

Health data sharing

– a solution to Nordic
health care challenges

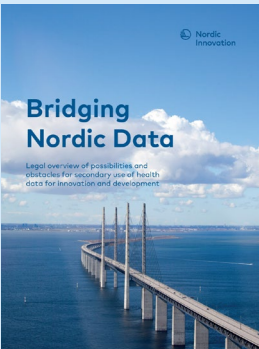


Sharing of health data in the Nordics

Nordic Innovation's *Health, Demography and Quality of Life* program addresses the challenges the health care systems in the Nordics are facing. Our welfare system is at risk of breaking down because of a growing proportion of elderly people, increasing amounts of chronic illnesses and lifestyle diseases. There is an urgent need for change, and Nordic cooperation is a key factor. Sharing of health data could build our position as global welfare ideals, and to reach the vision that lays the foundation for this program:

VISION: *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.*

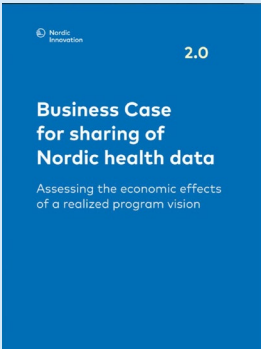
Highlights from three reports from Nordic Innovation:



1 Bridging Nordic Data



2 Health Use Case



3 Business Case

The Nordics as global frontrunners in digital health

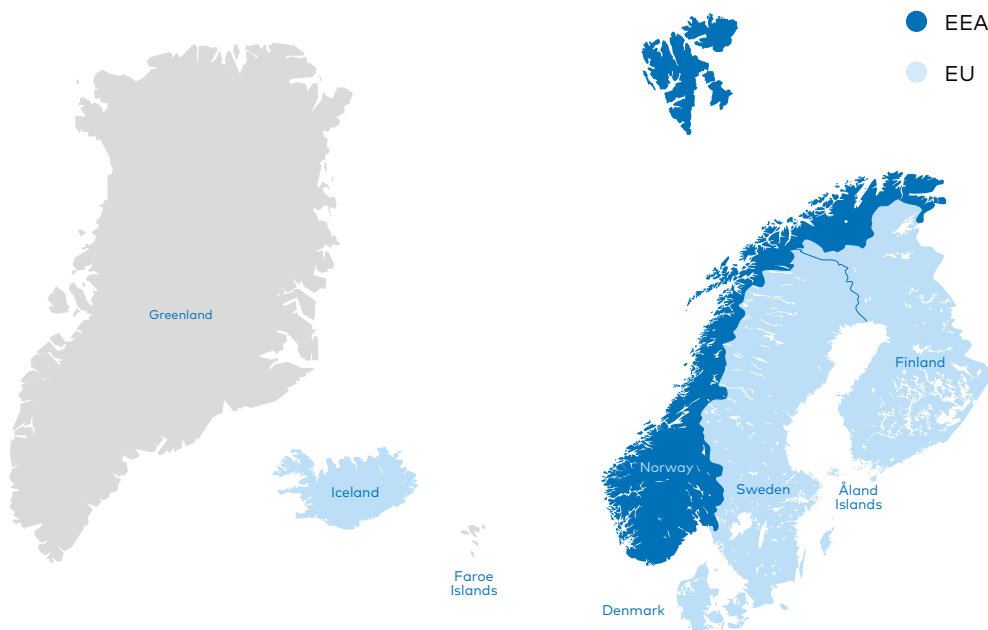
The Nordic citizens are early adopters of digital solutions, and the Nordic countries are among the world's most developed nations regarding health data and data infrastructure. The countries can in many ways be considered as frontrunners in digital health, moving towards a more open digital health ecosystem. This requires new ways of sharing data safely and effectively.



1 Bridging Nordic Data

Legal barriers and possibilities for health data sharing

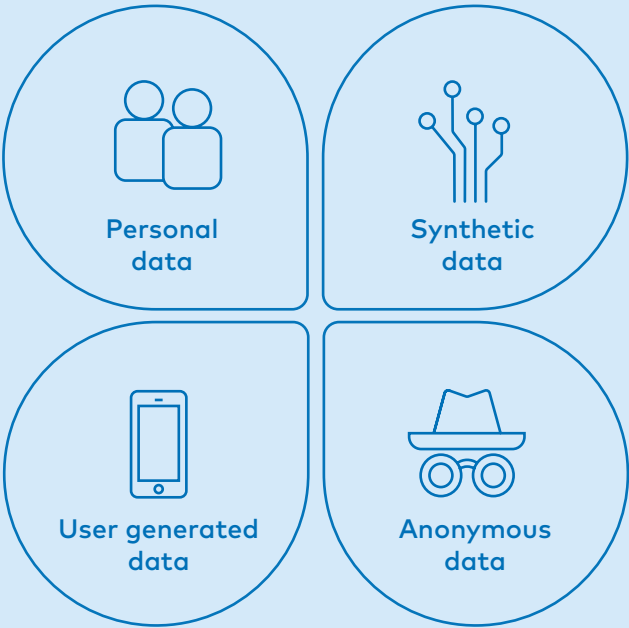
Health data is regulated by both EU regulations as the General Data Protection Regulation (GDPR), and national regulations. Åland and the EFTA countries Iceland and Norway have adopted the GDPR. While GDPR is not directly applicable in Greenland and the Faroe Islands, which are both outside the EEA and not part of the EFTA, their data privacy legislation is based on the GDPR. Therefore, utilization of health data in and from the Nordic region requires knowledge of the GDPR.



*GDPR is applicable in both EU and EFTA countries in the Nordics, except Greenland and Faraoe Islands.

Health data is necessary to service a patient for healthcare purposes, and considered a special category of personal data under GDPR. Innovation and development are considered secondary use purposes. Access to health data for secondary use varies in the Nordic countries.

Health data appears in various forms:



Overview of the legislation for data sharing in the Nordics

There are both possibilities and barriers for health data sharing in the Nordics. However, existing legislation is not aligned with national strategies and the use of the legislation is unclear. Finland is one of the pioneers in Europe with a specific legislation regarding secondary use of health data.

PRIMARY USE

Service to a patient for the original healthcare purpose (e.g. treatment)

Service to a client for the original social care purpose (e.g. welfare, benefits)

SECONDARY USE

	Research
	Statistics
	Quality assurance and development
	Education
	Health analysis
	Planning
	Administration planning monitoring evaluation and supervision of the healthcare
	Knowledge management
	Clinical trials
	Epidemiological studies
	Development and innovation RDI
	Authorities, guidance, enforcement, planning and reporting duties

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It is worth noting that EU in 2020 started working on the European Health Data Space, a legal, governance, data quality, and operability framework.

Summary of barriers and possibilities in the existing legislation

MINUS

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Lack of innovation specific regulation (except Finland)

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Decentralized information structures (no full overview or access)

÷

Lack of standardization and interoperability with different technical systems and practises (difficult to identify and collect data)

PLUS

+

Few limitations to transfer of data across national borders

+

Legal bases for health data use can be regulated by law (Finland)

+

GDPR applies in the Nordics except Faroe Islands and Greenland

WHAT NEXT?

1) specific legislation addressing innovation and development

2) centralized systems and standardized procedures

2 Health Use Case

The ideal future of Nordic healthcare

Research and simulations with participants and experts from across the entire Nordic region, show that sharing of health data could contribute directly to an ideal future for Nordic healthcare.



Seven key themes the Nordics need to work on to develop a sustainable health ecosystem:

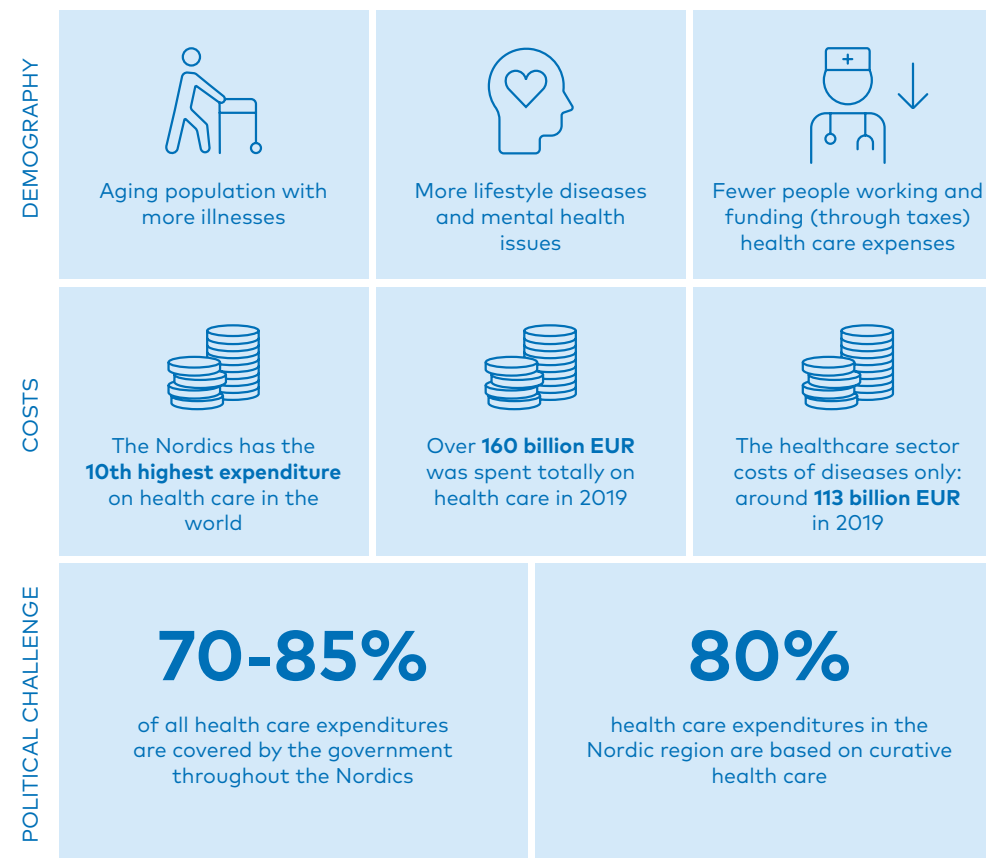
- ✗ Improved Interoperability
- ✗ Mental Health and Well-Being
- ✗ Personalised Treatments
- ✗ Telehealth and Decentralised Patient Monitoring
- ✗ Decentralised Clinical Trials
- ✗ Sustainability Data Measurement and Transparency
- ✗ Transition to Preventive Care

3 Business Case

A Nordic welfare system at risk versus billions of euros saved

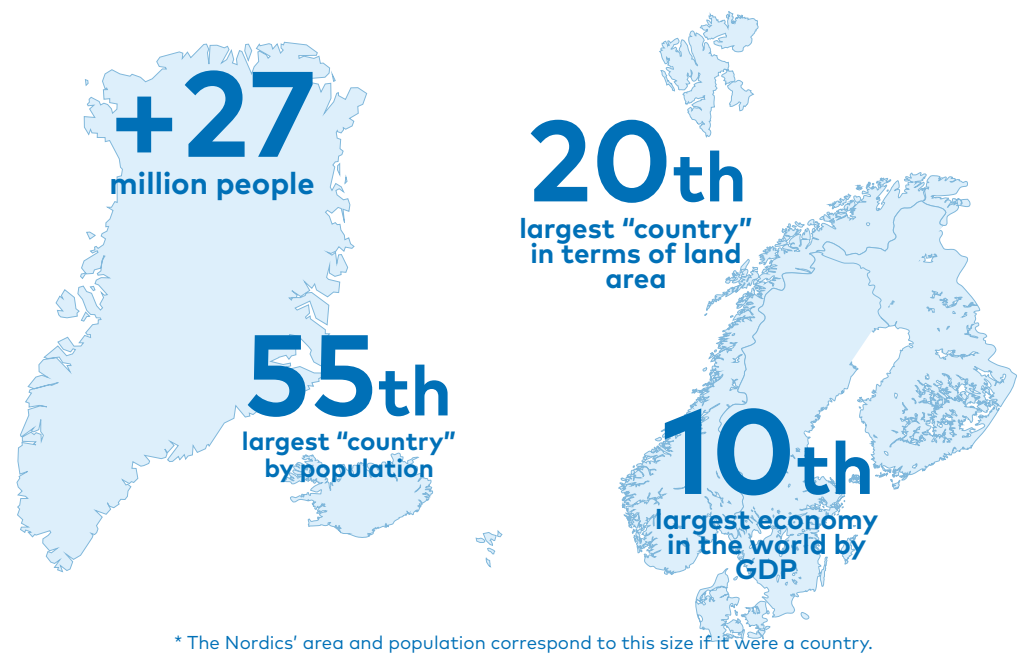
Realizing the economic benefits of sharing Nordic health data will require substantial effort and it is a matter of urgency. Even though the Vision 2030 is fulfilled, the economic benefits may not materialize until 2040.

The existing healthcare situation is not sustainable:



Sharing health data is a key factor for change going forward

Scale: The Nordics is a region of size in the global economy and effective sharing of health data has the potential to realize value in many areas.

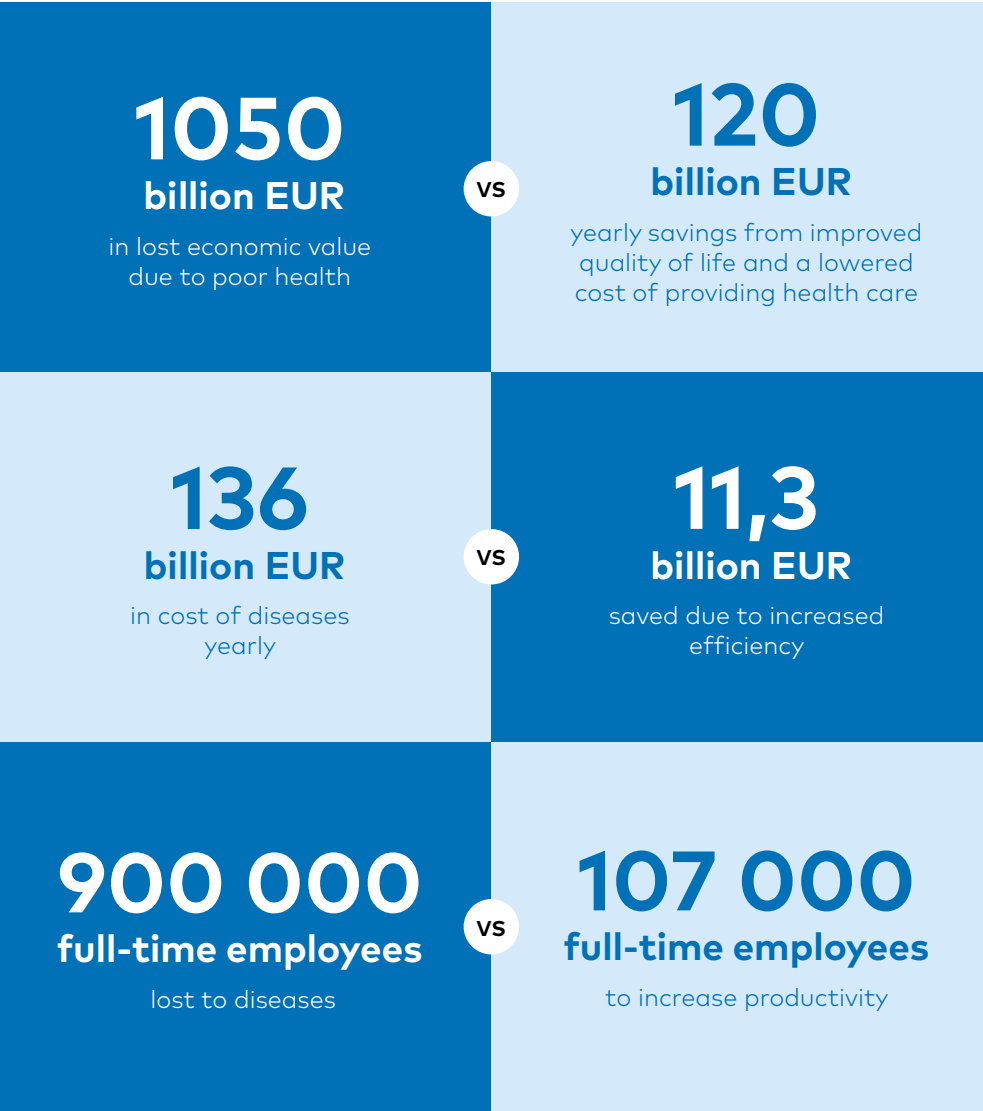


Outcomes: Better use of health data means better treatment, more preventive health care, and increased innovation.



Considerable economic opportunities in sharing health data across the Nordics

Estimated economic worst-case scenarios VERSUS savings in 2040:



Want to read more?

The three reports are connected to Nordic Innovations two programs focused on health. For more information follow the links or scan the QR-codes below.

Health, Demography and Quality of Life:

nordicinnovation.org/health



Life Science and Health Tech:

nordicinnovation.org/programs/life-science-and-health-tech

