic intervention such as CT (computed tomography) or PET (positron emission tomography) scans. However, the ability to provide diagnostics on a more personalized level requires big and continuous datasets. Molecular diagnostics such as for "liquid biopsy," DNA, synthetic biomarkers, and protein biomarkers, are emerging as a promising new tool for high-precision detection of many early-stage diseases[51]. Novel technologies such as flexible electronics and biosensors will cause further improvements in the diagnostic abilities[52].

What is the economic potential?

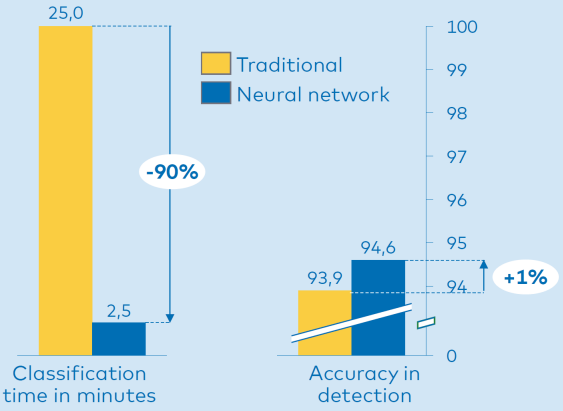
Taking the proactive approach of early diagnostics, which aims to identify and characterize diseases at an early stage, may significantly improve the patient outcome for many diseases. This causes direct economic effects in reductions of DALY.

By improving the diagnostic abilities there are several economic effects. We expect a decrease in the health care expenditures because of less resource use for detection and increased value for the society because of a decrease in sick days.

With increased access to data comes the possibility of identifying the causal relationships in patients. However, increased predictive power may not directly lead to improved clinical care. Many times, there is a high accuracy in predicting the outcome, but little opportunity to reduce the risk or changing the outcome[53]. In this case, the treatment methods end up being the critical task.

51. Liangliang Hao et al., "Microenvironment-Triggered Multimodal Precision Diagnostics," *Nature Materials* 20, no. 10 (October 1, 2021): 1440–48, https://doi.org/10.1038/s41563-021-01042-y.
52. Rebecca C. Fitzgerald et al., "The Future of Early Cancer Detection," *Nature Medicine* 28, no. 4 (April 1, 2022): 666–77, https://doi.org/10.1038/s41591-022-01746-x.
53. Jonathan H. Chen and Steven M. Asch, "Machine Learning and Prediction in Medicine — Beyond the Peak of Inflated Expectations," *New England Journal of Medicine* 376, no. 26 (June 29, 2017): 2507–9, https://doi.org/10.1056/NEJMp1702071.

Opportunity in improved diagnostics – predictive machine learning algorithms



Improved accuracy and speed of disease detection through implementation of machine learning algorithms. An example where machine learning directly leads to increased economic value through less use of resource to do the same task and improved accuracy in diagnosis. Access to high quality data is critical for developing accurate algorithms for medical applications such as image recognition.

Vision

We have developed a detailed understanding of the most prioritized illnesses to significantly cut down on the number of patients who receive an incorrect diagnosis or a delayed treatment. This enables a decrease in adverse effects to patients from erroneous or delayed treatments, in turn improving quality of life and simultaneously decreasing health care spending.

4.5 Opportunity 5 - Improved treatment

What do we mean by improved treatment?

As the scientific literature grows rapidly, treatments and medicine are becoming increasingly specialized. This hinders medical personnel from knowing all available treatments and the efficacy of the various drugs in in disparate fields[54]. However, clinicians are often put in a situation where they must evaluate and compare risks and benefits of different treatments outside of their specialty. As the pressure on the healthcare system increases, the time for consultation is reduced and the time to

54. Hilda Bastian, Paul Glasziou, and Iain Chalmers, "Seventy-Five Trials and Eleven Systematic Reviews a Day: How Will We Ever Keep Up?," *PLoS Medicine* 7, no. 9 (September 21, 2010): e1000326, https://doi.org/10.1371/journal.pmed.1000326.

choose the best therapy is reduced. Consequently, biases such as prior personal experiences and knowledge plays an increasingly large part of the health outcome. Because of the variations in the quality of care[55], the outcome for patients may differ depending on where they are referred or whom they consult.

Since there are high deviations in outcomes and efficacy of medicines, there is a large potential to improve treatment simply by giving access and insights into the efficacy of various medical treatments[56] to clinicians. Real-world data is a key to evaluate the patient outcomes and improve the clinical effects. Furthermore, with an increasing amount of people having more complex health situations and chronic diseases, the number of accurate data sources and their quality becomes critical to drive decisions for improved treatment. By leveraging the opportunities presented by the access to a wealth of health data we can more precisely provide actionable treatment paths based on patient characteristics, such as genetics, lifestyle, and environmental variables[57]. Taken together, this lays the foundation for precision medicine as it becomes possible to combine a detailed understanding of patients with a vastly improved understanding of exactly how they should be treated.

When decisions on treatment are made on inadequate information the operating procedures may be ineffective, and in the worst case, can lead to direct harm[58]. Sharing of data and machine learning can be used to identify patients with different risk-benefit profiles regarding both clinical and economic outcomes. Personalized medicine is most valuable for expensive treatments and treatments with frequent and severe side-effects. Consider the different components that may affect improved treatment methods and precision medicine: internal data (genomics), lifestyle data (diet, exercise, drinking, and smoking status), and external data. The rise of electronic health records and information technology is supporting this opportunity.

Access to data may help the transition to more evidence-based medicine. Currently, about 90% of the treatments are not supported by high-quality evidence. This means that there is an immense potential to better support and strengthen the quality and security for both patients and the medical staff.

Who does it affect?

Improved treatments will be relevant for all patients as the purpose of it is to personalize the treatments based upon individual factors. This is applicable not just for medications, but also for mental health and physical therapy which can all be made more effective. Among the most promising ways that improved treatments will create value for patients is through fewer complications, shorter hospital stays, a reduced number of interventions, as well as a lowered need for in-patient care and a reduction in adverse side effects.

55. Helge Haugland et al., "Mortality and Quality of Care in Nordic Physician-Staffed Emergency Medical Services," *Scandinavian Journal of Trauma, Resuscitation and Emergency Medicine* 28, no. 1 (October 14, 2020): 100, https://doi.org/10.1186/s13049-020-00796-9.
56. Stefan Leucht et al., "How Effective Are Common Medications: A Perspective Based on Meta-Analyses of Major Drugs," *BMC Medicine* 13, no. 1 (December 2015): 253, https://doi.org/10.1186/s12916-015-0494-1.
57. Kazuki Nakamura et al., "Health Improvement Framework for Actionable Treatment Planning Using a Surrogate Bayesian Model," *Nature Communications* 12, no. 1 (May 25, 2021): 3088, https://doi.org/10.1038/s41467-021-23319-1.
58. Robert M. Califf et al., "Transforming Evidence Generation to Support Health and Health Care Decisions," *New England Journal of Medicine* 375, no. 24 (December 15, 2016): 2395–2400, https://doi.org/10.1056/NEJMsb1610128.

What are the technologies and data involved?

There are many technologies that will be relevant to improving the treatment of illnesses and injuries, including personalized dosage of medication, hybrid care that leverages physical and digital care, as well as more accurate physical therapy. The key factor underlying them all, however, is that doctors and medical providers have a better understanding of the patient as well as how they will be impacted by the available treatment methods. This may mean that two patients with the same underlying mental health illness who historically would have received the same treatment may need to be treated in different ways going forward. The enabler for making these decisions is the shared and utilized data that provides the foundation for understanding not just the illness but can also empirically guide care providers to the tailored treatment that will provide the optimal health outcome.

What is the economic potential?

The economic potential of improved treatments is both a positive and a negative for the healthcare sector. From the positive side, it will help with bringing down costs associated with ailments already mentioned, such as the length of hospital stays and the number of complications and side effects. On the other hand, the personalization of care is likely to make the provided health care more expensive as the one-size-fits-all approach is retired. Overall, however, the expected savings are likely to greatly outweigh the costs, especially since the economic benefit from a higher quality of life tends to significantly surpass that of direct health care costs.

Vision

The Nordics have transitioned to a treatment model that utilizes data and empirical findings to provide accurate and personalized treatments, thereby improving the quality of life of patients and reducing the overall pressure on the health care ecosystem.

4.6 Opportunity 6 - Improved monitoring

What do we mean by improved monitoring?

Monitoring is the passive action of continually tracking various health indicators for personal interest or for use by health care professionals. Since the advent of relatively cheap and user-friendly wearables, such as smart wristbands and watches, this market has skyrocketed, and we expect it to continue to expand over the coming years. While we often think of personal wearables, the potential behind improved monitoring also extends to the use of other smart devices and sensors that are internet of things (IoT) enabled. Based upon medical needs and guidance, this can include devices such as blood pressure monitors and apps tracking a patient's diet.

Who does it affect?

Monitoring has historically been used by doctors to ensure that the health of at-risk patients does not rapidly deteriorate without their knowledge. While this will continue to be an important patient group in the future, there is also a strong connection between passive monitoring and the potential to spot the onset of medical ailments in healthy individuals. This means that monitoring is relevant for all individuals, and it effectively makes monitoring a bridging health care practice, turning the straight-lined patient journey into a continuous loop. We expect there to be a lower threshold for individuals to adopt monitoring solutions and share that data because in many cases monitoring takes place after a disease has been detected and/or cured.

What are the technologies and data involved?

Because of the vast number of data points that could theoretically be useful in monitoring, it is more applicable to think of relevant technologies and data as all things that can realistically be used to better understand individuals' health over time. Some of these are already well established, such as blood pressure monitoring, but new methods continually push the boundaries of what we previously thought possible. One example is a study indicating that driving performance can be used in early detection of Alzheimer's disease[59].

What is the economic potential?

Since monitoring of health indicators is a passive act, it mainly provides direct economic benefit from the standpoint of developing and selling technologies and solution that are relevant for health monitoring. However, the most significant economic benefits come from monitoring being a key precursor to knowing when it is necessary to take steps to either improve health or to prevent its deterioration. This puts the potential of improved monitoring in close collaboration with the other steps in the patient journey, going from prevention to diagnostics and finally to treatment.

Vision

We have connected passive health care monitoring services to a single output that enables health care providers to work together to care for patients with complex and/or multiple illnesses. In addition, the combination and analysis of health care indicators enables health care providers to distinguish when formerly healthy individuals require medical attention, whether for preventative measures, more detailed diagnostics, or treatment.

59. Ryan Blanchette et al., "Predicting Alzheimer's Disease Using Driving Simulator Data," *Annual International Conference of the IEEE Engineering in Medicine and Biology Society. IEEE Engineering in Medicine and Biology Society. Annual International Conference* 2020 (July 2020): 5432–35, https://doi.org/10.1109/EMBC44109.2020.9176118.

4.7 Opportunity 7 – Increased innovation

What do we mean by increased innovation?

Innovation using data and data sharing has dramatically transformed many industries, such as banking and telecom, but the healthcare sector has not yet fully seized the potential benefits to innovate with these new technologies. This puts the healthcare sector in the position of seeing various forms of potential improvements but being unable to use them prior to setting the right foundation in place. Various actors within the ecosystem are betting on innovation to reach the potential improvements which has led the sector to see a significant number of new services and solutions based on data and data sharing. Unfortunately, many of these new services and solutions have not yet been adopted, including image analysis using AI, and innovation organizations are keen to progress faster.

With improvements in data and data sharing, the Nordic countries have the potential to boost businesses' ability to innovate while simultaneously enabling the utilization of new services and solutions. At present, we expect a time lag of 17 years from research output to clinical practice[60]. Considering the challenges facing the healthcare sector, these lead times need to be shortened, and improved data sharing is a key building block to do so.

Who does it affect?

There are several actors in the health innovation ecosystem that may benefit from increased data sharing. First of all, established innovation actors such as drug developers and various forms of companies, including MedTech and digital health, will stand to benefit from the improved potential to innovate. Similarly, early-stage innovators such as entrepreneurs and startups will be positively affected by an ecosystem that makes it easier for them to develop and launch their ideas. On the other side of the spectrum are the health care providers and patients who make use of the new innovations as they are released to the market.

Overall, however, while health care innovation ends up benefitting patients and care providers, the improved potential to pursue innovation is especially a benefit for businesses and other forms of innovation entities since they need a market to sell their services and solutions. We believe that better and more affordable access to relevant and high-quality health data will affect startup companies which today struggle to get hold of data to test and verify their hypotheses.

What is the economic potential?

In contrast to many other opportunities discussed above which are centered on how costs can be reduced and how quality of life can be improved, the economic potential of increased innovation is largely tied to additional revenue streams and increased investments for organizations that are developing novel solutions and services within the health care ecosystem. These factors make the overall economic potential of

60. Zoë Slote Morris, Steven Wooding, and Jonathan Grant, "The Answer Is 17 Years, What Is the Question: Understanding Time Lags in Translational Research," *Journal of the Royal Society of Medicine* 104, no. 12 (December 2011): 510–20, https://doi.org/10.1258/jrsm.2011.110180.

how this area will develop especially difficult to estimate. On the low end, the Nordics will likely see a great expansion of the number of well-tested, innovative services and solutions being brough to market, while on the high end there is potential for significant international exposure which can lead to the resulting growth being far beyond the potential within the Nordics.

Vision

The Nordic countries have developed and implemented the foundation for readily sharing anonymized health data with businesses and academia, enticing international investments in the region, and supporting a fruitful and innovative ecosystem.

4.8 Building consensus on impact and timeframes of sharing Nordic health data

Developing shared frameworks and politics on a Nordic level is a time-consuming task and any decision regarding sharing of Nordic health data requires a broad-based stakeholder involvement. The different countries and regions may have slightly different targets, goals, and ambitions, and may also reach different levels of maturity at different times. To estimate a consensus on the potential timescales that is expected for the broad implementation and use of Nordic health data, we asked experts from industry, research, and healthcare sector to provide estimates. These do not represent any general view held by these communities and do not represent a fixed picture. Rather, they represent the expected timeframes at the current pace of progress. The timeframe may therefore shorten if the pace of collaboration, funding, and technology changes.

Our results show that broad use of Nordic health data across the different opportunities in the patient journey as described in this chapter is expected to be reached within a 5-to-20-year timeframe, with an average of 11 years. Some areas where the effects of sharing data are more tangible and readily recognized may grasp the opportunities quicker. As health data by itself does not represent any significant value, achieving seamless data sharing of health data across the Nordic countries is no guarantee for realizing economic value. To address the prospect of Nordic health data, we therefore asked the experts about the current state of use of health data and the overall potential within the different opportunity areas. The overall impression of our panelists is that sharing of Nordic health data represents a high to very high value potential and that the current potential of using health data varies from 10% to 30%.

Realizing the full value potential of health data, however, is not expected to occur at the same time as the implementation. Our research and modeling show that a time lag of approximately 5 to 10 years from implementation is expected before the value realization may have a significant effect on the Nordic economies. To estimate the economic value of sharing Nordic health data for this business case, we therefore use the year 2040 as a cut-off.

5. Business case

5.1 Drivers for Nordic data sharing and summary of opportunities

The Nordic healthcare sector is facing mounting challenges caused by a combination of demographic changes, increased cost (Baumol effect[61]), and increasing expectations of the quality (Wagner effect) of health care[62] (chapter 4). The fiscal impacts of these factors represent a significant challenge to the Nordic countries, with the effects expected to take place in the coming decades. According to an EU report, the Nordic countries will spend significantly more of GDP on health care and long-term care than the EU average in the coming years[63]. Sharing of Nordic health data is one promising step to mitigate the unsustainable growth in public spending and with the rapid development of artificial intelligence solutions and emerging technologies within data collection and analysis, the Nordic region may place itself in the forefront of the new healthcare system.

Data sharing between the Nordic countries can lead to three fundamental outcomes: maximizing the population health, reducing the health care costs, and increasing the income from new treatments, services, and solutions. If we look past the sensitivity of the data, the legal issues, and the technical issues, there is an enormous economic potential in sharing of health data across the Nordic countries. Better access to and sharing of health data in the Nordic region will play a key role in reinventing health care for an area characterized by an aging population and tighter public budgets. Better access to and sharing of health data will improve the way we deliver health care services to an aging population.

The business case for data sharing across the Nordic countries is composed of several unique attributes, including increased quality adjusted life years and productivity, a reduction in operating costs and expenditures, and increased entrepreneurship (chapter 4). However, because the healthcare sector is affected by a complex set of attributes ranging from national policies, globalization, and socio-economic conditions, many of the economic effects are difficult to demonstrate systematically. The seven opportunities presented in chapter 4 should not be seen in isolation, but rather as an integrated and holistic view towards the new healthcare system. The economic impact of the different areas will depend on the timing, speed of implementation, and effectiveness. On the other hand, the digitalization journey related to different opportunities themselves can be stepwise. The common denominator is, however, a common data architecture for all applications to enable exchanging of data across organizational and country borders. Data privacy and security must be built-in functionalities in this networked architecture – taking care of different legislation in different countries. An example of such legislation is patient consents and denials.

61. Marc Pomp and Sunčica Vujič, *Rising Health Spending, New Medical Technology and the Baumol Effect*, CPB Discussion Paper 115 (The Hague: CPB, 2008).
62. Andersen et al., *The Nordic Model. Embracing Globalization and Sharing Risks.*
63. *The 2021 Ageing Report: Economic and Budgetary Projections for the EU Member States (2019-2070)* (Luxembourg: Publications Office of the European Union, 2021).

Table 6: Opportunities and estimated impacts

Opportunity	Estimated impact
Equitable access	+
Efficient systems	+
Preventive health care	+ + +
Improved diagnostics	+
Better treatment	- / + +
Improved monitoring	+
Increased innovation	+ +

5.2 Scenarios and range of opportunities

At the current trajectory, the total health care spending will exceed 136 billion EUR for the Nordic countries in 2040. To mitigate the financial problems caused by the drastic demographic changes there are three options, increase taxes, cut expenditures, or increase employment. Our models and interviews show that by capitalizing on cross-border data sharing and emerging technology, we can slow the growth in health care expenditure through increased efficiency and improved health conditions. At the same time, improving health outcomes is critical to increasing productivity.

Below, we present three scenarios that may result from different levels of implementation of Nordic health data sharing. The scenarios reflect the different outcomes we expect from the realization of the 2030 vision of becoming the most sustainable and integrated health region in the world. If we assume that we can reach the vision by 2030, it will still take some time for the value to be fully realized (see chapter 4.8). In our scenarios we therefore use 2040 as the cut-off for estimating the potential values. The scenarios build on the findings in chapter 3 and 4 which shows that the five largest disease groups, both in terms of economic value and health care impact, may benefit especially from the sharing of health care data. Some of the identified effects, such as patient empowerment, the value of hope for patients, and scientific spillover have unknown economic effects and have not been assessed in this business case. In addition, indirect benefits in society may also arise, such as improved community services, welfare for those in need, and better city planning. However, achieving broad and effective sharing of Nordic health data is no guarantee for the value realization described in the scenarios. To realize the economic benefits assumed to arise from reaching the vision of the Nordic region being the most sustainable and integrated health region in the world requires a significant effort and collaboration between actors across the health ecosystem.

Scenario #1: Increased health care spending and slow adoption

Our analysis shows that by following the current health care trajectory, we will spend over 136 billion EUR by 2040. The increase in the population above 70 years of age is estimated to put additional stress on the healthcare system, and activities related to supporting the elderly population are expected to account for 50 percent of the spending.

In this scenario, new solutions and technology implementations are driven top-down, with little interaction between leaders and health care personnel. The governance framework will continue to be fragmented, which will leave the individual countries unable to grasp the full potential of data sharing outlined in chapter 4. Ineffective implementation of new solutions may reduce productivity, increase stress for workers, and worsen conditions for patients as seen in some cases. The outcome of this will probably lead to the generation of additional costs, such as operating local and national data initiatives, inefficient administration, and potentially lower quality of health care services. Gaining access to health data continues to be time-consuming, and it is provided on a register and country basis, meaning that 1) data may become irrelevant by the time access is given, and 2) not reflective of the population at large.

The pressure exerted on the healthcare system throws the sector into a downwards spiral with work overload making it an unattractive career option. The number of available technologists is too low, and they are also in competition with other industries. This may be the reality if we fail to bridge and capitalize on the Nordic health data and adopt a strict interpretation of current legislations[64], which causes health costs to increase rapidly while the quality of life decreases.

Scenario #2: Shifting focus from curative to preventive health care

Today, around 80% of health care expenditures in the Nordic region is based on curative health care. Through shifting the focus towards personalized and preventive health care, we expect the spending on curative health care to decrease. In the second scenario, however, we see the use and value realization of Nordic health data as remaining in an infant state. There is a slow transition and partial implementation of data sharing initiatives meaning that rapid progress is hampered. In this situation, we experience fragmented value realization and few incentive structures for individuals and public actors to innovate and fast-track new solutions.

In scenario #2, we might experience improved public-private collaborations and the evolution of certain new business models that might cause larger market opportunities and ecosystem innovations. In this scenario, we expect that similar initiatives, that at present only exists on a national level, are merged and the Nordic resources are pooled together. This will enable a simpler and more effective access to parts of the data.

Our models show that shifting focus from curative to preventive health care will increase quality of life, reduce costs, and increase the productivity. Rather than focusing on curative health care, the health data will reduce the occurrence of the

64. Nordic Innovation, *Bridging Nordic Data Legal Overview of Possibilities and Obstacles for Secondary Use of Health Data for Innovation and Development.*

five diseases that affect the population the most. This will be possible because the partial implementation of health data will enable i) a reduction in the number of people who get the disease in the first place and ii) more efficient diagnostics and treatment of diseases. The value realization is estimated by reducing the burden of disease[65] for malignant neoplasm, cardiovascular diseases, mental and substance use disorders, neurological conditions, and musculoskeletal diseases compared to a situation with increased health care spending and slow adoption. The percentage reduction is shown in Table 1. Despite the slow transformation towards a more sustainable healthcare system, even a small reduction in the burden of disease will have a big economic impact. Increased focus on preventive health care would lead to additional 1,1 billion EUR in cost savings, 10,5 billion EUR in potential health care benefits and 0,7 billion EUR in increased productivity each year.

Table 7: The reduction in DALYs when shifting from curative to preventive health care in scenario 2.

Disease	Reduction in DALYs (in percentage)
Malignant neoplasms	2 %
Cardiovascular diseases	1 %
Mental and substance use disorders	2 %
Neurological conditions	1 %
Musculoskeletal diseases	1 %

Scenario #3: A new, integrated, and sustainable healthcare system

Our findings and models show that bridging Nordic health data and a common interpretation of the legal framework will lead to a significant reduction in costs, thriving innovation ecosystems, and an increase in the quality of life across the Nordic region. Rather than focusing on curing diseases, the health ecosystems and businesses will build on technological advances and access to high-quality data, to deliver health care services directly to the inhabitants more efficiently and at a lower cost. Deep insights into contextual and longitudinal data allow for precision medicine and efficient treatment of diseases. This requires proper handling of metadata and automatic data collection throughout the health care ecosystem. The combination of contextualized and longitudinal data combined with next-generation artificial intelligence enables the development of personalized and actionable treatment plans that empowers patients and aid the decision-making processes at various levels within the care setting.

New digital technologies such as digital twins and metaverse facilitate preventive health care and improved treatments on a broad scale. Nordic individuals can use digital twins as a testbed to evaluate how new behaviors will affect their health. With this information, the transition to preventive health care becomes rapid and

65. A percentage reduction in DALYs

highly effective. Also, new market and business opportunities may arise because of access to datasets that have high predictive and prescriptive features. Through the emergence and growth of new market areas and innovations in the health care ecosystem, we retain the high employment and high productivity which characterize the Nordic region[66].

In the scenario where we reach the 2030 vision, data-driven insights give a better understanding of operational effectiveness which increases workforce utilization and planning. We rethink and reframe the workforce's needs and abilities paving the way for alternative and novel use of technology. Fueled by these insights, the Nordic region can attract and retain the necessary talent that is required to transform the current health ecosystem. The ability to test and evaluate procedures and treatments also means that in this scenario, we may raise the level of risk-taking to realize the economic benefits more rapidly. Based on this, we expect a faster growth of the digital health market resulting in the creation of jobs, an increased number of startups and scaleups, and a growing health industry.

In our models, this is estimated by greatly reducing the burden of disease for malignant neoplasm, cardiovascular diseases, mental and substance use disorders, neurological conditions, and musculoskeletal diseases permanently compared to a situation with increased health care spending and slow adoption. The percentage reduction is shown in Table 2. Such rapid and transformative rollout of data sharing initiatives as described in scenario #3 would lead to 11,1 billion EUR in cost savings, 110 billion EUR in potential health care benefits, and 7,5 billion EUR in increased productivity each year. In this scenario, increased adoption of telemedicine not only leads to a reduction in the annual cost and increased equity of health care, but also leads to other environmental and health benefits such as lower greenhouse gas and NOX emissions, and less fine particulate matter and microplastic release because of fewer travels.

Table 8: The reduction in DALYs when a new, integrated, and sustainable healthcare system is in place

Disease	Reduction in DALYs (in percentage)
Malignant neoplasms	20 %
Cardiovascular diseases	10 %
Mental and substance use disorders	20 %
Neurological conditions	15 %
Musculoskeletal diseases	10 %

In addition to the economic benefits caused by increased health outcomes, we also expect to see an expansion of the healthcare industry. The market size of the health tech industry in the Nordic region depends on the industry's ability to trigger willingness to pay. Although individuals and patients can pay for health tech services,

66. Andersen et al., *The Nordic Model. Embracing Globalization and Sharing Risks.*

we do not think the industry will capture much of the direct gain from more healthy lives, as measured by DALY in our study.

More realistically, however, the industry will find a potential high willingness to pay among public health care providers and employers. Their willingness to pay stems from the prospects of reduced costs in providing services, being able to offer better and more cost-effective treatment, and for employers to reduce sick leave and improve the productivity of workers.

These two sources of gains from vision 2030 are calculated to be between 10% to 20 % under scenario #3, depending on which disease we focus on. For illustration, if the health tech industry in the Nordic region can retrieve 10% of the gain from reduced health care costs and increased productivity by selling services and products, this will increase the health tech market's annual turnover by 3 billion euros. Note again that the economic return from this market turnover, does not add to the value, but it illustrates how important an innovative health industry will be for realizing its full potential.

5.3 Recommendations to capitalize on integrated Nordic Health data

In the coming years, the Nordics will generate exabytes of health data, which by itself may only hold little value. The key to unlocking the largest amount of value from the data requires handling, transforming, and putting the data into context, as well as adopting legislation that allows for widespread use and innovation. These changes will take time to implement, and the transition of the health care model to a more data-driven approach requires widespread involvement of ecosystem stakeholders, as well as for regulators and policymakers to better understand the economics of the new, integrated healthcare system.

While these changes will not be quick or easy, it is critical to consider the ramifications of not transitioning to a health care ecosystem where data can be shared and utilized more effectively. To summarize some of the challenges the Nordics are facing from the earlier chapters, an important starting point is the ongoing, significant demographic shift. In particular, we will see many more elderly people, who account for a disproportionate amount of the necessary health care due to chronic illnesses, and simultaneously a flatlining working age population. An example of this is that already by 2030, Sweden will have 50% more seniors over the age of 80 than in 2020, and by 2040 the increase will be nearly 90%[67]. This growth is a testament to the enormous quality of life improvements that have been made in recent decades, but it will also put significant pressure on the already strained healthcare system.

As a result of the demographic shift, there are challenges related to personnel and costs. Many care providers in the Nordics are already struggling to meet their obligations to their listed patients, and this will continue to get worse as demand increases. From a personnel perspective, this will lead to more overworked care providers who choose to leave the profession and fewer new recruits choosing to start, thereby propagating the vicious circle of reduced supply, leading to overwork,

67. Den framtida befolkningen i Sveriges län och kommuner 2021–2040 (scb.se)

reducing supply, etc. Viewed from a cost perspective, the personnel costs are roughly 50% of the health care expenditures, which makes significant salary and benefit increases to counteract poor working conditions untenable for the taxpayers. In addition, the increasing demand will require more hours of labor across the board in order to retain the expected quality of care, again further increasing costs even if the Nordic countries manage to recruit and retain enough care providers to meet the growing demand.

These facts paint a bleak picture of the future of health care in the Nordics if nothing is done, but they also serve as further motivation to take action and set us on a course where innovation serves to turn these challenges into opportunities. With this in mind, the recommended actions to take, along with the associated barriers they help to resolve (chapter 2.3), are listed below:

1. **Building the data sharing strategy and related action plan for the Nordics:** To create an environment that fosters utilization and implementation of data-driven solutions, while retaining the interoperability with other European initiatives (but not limited by them), an interlinked data sharing strategy for the Nordics needs to be developed and set in motion as an action plan. The full scope of this strategy will likely take time to develop due to its complexity, but it is important that immediate action is taken to start this process now, and that portions of the grander strategy are released as they are finalized.
    - Barrier type: Governance and leadership model

2. **Communicating the strategy and the potential benefits:** Communication is an essential part in succeeding with the overarching strategy, and a wide audience needs to be reached, including health care professionals and citizens, in order to show the expected benefits and also establish trust in the sharing and utilization of data for health purposes.
    - Barrier type: Trust and transparency & Governance and leadership model

3. **Founding of clear leadership in each country:** In order to align stakeholders and secure long-term traction, each country needs a form of leadership (a national body) that can be looked to for guidance by country stakeholders who are deciding what their roles should be and how they can best support the Nordic and country goals. This national body would also take care of the local data access control layer according to the local legal environment. Tied to this recommendation is the availability of targeted ecosystem financing that supports relevant initiatives, thereby enhancing the pace of innovation in line with the overarching goals and strategies. The current country-based financing programs should be extended to meet the needs of Nordic level development.
    - Barrier type: Governance and leadership model

4. **Finding and succeeding with easy wins:** Quick and easy wins should be utilized to concretely showcase the potential behind data sharing and the implemented solutions, thereby building the necessary momentum to reach the established long-term vision and strategy. Among the many examples of quick wins is utilizing telemedicine to treat wounds and skin infections. Alternatively, improvements can be focused on one of the costliest disease groups and then the knowledge gained can be transferred to other illnesses.
   This recommendation can be supported by small companies and organizations who are allowed to take reasonable risks, thereby pushing the boundaries and driving innovation forward more rapidly than larger actors. In addition, there could be specific financing for these agile vendors to showcase innovation with a low threshold. Special pilot laws might also be used in the early adopter projects.
   - Barrier type: Governance and leadership model & Legal

5. **Establishing national Nordic data sharing bodies:** To enable a trusted and secure exchange of data across the Nordics, national data sharing bodies can be established and charged with important duties. This can include setting up a network of connected data repositories (local, regional, and national) where data has been separated from applications to open platforms, enabling its use for primary and secondary purposes in a trusted and secure way. Considering the importance of data sharing bodies within the ecosystem, it may be preferable to place responsibility and ownership of its development and continual operation under the purview of the national governments.
   - Barrier type: Data and infrastructure

6. **Upkeeping an overview of the ecosystem:** By accurately and simply visualizing the ecosystem, stakeholders can see their role within it, understand their relevant collaboration partners, and pursue new initiatives in cooperative partnerships. It could also be beneficial for the ecosystem to be augmented to better support public-private collaboration, such as through clear ways to share revenues to attract the best talent. Tied to this recommendation is also the simplification of joint investments between public and private actors, enabling collaboration on initiatives that require specialty knowledge.
   - Barrier type: Governance and leadership model

7. **Harmonizing Nordic legislations:** In the longer run it is recommended to harmonize the various Nordic legislations regarding primary and secondary use and sharing of health care data. This is also possible to achieve with upcoming EU legislation, but the Nordics should harmonize their own legislation without waiting for the EU, thereby being a leader in the larger region. Succeeding with harmonization will further enable innovation and cooperation, and, if necessary, the transition can be facilitated by the Nordic data sharing body. For additional information about this recommendation, a more detailed mapping of the legal overview of health data sharing has been published by Nordic Innovation.
   - Barrier type: Legal

8. **Agreements on open standards and terminologies:** To build and fully utilize the connected network of data repositories, the data needs to be simple to transmit and easy to understand. This action is vendor-driven and demands collaboration around possible localization of the chosen open standards on the Nordic level.
    - Barrier type: Data and infrastructure

9. **Launching Nordic initiatives for networked expertise:** To access the disperse array of subspecialties that are required to make full use of data and data sharing, the Nordics would benefit from initiatives supporting networked expertise. This would include the establishing of a collaborative space with appropriate tools for data sharing, but also communication between professionals. In addition, eMarketplace type of set-ups would help freelancers to offer their subspecialty knowledge for the whole Nordic area, supporting both health care delivery entities and citizens themselves. Together, these initiatives, which can be supported either by public or private financing, would enable more effective resource utilization by lowing geographic barriers through cross-border collaboration, thereby making it easier to find the right types of competencies.
    - Barrier type: Governance and leadership model & Trust and transparency

10. **Aligning health care IT and digital health vendors behind an open ecosystem:** Vendors will need to have capabilities and resources for transforming their legacy systems to meet the new requirements for inter- and even intra-operability. This is particularly relevant for the large vendors who may use their size to block or slow down necessary improvements due to the associated costs and impact on the companies' market positions.
    As of today the data is still in vendor-specific formats in various silos and does not follow open standards. And since data migration costs are high when changing systems and the vendors can restrict the amount of data to be exchanged, it therefore becomes important for the future ownership of data to be within the health care delivery entities and the citizens themselves.
    - Barrier type: Data and infrastructure

Methodology

Literature review

A literature review has been performed to set a baseline of qualitative information for the report. In addition, the gathered information has been used to compare with expert interviews to provide a comprehensive and balanced analysis.

Interview method

A total of 47 interviews have been conducted, with interviewees from both public and private sectors as well as academia. The vast majority interviewees are based in the Nordics but additional interviews outside of the region were also performed to create a broader base of perspectives.

The interviews were conducted in a semi-structured qualitative style, and the resulting information was reviewed and analyzed in conjunction with other interviews as well as the information gathered during the literature reviews.

Economic modelling and projections of health expenditures

We have analyzed data from OECD, WHO, World Bank, Eurostat, and the individual countries' statistical databases to estimate the potential economic benefits that data sharing between the Nordic countries may have.

Assumptions and further research

Developing a business case on the potential behind the utilization and sharing of healthcare data is a complex task that requires simplifications in the form of assumptions, as well as various decisions to be made in order to set the boundaries for the report. In addition, the wide scope of the business case has required us to keep to a high-level perspective, meaning that plenty of topics could be explored in more detail.

In order to be transparent about these assumptions, decisions, and topics to explore further, this section will be used to describe the most important factors that have the potential to significantly influence the results in the report, as well as to lay out examples of topics for future research.

Assumptions behind the economic calculations

The baseline forecast towards 2040 is based on estimated population growth within different age groups which is generally well-established. The burden of disease per capita within each age group and each type of disease is more uncertain. In the baseline, these are kept constant in order to establish a reference for different scenarios.

The economic gains are calculated as deviation from the baseline, and as such are less vulnerable to uncertainty about the exact level of the baseline development.

Total costs are allocated in the standardized measure of burden of diseases, productivity loss and health care costs. Such figures are complex to derive and under continuous review and investigation among public health researchers and governments. In our model, we benefitted from the results from a detailed study in Norway, with calculation of the main costs factors associated with different diseases. This study is used to calibrate the same main cost drivers in all Nordic countries. Of course, this adds uncertainty to the exact figures, but given aggregate nature of our scenarios, this is an acceptable degree of uncertainty. We have checked robustness for this calibration, by using a recent study of cancer costs in all many European countries. According to this study, the ratio between direct treatment costs and productivity does not show significant variation across Nordic countries.

We have assumed that people of age 70 and older are outside the labor force, and hence do not generate direct productivity loss from diseases. Towards 2040, older people may stay longer in the labor force. Although this represents a productivity gain for society, it will add to the costs of illnesses (productivity loss). It is extremely hard to predict labor market participation for the elderly under different scenarios and we have therefor chosen to keep this constant.

In the different scenarios, we have focused on the five disease areas with the largest contribution to the overall disease burden. The healthcare sector will benefit from

data driven health care for most other illnesses, but given the weight of the five costliest ones, this will not have a significant impact on forecasted aggregate benefits. In addition, in our research and interviews with stakeholders and experts, the five diseases often appeared as target areas.

The estimated economic benefits calculated in this report are based on country-level data. At this phase it is difficult to estimate the additional benefits gained from cross-border sharing and utilization of health-related data. Even nation-wide data sharing in the Nordic countries is still in an evolutionary process. The current document-based data sharing is limited and cannot be the source for AI and clinical decision support. Most of the barriers for data sharing need to be overcome locally, regionally, and nationally before a more extensive reach out to other countries. On the other hand, it will be a lot easier to accomplish cross-border data exchange when the basics are right in individual countries. We believe that Nordic level data sharing would bring even more economic benefits compared to our current calculations based on country-specific data.

Our study was not a cost-benefit analysis, as the costs related to our recommendations are difficult or almost impossible to estimate. Harmonization of the local legislations on the Nordic level would decrease some of the costs needed for the realization of the integrated Nordic healthcare region. Harmonization would enable cross-border data sharing with less complexity in building the local country-level access control layers. The possible costs range from data conversions and localization of open standards up to setting up national data sharing bodies that collaborate and set the governance framework for cross-border data exchange. Some of the costs will be taken by the vendor community, as they see open standards as a tool for internationalization also beyond the Nordics.

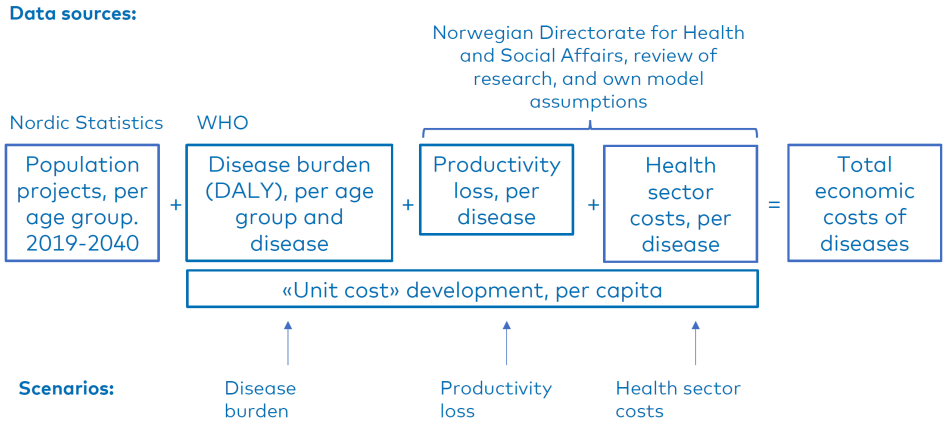
There are clear benefits in building Nordic-level data sharing instead of national-level data sharing only. There are close relationships between the Nordic countries resulting in strong mobility of citizens across borders for work and pleasure, as well as relocation of inhabitants. The economic benefits of cross-border data sharing can be derived from a variety of different things. Nordic countries are relatively small countries, and it may be more economical to share resources on the Nordic level. These resources include expensive specialized diagnostic and treatment equipment, technology, and services as well as expertise related to rare diseases. The lack of human resources related to major diseases can also be supported by common shared resource pools. The EU-level cross-border healthcare directive enables utilization of healthcare services across the country borders in the EU. Data sharing across borders is a pre-requisite in forming a larger healthcare market. Data must follow the patient wherever the care is given, and networked professionals need to have access to the data in order to give consultations or services in a remote manner. Data sharing has to happen seamlessly, but in a trusted and secure way. With active Nordic-level capacity management we can utilize both physical equipment, but also human resources in a more economical way. One example is teleradiology or radiological eMarketplaces where radiologists can log in and reporting tasks are allocated according to availability, subspecialty and language skills. This kind of a brokering service can also guarantee certain response times for the reports and hence increase the quality of diagnostic radiology. A more integrated Nordic healthcare market provides an opportunity to establish various professional networks for sharing knowledge and centers that attract a highly skilled and dedicated workforce. These networks can offer services to healthcare delivery

entities, but also directly to Nordic citizens if they want to ask a second opinion and reach out to another professional, for instance.

The Nordic trend is towards open ecosystems, where open standards are used, and data is separated from applications and stored on an open platform. Applications can understand each other's data. This development will enable data sharing on all levels – including cross-border. This trend will accelerate developing of applications which fit to various open ecosystems in all Nordic countries. This is extremely beneficial for small companies that want to grow their business beyond their local countries. The applications can fit to any Nordic ecosystem if there is a common agreement on the open standards and possible localizations on the Nordic-level. It is also easier to develop applications and services if there is an access to high quality datasets over larger geographic areas – not only in a specific region or a country. This may result in better and more cost-effective treatment methods.

Nordic-level data sharing can also be a precaution for future major unexpected diseases such as Covid-19 or large flows of refugees. Cross-border access to Covid-19 related data could have helped to understand the disease better and earlier resulting in more efficient treatment and prevention as well as better outcomes and cost savings. The German Codex platform is a good example of this kind of national Covid-19 data sharing platforms. All Covid-19 related data was stored there and shared for research across the German states. As stated earlier, refugees are often in a weaker position when equitable access is discussed. Cross-border data sharing could result in more efficient prevention programs taking the minorities into account.

High level summary of economic model including components illustrated below.



Further research

This study was about health data. The trend is, however, to move towards integrated care, where health and social care are integrated seamlessly on the individual and population level. Finland is a forerunner for integrated care in the Nordics: from the first of January 2023 onwards the Finnish wellbeing services counties will be responsible for both social and health care services for their population. The data has to follow the citizen seamlessly across all social and health care delivery entities. It is already possible to integrate social and health care data with the patient's informed consent in come Finnish counties. The legacy systems are integrated to a sharing platform and the data is harmonized in order to create overviews of the patient status - consisting of both social and health information.

To complement this report, further research is recommended to study the effect of social care related data sharing to the economic calculations. Social care related data sharing may have remarkable effects especially in the long-term care of the major diseases amongst the elderly population. Adding social care to the calculations will increase economic benefits, as the population is aging and needs support at home and in care centers.

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About this publication

Business Case for sharing of Nordic health data – Assessing the economic effects of a realized program vision

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