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Value from Nordic health data – VALO project

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Contents

Executive summary

This report examines the current state, challenges, and opportunities for enhancing Nordic cooperation in the secondary use of health data. The Nordic countries possess a unique advantage in this domain, sharing many strengths that position them well for collaboration, such as: comprehensive population-based health registries with data collected over long periods, unique personal identification numbers (PINs) enabling data linkage, high levels of public trust and willingness to participate in research, and similar healthcare systems with shared values around data protection.

Despite these advantages, the rich datasets of the Nordic countries are currently underutilised for research, healthcare improvements, and innovation. Several challenges hinder fuller cooperation, including legal and regulatory fragmentation across countries, complex and time-consuming data access procedures, lack of standardisation in data formats and systems, ethical concerns around consent and privacy protection, and institutional barriers to data sharing.

However, significant opportunities exist to strengthen the Nordics' position as leaders in health data utilisation, particularly in light of the forthcoming European Health Data Space (EHDS). These include supporting use of secure federated solutions for both national and cross-border data processing, establishing common ethical frameworks and governance models, developing shared metadata standards according to the FAIR principles, building competencies in AI and data science, and fostering public-private partnerships for innovation.

Realising this potential will require coordinated policy efforts across the Nordic region. Key actions include harmonising relevant legislation and regulations, streamlining data access procedures, and promoting skills development and knowledge sharing.

By addressing these challenges and capitalising on their unique strengths, the Nordic countries can unlock the full value of their collective health data resources. This would significantly advance medical research, improve healthcare delivery, drive innovation, and ultimately lead to better health outcomes across the region. The implementation of these strategies has the potential to not only maintain but significantly strengthen the Nordic countries' position as global leaders in the secondary use of health data, setting a model for international collaboration in this important field.

1 Introduction

The purpose of this report is to review and analyse the literature on secondary use of health data in Nordic cooperation, with the aim of identifying:

1. Potential gaps in knowledge and infrastructure, including technical, semantic, legal, and governance aspects.
2. Strengths and challenges that are common for the Nordic countries.
3. Unique strengths and/or weaknesses of each Nordic country.
4. Complementary societal factors that influence health data cooperation.
5. Commonalities and dissimilarities that affect Nordic cooperation.

This report aims to provide a comprehensive analysis of the current state of Nordic cooperation in the secondary use of health data, with a specific focus on research, innovation, and policymaking. Our scope encompasses the five Nordic countries: Denmark, Finland, Iceland, Norway, and Sweden. We examine the existing health data infrastructure and collaborative initiatives across these nations. Health data infrastructure refers to the comprehensive system that enables secure storage, sharing, access, and analysis of health-related data across organisations and countries. Additionally, health data infrastructure incorporates technical, legal, semantic, and organisational components to facilitate research and innovation while protecting privacy. (1) The report's primary objective is to identify the challenges as well as the opportunities in enhancing Nordic cooperation for secondary use of health data, particularly in light of the forthcoming European Health Data Space (EHDS). By analysing the current landscape, we aim to offer insights which will serve as a basis for future recommendations to strengthen the Nordic region's forerunner position in the utilisation of health data. While we touch upon primary use of health data where relevant, the main focus remains on secondary use applications.

While we acknowledge the essential role of patient engagement, perspectives, and diverse patient associations as drivers for change in healthcare innovation and data utilisation, these aspects remain outside the scope of this report. Similarly, we recognise the contribution of innovative companies in increasing quality, efficiency, and creating growth. However, these perspectives, while valuable, are not the primary focus of this analysis.

Our goal is to provide a focused examination of the current state, challenges, and opportunities in Nordic cooperation for secondary use of health data, with the aim of informing future initiatives and policies in this rapidly evolving field.

1.1 General Data Protection Regulation (GDPR)

Health data is utilised for research, development and innovation. Health data is considered sensitive personal data and is strictly regulated within each Nordic country, as well as across the European region. (2) To address the need for consistent data protection across Europe, the General Data Protection Regulation (GDPR) was introduced. The GDPR was approved by the European Parliament and entered into force in 2016, with a two-year transition period.

As European Union (EU) members, Denmark, Finland, and Sweden were required to apply the GDPR from May 25, 2018. (2–6) For Iceland and Norway, being a part of the European Economic Area (EEA) but not the EU, the process was slightly different. The GDPR was incorporated into the EEA Agreement on July 6, 2018, after which it became applicable in these countries as well. (2) To implement and supplement the GDPR, each Nordic country enacted or updated national legislation in 2018. Denmark and Sweden introduced new Data Protection Acts to complement the GDPR, effective from May 25, 2018. Finland enacted its Data Protection Act slightly later, on December 5, 2018. (2) Norway incorporated the GDPR through the Norwegian Personal Data Act of June 15, 2018, (7) and Iceland through its national data protection law of July 15, 2018 to align with the GDPR. (8) These national laws serve to specify and supplement the GDPR's provisions within each country's legal framework. They often provide additional conditions or safeguards for processing sensitive data like health information, which is particularly relevant given the Nordic countries' extensive health data resources. (3) The GDPR aims to ensure consistent data protection across the EU countries by removing discrepancies among EU member states. It seeks to protect the fundamental rights and freedoms of individuals by establishing rules for processing personal data. With this, the EU aims to prevent unauthorised access and processing of personal data, enhancing trust in the digital environment. (6)

The GDPR presents several limitations regarding the secondary use of health data. The GDPR lacks a comprehensive framework specifically tailored to health data. (9) Its emphasis on purpose limitation and data minimisation (i.e. to minimise privacy leakage) can create barriers for research and innovation, where health data may need to be used for purposes not initially specified. (6,9) Additionally, the varying implementation of GDPR across EU and EEA countries has complicated access to electronic health data for research, innovation and policymaking at both national and cross-border level. This poses challenges for pan-Nordic collaboration, requiring legal expertise in multiple countries. (9,10) The regulation's strict consent requirements can also hinder the use of historical data or large-scale data analysis where obtaining individual consent may be impractical. (9,10) Furthermore, GDPR doesn't provide clear guidelines on anonymisation or pseudonymisation standards for health data, which is crucial for secondary use. (6,9) GDPR allows for processing of health data promoting public health, but it does not offer a detailed framework for balancing individual privacy rights with the potential societal benefits of health data research. (9)

The interpretation and implementation of GDPR criteria can vary between data controllers and countries, leading to inconsistencies in data access procedures. (9,10) This has resulted in what some researchers describe as an "extra burden" of compliance, with the prospect of large institutional fines for non-compliance. (10,11) Finally, the GDPR's requirements for data protection impact assessments and the involvement of data protection officers can add complexity and potential delays to collaborative projects. (10)

These limitations have contributed to uncertainties and inconsistencies in how health data can be used for secondary purposes across the EU, possibly hampering the potential benefits of secondary health data use, such as improved health research, innovation, policymaking, better health outcomes, and engagement for patients.

1.2 European Health Data Space (EHDS)

The EU is developing the European Health Data Space (EHDS) to address cross-border data use barriers in healthcare, creating a cohesive and interoperable framework for efficient and secure use of health data across the EU, for both primary and secondary purposes. (12) EHDS is the first European regulation to propose the establishment of a domain-specific common European data space. It will address challenges in electronic health data access and sharing and be an integral part of building a European Health Union. (9,13) The EHDS will make it possible for researchers, innovators, and policy makers to use electronic health data in a trusted and secure way that preserves privacy. One general objective of the EHDS is to ensure that individuals in the EU countries have better control over their electronic health data. (1,9,12) In addition, the EHDS provides a legal framework for a trusted EU and Member State governance mechanism and specification for secure processing environments (SPEs). This will allow researchers, innovators, policymakers and regulators at EU and Member State levels to access relevant electronic health data to improve diagnostic accuracy, treatment and well-being of natural persons, leading to more informed policies. By harmonising rules, it will also enhance the efficiency of healthcare systems. (9)

The EHDS regulation (9,13) addresses both primary use and secondary use of health data, recognising their distinct yet interconnected roles in improving healthcare and driving innovation. Primary use of health data refers to its direct application in individual patient care. This includes data stored in electronic health records, patient summaries, ePrescriptions, and other medical documents used to support or provide healthcare delivery to individuals from which the data stem. Regarding primary use of health data, the EHDS aims to empower citizens by giving them greater control over their data and ensuring it can follow them across borders. This improves the continuity of care and supports free movement within the EU, as well as promoting interoperability to ensure seamless data sharing between healthcare providers.

Secondary use of health data involves the broader application of health data beyond direct patient care. This encompasses using individual-level or aggregated datasets for research, innovation, policymaking, and regulatory activities. (13) The EHDS regulation outlines specific purposes for secondary use of health data, including activities for public health and occupational health, supporting regulatory tasks. It also includes producing health-related statistics, education in healthcare sectors, scientific research, development and innovation of health products and services, training and evaluation of AI algorithms in healthcare, and providing personalised healthcare based on data from other individuals. (9) The scope of secondary use of data is much wider as compared to primary use of data. It includes not just electronic health records but also claims data, administrative healthcare registries, disease registries, genetic information, and relevant social data. The EHDS seeks to create a consistent and efficient framework for secondary use by facilitating access to valuable health data for researchers, innovators, and policymakers while maintaining strong data protection safeguards. It proposes establishment of a network of national Health Data Access Bodies (HDABs) and development of an infrastructure for secure data sharing and processing. (13) The utilisation of secondary use of data offers advantages like availability, time and cost savings, large sample sizes, reduced biases, and opportunities for record linkage. However,

it has disadvantages, including lack of control over data quality, difficulty in validation, incomplete coverage, accessibility and cost issues, and missing information on potential confounding variables. While secondary use of data enhances statistical power and generalisability, especially in epidemiological research, researchers must consider its limitations in data validity, reliability, and completeness. (14)

By addressing both primary and secondary use of health data, the EHDS aims to unlock the full potential of health data in Europe. It seeks to improve healthcare delivery through better primary use of data, while also fostering innovation and supporting evidence-based policy making through enhanced secondary use. This dual approach recognises that while protecting individual privacy and control over personal health data is paramount, there is also immense societal and economic value in aggregating and analysing health data at a population level. (13) The EHDS thus represents a comprehensive attempt to balance these different uses of health data, aiming to create a framework that protects individual rights while also enabling the broader societal and economic benefits that can come from responsible data sharing and analyses of data in the health sector.

Specifically, regarding the secondary use of health data, the EHDS aims to strengthen research, innovation and policymaking across Europe by providing a consistent, trustworthy, and efficient system for reusing health data. (9,15)

1.3 Value from Nordic Health Data (VALO)

The Nordic Council of Ministers supports the VALO (Value from Nordic Health Data) project to establish common Nordic principles for implementing the EHDS regulation and to explore ways to maximise the benefits of Nordic cooperation in research, development, and innovation. The project aims to reinforce the Nordic countries' leadership and competitiveness in this field. The VALO project will enhance cross-border Nordic cooperation in the secondary use of health data and jointly prepare the Nordic countries for implementing the EHDS legislation. (16)

Building on this regional collaboration, the Baltic countries have recently joined the VALO project as observers. Through their participation in a competence forum, they will contribute to joint preparations for implementing the EHDS legislation, further strengthening the regional approach to health data management.

This initiative will allow the Nordic countries to share experiences and advice, leading to improved research, development, and innovation opportunities. As a result, the Nordic region will move towards becoming the most integrated area in the world, serving as a model for others and providing better healthcare, treatments and medications for its citizens. The Nordic countries excel in the quality and secure use of their social and health data registries, which have been compiled over many years. The use of personal identifiers facilitates the linking of data from various registries. Additionally, the Nordic countries were early adopters of electronic health record systems. (2) By sharing best practices, standardising methodologies, leveraging digital tools, and addressing common challenges collaboratively, Nordic countries can enhance the quality and comprehensiveness of strategies within Nordic collaborative projects. (17)

2 The Nordic countries

The Nordic countries, home to over 27 million inhabitants, (18) have long been recognised for their shared commitment to social welfare, equality and sustainability. (17,19,20) This dedication extends to their healthcare systems, which are for the most part characterised by welfare state, with tax-funded healthcare and a low out-of-pocket spending. (2,10,19) These similarities have enabled the creation of comprehensive population-wide health data collection systems that yield comparable datasets across national borders.

2.1 Healthcare systems in the Nordic countries

Denmark's healthcare system is primarily and publicly funded and organised through state, regions and municipalities. Private operators contribute alongside public institutions to maintain and develop the system. (2,21) Denmark has advanced digital infrastructure, including electronic medical records (e-journals) accessible through www.sundhed.dk and a Joint Medicine Card system containing medication information. (2) The country maintains several registries and biobanks for health data storage, both public and private. Denmark has well-established digitalised registries practices with extensive nationwide data coverage. (2,21)

Finland's healthcare system is constitutionally mandated and, after the recent launch of the national service reform implementation (22), based on social welfare and healthcare services from 21 wellbeing services counties with state funding. The system features both public and private service providers operating in parallel, with multiple governmental agencies and organisations participating. Finland has comprehensive high-quality information resources and advanced digital services provision, supported through the extensive Kanta services system. (23) Additionally, the Finnish Institute for Health and Welfare (THL) serves as a statistical authority and produces statistics in the field of social welfare and healthcare to support decision-making, development, and research. THL also maintains and develops a large selection of national-level registers and population surveys, making part of their content available as open data or providing them for research, development and innovation (RDI) activities, either directly or through Findata's application process (24). Finland stands out for having established the Act on the Secondary Use of Health and Social Data, (25) and Findata in 2019 as a centralised access point for health and social data for secondary use, making Finland the most advanced Nordic country in terms of health data management and access. (2)

Iceland's healthcare system is mostly publicly funded, with the state guaranteeing necessary health services regardless of individual financial standing. The Minister of Health directs health affairs, with healthcare institutions and other bodies under the Ministry playing vital roles. Private providers operate alongside the public sector. Iceland has comprehensive information resources with electronic records and uses interconnected health information systems. The country has succeeded in implementing a nationwide uniform medical record system, and health data exists for most citizens throughout their lifetime due to low emigration rates. (2) Iceland has numerous nationwide health registries, most of which are managed under the responsibility of the Directorate of Health.

Norway's healthcare system features state responsibility for overall provision, with municipalities responsible for primary health/social care and specialist care provided through the Ministry of Healthcare Services via hospitals. The system includes several governmental agencies/organisations in the public sector, complemented by private health service providers. All providers must keep electronic medical records. Norway maintains several significant sources of health data, including biobanks, registries, and national health surveys. The system emphasises both state oversight and local delivery of services. (2)

Sweden's healthcare system operates on three administrative levels: government, 21 regional bodies, and 290 municipalities. The regional bodies are primarily responsible for organising and funding healthcare, while municipalities handle elderly and disabled care. The system is mainly financed by regional and municipality taxes with government subsidies. The Ministry of Health and Social Affairs establishes principles and guidelines. Sweden has a long tradition of digital health data documentation and uses both primary information sources (medical records) and secondary sources (registries, biobanks). The system balances central oversight with regional autonomy in healthcare delivery. (2)

2.2 Common themes across Nordic healthcare systems

The Nordic healthcare systems share fundamental characteristics that reflect their common societal values and approaches to healthcare delivery, overview provided in Table 1. These systems are predominantly publicly funded through state, regional, and municipal sources, supporting the core principle of universal access to healthcare regardless of individual financial standing. (2)

The Nordic countries also share a high level of digitalisation in their healthcare systems and have a similar focus on innovation in healthcare systems. They all rely heavily on electronic health records and have made significant strides towards implementation of integrated digital health infrastructure, allowing increased data accessibility. Moreover, the Nordics are actively working towards incorporating AI and automation in healthcare processes, as well as initiatives to improve data standardisation across different health registries and systems. (20,26,27) The shared commitment to technological advancement, combined with similar system structures, facilitate cross-border collaboration and knowledge sharing. This common foundation positions the Nordic region as a potential leader in healthcare innovation, especially in health data utilisation and digital healthcare solutions. (2)

All the Nordic countries demonstrate a strong commitment to leveraging health data for innovation and research and share significant similarities in their approach to health data management and access. Across these nations, health data is considered highly sensitive, and data minimisation is a key principle, entailing that data collected must be sufficient, relevant, and restricted to what is essential for its intended purpose, and researchers must provide justification for their data requests. (2,28) Additionally, access to health data is strictly regulated. This stems from a shared commitment to protect individual privacy and maintain professional secrecy in healthcare. (2,10) This is supported by advanced legal frameworks that aims to balance data protection with the need for scientific research and healthcare improvement. (2,10)

A key common denominator, central to the Nordic healthcare systems, is the use of unique personal identity numbers (PIN) assigned to each resident at birth or upon immigration. The PIN is unique to every individual, and it remains with them throughout their life (except in rare cases, e.g. gender reassignment). Typically, PINs comprise 10 or 11 digits, with the first six digits representing the date of birth. (19,29–35) The PINs are primarily utilised for administrative purposes (i.e. healthcare systems, schools, banks, etc.), and were originally introduced to manage and monitor tax payments. Although the PINs were implemented at various times across the region (1947 in Sweden, 1954 in Iceland [1987 in its current form], 1964 in Finland and Norway, 1968 in Denmark) (29–35) they are indispensable tools as key identifiers across all registries and databases, making individual-level linking within each country simple, precise and clear. Therefore, they are crucial for utilising registry data to its full potential. (10,19,36)

A distinctive feature of Nordic societies is the high level of trust that citizens place in their institutions and their strong willingness to engage in research. This is evident in the healthcare sector, where more than 73% of residents in Nordic countries within the EU are open to sharing personal information for advancing healthcare and research, compared to less than 30% in some other European nations. (36–38)

Lastly, there is a shared recognition across the Nordic region of the immense value of collaborative health research utilising the extensive health data resources available. All these countries are involved in various Nordic and international research initiatives, leveraging their collective data resources and expertise to tackle complex health challenges. (2)

These common denominators create a unique ecosystem for health research and innovation in the Nordic region. The shared values, similar healthcare systems, and collective commitment to leveraging health data position the Nordic countries as a powerful collaborative force in the global health research landscape.

Table 1. Nordic similarities compared to the rest of European countries.

Characteristic	Nordic Similarities	Nordic Uniqueness Compared to Rest of Europe
Health Data Resources	Extensive, high-quality health registries with long-term data (some dating back to the 1960s) (19,39)	More comprehensive and longer-term data collection than most European countries (19)
Personal Identification	Unique personal identification numbers (PINs) used across all registries and databases (10,19,36)	Facilitates easier and more accurate data linkage across various health and social datasets (19)
Public Trust	High levels of trust in institutions and willingness to participate in research (>73% open to sharing health data) (36–38)	Significantly higher than in some other European nations (<30% in some cases) (37)
Healthcare Systems	Similar tax-funded healthcare systems with low out-of-pocket spending (2,10,19,36)	Facilitates more comprehensive population health data collection
Data Linkage	Ability to link health data with other types of data (e.g., socioeconomic) (10,19,36)	Provides richer, more contextual datasets for research (19)
Biobanks	Well-established biobanks with some collections dating back to the 1970s (2)	Offers unique historical perspectives on health trends
Population Size	Significant combined population size (27 million) (1,18)	Large enough for meaningful studies, including on rare diseases, while still manageable (1,19)
Cultural and Social Similarities	Shared commitment to social welfare, equality, and sustainability (17,19,20)	Creates a more homogeneous environment for health research and policy implementation
Digital Adoption	Early adopters of electronic health record systems	Potentially more advanced in digital health infrastructure
Legal and Ethical Frameworks	Similar legislative frameworks and shared values around data protection (2,36)	Facilitates easier collaboration and data sharing within the Nordic region

2.3 Complementary denominators of each Nordic country

While the Nordic countries share many similarities in their approach to health data management, each nation has also developed unique features that contribute to the overall richness of the Nordic health data landscape. These individual strengths, combined with shared characteristics, position the Nordic region as a valuable resource for health data research and innovation.

Denmark stands out with its advanced digital health infrastructure and well-established systems for facilitating access to health data. Danish health data is collected, stored and managed in national health registries at the Danish Health Data Authority. The country has developed a national data catalogue and a researcher machine, Forskermaskinen, that enables simultaneous access to data from several registries. Currently the processing time for applications is around 30 business days. (10) This sophisticated infrastructure could potentially benefit cross-border collaborations by providing easy access to comprehensive data. However, Denmark faces a significant challenge in its strict legal restrictions on transferring data out of the country. (2,10) This limitation often requires other Nordic countries to transfer their data to Denmark for joint studies, rather than vice versa, which can complicate collaborative efforts.

Additionally, the Danish National Hospital Medication Register (Sygehusmedicinregisteret) represents a unique advancement in healthcare data integration, as it enables the comprehensive tracking of both in-patient and out-patient drug use at the patient level. (40,41) This distinctive feature allows researchers to merge hospital drug utilisation data with detailed patient characteristics, creating unprecedented opportunities for healthcare analysis. This comprehensive data linkage capability across all national health registries and other registry data in Denmark makes the system particularly valuable for various applications. (40) The register's establishment in 2017 and subsequent implementation in 2018 has created one of the most complete and integrated medication tracking systems available for research purposes. (41)

Pharmaceutical studies in Denmark leverage extensive health data to drive innovation and improve patient outcomes. A prime example is Novo Nordisk, a leading global healthcare company based in Denmark. Novo Nordisk utilises data from the Danish National Diabetes Register to conduct research on diabetes management and treatment. This registry provides comprehensive data on patient outcomes, enabling the company to develop and refine insulin therapies and other diabetes treatments. (42)

Finland has taken a pioneering approach by implementing specific legislation for secondary use of health and social data, including its use for innovational and developmental purposes. (2,25) The establishment of Findata (the Finnish Social and Health Data Permit Authority), a centralised authority for health data access, serves as a single point of contact for data from multiple controllers, which could significantly streamline cross-border research processes. (2,43) Findata has already shortened the time from approved data permit to data provided to 60 business days (43) as compared to 16 months in some cases before. (44)

To support transparency and accessibility, Finland maintains a national health metadata catalogue (Aineistokatalogi / Data Resources Catalogue). (45) In accordance with Findata's Regulation on data descriptions, all data falling under the Secondary Use Act must be documented in this catalogue, providing researchers and stakeholders with comprehensive metadata about available health data resources. (46)

Additionally, the Finnish biobank system demonstrates a unique capability for conducting recall studies, as evident by the FinnGen pilot clinical recall study (47) and the TWINGEN protocol. (48) Finland's robust legal framework, comprehensive health registries, and long-

term cohort studies create an ideal environment for longitudinal research, with the FinnGen pilot achieving a 19% participation rate despite challenging circumstances (SARS-CoV-2 outbreak). (47) The TWINGEN study builds on this foundation, leveraging decades of follow-up data from the Finnish Twin Cohort and genome-wide genotyping data to explore complex health conditions, e.g. Alzheimer's disease. (48) This highlights the feasibility of remote assessments and the use of blood-based biomarkers, potentially improving screening efficiency for various diseases. (47,48) The success of these recall studies demonstrates the potential of biobanks to accelerate medical research by facilitating the identification and recruitment of specific population subgroups for studies and trials, underscoring the value of comprehensive biobank infrastructures in driving precision medicine initiatives and potentially improving early detecting and intervention strategies for a wide range of health conditions.

Iceland's highly centralised state healthcare system is unique among the Nordic countries, (19) which could potentially offer advantages in terms of data consistency and accessibility for cross-border collaborations.

Iceland has a solid legal basis where nation-wide health-related databases and registers are organised and maintained by the Directorate of Health (DoH). A key responsibility of the DoH, as mandated by law, is to systematically gather, analyse, store, and share healthcare data. (49,50) This enables effective service monitoring, quality assurance, and medical research. (50)

Iceland's unique position as an isolated island nation has created a valuable resource for genetic research. The country's small, relatively stable population descends from a limited number of ancestors, resulting in a more uniform genetic makeup compared to larger, more diverse populations. This genetic homogeneity makes it easier for researchers to identify genes associated with diseases. Despite its small size, Iceland's population is large enough to study a wide range of common European diseases, yet small enough to conduct comprehensive genetic studies efficiently. (51) This unique combination allows scientists to more easily uncover genetic factors contributing to complex diseases, making Iceland's genetic data a powerful complement to the broader Nordic health data landscape. The country's extensive genealogical records and centralised healthcare system further enhance the value of this genetic resource, positioning Iceland as a key player in advancing genetic research in the region.

However, Iceland's small population size may potentially present a challenge in cross-border Nordic research collaborations. Other Nordic countries may hesitate to undergo a complex application process for access to Icelandic data, given the relatively small number of additional participants it would provide. This may affect Iceland's inclusion in some large-scale Nordic studies.

Norway has established Helsedataservice as the Norwegian National Data Permit Authority. (52) Serving to both users of health data and health registries, Helsedataservice represents a major step towards streamlining data access for researchers, health analysis, and other health related projects. The national health data portal helsedata.no, offers a unified application process for accessing health information from various Norwegian health authorities. The platform's variable explorer allows researchers to search and explore

variables across multiple health data sources, facilitating more efficient study design. Additionally, helsedata.no provides detailed guidance on application processes for both personally identifiable and anonymous information. This centralised approach could facilitate cross-border research by streamlining data access processes. (10,53) From 1 January 2024, Helsedataservice and all the National health registries were gathered in the Norwegian Institute for Public Health. This was an important organisational change made by the Ministry of Health and Care Service to increase the utilisation of health data.

Norsk helsenett, Norway's national e-health service provider, plays a pivotal role in connecting Norwegian health services through secure and efficient digital solutions. Its core responsibilities include managing the National Health Network – a secure digital arena for healthcare operators to exchange patient information safely – as well as administering national e-health solutions on behalf of the Ministry of Health and Care Services. Operating on the values of curiosity, drive, and care, Norsk helsenett aims to ensure that both citizens and healthcare providers have timely access to essential patient information, advancing Norway's digitalisation goals in the health and care sector. (54)

However, the Norwegian Patient Registry first included PINs from 2008 and onwards, which might limit its utility in long-term cross-border studies requiring individual-level data linkage over extended periods. (19)

Sweden's system of National Quality Registries is a pioneering initiative in healthcare quality monitoring and improvement. With more than 100 registries collecting individualised data on medical interventions, procedures, and outcomes, this system provides real-time insights into the effectiveness of various healthcare practices. These registries, supported by healthcare professionals and patient representatives, have contributed significantly to Sweden's outstanding healthcare outcomes, particularly in areas such as heart attack and stroke survival, cancer treatment, and specialised care like diabetes management and hip replacement surgery. Beyond improving patient care, the registries also drive innovation, patient-centred approaches, and decision support tools. The vision for these registries is to integrate them actively into continuous learning, improvement, research, and management processes, ultimately aiming to create the best possible health and care outcomes in collaboration with individual patients. (55)

Another category of registries could be seen as infrastructural research data bases such as the Swedish Twin Registry, which is a population-based individual database with information on twins maintained by Karolinska Institutet (KI) since the 1960s. (56) The registry is maintained on the basis of an ethical review permit. Another such example is the LifeGene registry, also kept by KI. (57) These registries have both been maintained for more than a decade under the temporary Act on Certain Registers for Research on the Significance of Heredity and the Environment for Human Health. There is also a special secrecy regulation in the Public Access to Information and Secrecy Act (58) for research databases maintained under that Act. As result of a number of inquiries, the Swedish Government has recently presented to the National Parliament the Government Bill 2024/25:19 for long-term regulation of certain research databases such as the above.

In some regions in Sweden, patients can refer themselves to hospital specialists by completing an online form, after which a hospital specialist determines if they will see the patient without needing a referral from a general practitioner. (19) Sweden has also taken steps towards centralising, on regional level, data access e.g. through the Region Stockholm's Centre for Health Data (10) or through the National Genomics Platform. However, the lack of a legal requirement for electronic medical records or a shared national system might complicate data harmonisation efforts in cross-border studies. (19)

While each Nordic country has unique strengths that could enhance cross-border collaboration in health data research, they also face individual challenges. Addressing these country-specific issues, alongside shared challenges, will be crucial in fully realising the potential of Nordic cross-border health data collaboration. The Nordic countries collectively demonstrate different approaches to health data management. Finland and Denmark stand out with their centralised data systems (Findata and Forskermaskinen respectively), while Sweden's strength lies in its comprehensive national quality registries. Iceland contributes unique genetic research capabilities through its homogeneous population data, and Norway advances towards centralisation through Helsedata. The combination of national variations in infrastructure and resources, with all five countries sharing core characteristics, makes the Nordic region particularly valuable for health data research and innovation. (2)

3 Health data sources in the Nordic countries

Nordic health research shows great promise, with collaborative efforts having the potential to achieve scientific breakthroughs that might be unattainable individually. Through collaboration the Nordic countries can significantly enhance the quality and scope of health research due to the pooling of large, diverse datasets, which improves the statistical power and generalisability of research findings, as the NordSOUND study has shown. (59)

The Nordic countries have similar health data sources in each country for secondary use in research and innovation. The different categories of health data can generally be divided into registry data from population-based registries collected mainly for statistical purposes, clinical quality registries in healthcare, biobank data collected mostly for healthcare purposes but also in research, and data from public health studies. The institutions responsible for the data may reside in the healthcare systems or governmental agencies, at universities, in tech or genome centres, or in the pharma industry.

By leveraging the Nordic region's collective expertise and resources, these countries can lead innovations in preventive healthcare, health technology assessments, and personalised medicine. Furthermore, such collaboration can streamline the sharing of best practices and successful interventions across borders, ultimately leading to improved health outcomes for their populations.

3.1 Population-based registries

Population-based registries are vital tools in epidemiological research, offering comprehensive, longitudinal data on health and diseases across entire populations. The

Nordic region is well-known for having strong comprehensive health records, which provide unique opportunities for high-quality, population-based research. (19,39)

Many population-based health registries were established in the 1960s, utilising unique PINs to facilitate linkage between different data sources. By using PINs to link data from various sources, it facilitates comprehensive longitudinal studies that track individuals' health trajectories over time. (39,60) This capability is particularly valuable for studies requiring detailed information on various health aspects, such as the interplay between different diseases or the effects of medication on long-term health outcomes. Moreover, the pooling of registry data across Nordic countries presents a unique opportunity to study rare outcomes in connection with rare exposures. This approach leverages the large size of combined registries, increasing the precision of estimates and enabling researchers to investigate health phenomena that would be challenging to study in smaller populations or individual countries along. (19)

The population-based nature of these registries ensures virtually complete follow-up of the populations they serve, providing extensive coverage, and reduces selection bias. The longitudinal aspect enables researchers to track health outcomes over extended periods, providing insights into disease progression and the long-term effects of treatments and interventions. (19)

Despite their strengths, population-based registries also have limitations, particularly concerning data quality. The validity and completeness of certain variables can vary, which directly impacts the reliability and utility of the data for epidemiological and public health research. (19) Validity in health registries is commonly defined in terms of the positive predictive value (PPV), which measures the proportion of true cases among those identified in the registry. To avoid misclassification and errors that can distort research findings, it is important to assess and ensure the validity of the registry data. (19,61) Completeness, often equated with sensitivity, refers to the proportion of all actual cases that are recorded in a registry. It is a measure of how comprehensively the registry captures the events or conditions it is supposed to track. (19,61) Both validity and completeness are critical for ensuring the quality and reliability of health registry data. (19,61) To address these limitations and enhance the robustness of research findings, ongoing validation studies, detailed knowledge of data production processes, and the integration of supplementary data sources are essential. By implementing these strategies, researchers can enhance the robustness of their findings, ultimately contributing to better public health outcomes through more reliable epidemiological research. (19,61)

In summary, Nordic health registries provide extensive longitudinal data and allow for data linkage, supporting robust epidemiological studies. (39) They offer opportunities for conducting large-scale, population-based research with complete follow-up, providing comprehensive data on various health aspects. These registries routinely and prospectively collect data on individuals' lives and health, making them invaluable resources for epidemiological research. (19)

3.2 Biobanks

Biobanks are organised collections of human biological samples and associated data used for research purposes. (62) They contain samples of the human body, such as blood, tissues and DNA, along with linked health and demographic information about the donors. (63,64) The Nordic countries have all established biobanks leveraging the unique advantages of these countries' healthcare systems and population registries. (1) Some Nordic biobanks have data collections dating back to the 1970s, offering unique historical perspectives on health trends and outcomes. (2) A notable example includes deCODE genetics, a private company located in Iceland, which has gathered health data from over 160,000 Icelandic volunteers and is a global leader in analysing and understanding the human genome. (2) Similarly Finland's Finngen project, a large public-private partnership, has collected and analysed genome and health data from almost 500,000 Finnish biobank donors. (65)

Nordic biobanks offer several key advantages for research. The combined population across the Nordic countries provides a unique asset for studying rare diseases and disease subgroups. (1) Nordic biobanks benefit from high-quality data due to comprehensive population coverage and standardised collection methods. (2,63) The ability to link biobank data with national health registries, socioeconomic data, and electronic health records creates rich datasets for research. (63) Additionally, there is strong public trust and willingness to participate in biobank research in the Nordic countries. (14) The regulated nature of biobanks ensures ethical use of data, typically requiring donor consent (with some exceptions, such as Iceland's opt out system for public biobanks) and following established access procedures. (2) These factors collectively position the Nordic region as potentially world-leading in health research and innovation using biobank resources.

Despite their advantages, Nordic biobanks face some challenges. Differences in national legislation and ethical frameworks across Nordic countries can complicate cross-border sharing and use of biobank data. (1) Strict regulations, while crucial for protecting individual privacy, can significantly hinder the utilisation of biobanks, especially for innovative or commercial applications. (2) A consent-based model could limit the use of samples for purposes not originally anticipated, which is problematic in the rapidly evolving field of biomedical research. (2) Anonymisation requirements, while protecting donor privacy, can limit the utility of biobank data for certain types of analyses. (2) The process of accessing biobank data is often time-consuming, involving multiple steps and approvals, which can deter researchers and innovators. (1,2)

A significant disadvantage of biobanks is their long-term financial sustainability. Maintaining and preserving biological samples and associated data over extended periods is extremely costly. (64) Biobanks face ongoing expenses for equipment, personnel, facility maintenance, and data management systems. (63) Finding a sustainable business model that balances affordability for researchers with the operational costs of biobanks remains a major challenge. (1) Many biobanks rely heavily on public funding or grants, which can be unpredictable and insufficient for long-term sustainability. (64) Some biobanks have explored cost recovery models, where users pay fees for samples and services, but setting appropriate fee structures that do not overly burden researchers while covering expenses is difficult. (63) The

lack of a widely accepted, sustainable funding model threatens the long-term viability of many biobanks and their ability to serve as crucial resources for medical research. (1)

Nordic biobanks represent a valuable resource for health research and potential innovation, offering unique advantages due to their comprehensive coverage, data linkage capabilities, and high-quality data. However, they also face significant challenges, particularly in balancing privacy protection with data accessibility and usability. Moving forward, the key will be finding ways to maintain robust privacy protections while increasing the accessibility of biobank data for a wider range of beneficial purposes, including innovation and development in healthcare. (1,2)

3.3 Clinical quality registries

Clinical quality registries (so-called quality registries) are databases containing individual-based information on diagnoses, treatments, and outcomes for specific patient groups or medical conditions. These registries serve as valuable tools for measuring, monitoring, and improving the quality of healthcare services across the Nordic region. (66,67) The development and centralisation of quality registry systems in the Nordic countries varies. Sweden (67,68) and Denmark (69) have the most developed national quality registry systems, with Norway following closely behind. (70) In 2022, Finland had built up nine national quality registries. (71) Iceland on the other hand, relies on various health registries that can be used for quality improvement purposes. (66)

The quality registries offer significant advantages, providing valuable data for healthcare quality improvement and research. They enable comparisons between healthcare providers and regions, facilitating the identification of best practices. (66) Additionally, quality registries serve as important resources for research and innovation. (66,67)

However, several challenges persist in utilising quality registry data effectively across the Nordic region. Decentralised information structures in many Nordic countries make it difficult to obtain a comprehensive overview of available data. The lack of standardisation and interoperability between different registries further complicates data utilisation. Additionally, the process of accessing data for research or innovation is often hindered by the need for additional permits from ethics committees or data protection authorities. (66) A significant challenge is the lack of specific regulation for using registry data for innovation purposes, as opposed to research, in most Nordic countries. (2) Finland has made notable progress in addressing some of these challenges by establishing Findata, a centralised authority that coordinates data access requests across multiple registries. (2)

Despite these challenges, quality registries remain a valuable resource in the Nordic countries. Realising their full potential for healthcare improvement, research, and innovation will require addressing issues around data access, standardisation, and governance.

3.4 Health Research Cohorts and Surveys

Health research cohorts and surveys are vital tools for health-related information from a sample of the population, typically through questionnaires, interviews, or clinical measurements. These types of studies can be cross-sectional, providing a snapshot at a specific time point, or longitudinal, following participants over extended periods. Population-

based studies are particularly valuable, as they are designed to collect data from representative samples of the entire population to assess health behaviours, conditions, and access to healthcare.

The Nordic countries have established numerous comprehensive health studies, both individually and through collaborative efforts. Notable examples include the HUNT Study [*Helseundersøkelsen i Nord-Trøndelag*] (72) and the MoBa Study [*Norwegian Mother, Father and Child Cohort Study*] (73) in Norway, the Healthy Finland survey (74) in Finland, the Reykjavík study (75) in Iceland. Together, the Nordic countries have also produced significant research initiatives, such as CoMorMent (76–79) and COVIDMENT (80,81). While national health registries excel at capturing health outcome such as mortality and disease occurrence, these research cohorts and surveys are essential for collecting data on health determinants that registries typically do not cover. (2)

Nordic health research cohorts and surveys offer several key advantages. They provide comprehensive data on a wide range of health topics, often conducted regularly, enabling researchers to track trends over time. A unique strength of Nordic health studies is their ability to be linked with national health registries using PINs, enhancing the depth and breadth of available health information. The longitudinal nature of many Nordic research cohorts offers valuable insights into health trajectories over time. (2)

However, Nordic health surveys also face certain challenges. As with all survey-based research, there is a risk of self-reporting bias, which can affect data accuracy. Additionally, conducting comprehensive population studies requires significant resources, both in terms of time and funding. (2) Nevertheless, these health studies remain fundamental to the Nordic regions' health ecosystem. When integrated with the extensive health registries and biobanks maintained by Nordic countries, their approach to health data collection has established the Nordic region as a leader in population health research, providing unique opportunities for understanding and improving public health outcomes.

3.5 Claims data

Claims data are administrative records generated from healthcare billing that can be used to study patterns of healthcare utilisation, costs, and outcomes across populations over time. (82) Claims data is available in all the Nordic countries; however, the nationwide health registries are more often used in research rather than the claims data. Utilising claims data more together with data from nationwide health registries and in collaboration within the Nordic countries could provide valuable information on utilisation of resources in healthcare and cost efficiency.

3.6 Clinical Trials

Clinical trials data represent a valuable but often considered underutilised resource for secondary use in health research. While clinical trials primarily generate new data to evaluate medical interventions, the resulting datasets can provide rich opportunities for secondary analysis, (83) particularly when combined with other Nordic health data sources.

The Nordic countries have experienced a concerning decline in the number of clinical trials over the past decade, with Denmark being a notable exception to this trend. From 2008 to 2018, there was approximately a 30% reduction in clinical trials conducted across the Nordic region. This decline stems from increased regulatory complexity, rising costs, and competition from regions with larger population bases for participant recruitment. (84)

This declining trend underscores the importance of both streamlining trial processes and better utilising existing trial data through secondary analysis. Currently, data from clinical trials is not used extensively in the Nordic countries for secondary use. However, according to the proposal for the EHDS regulation, clinical trial data is one of the categories of electronic data that shall be made available for secondary use. (85) In order to facilitate Nordic cooperation on clinical trials, the Nordic Trial Alliance was founded where the aim is to facilitate clinical research cooperation in the Nordic region and focus on multi-centre clinical trials. (1,86)

4 Challenges with Nordic cooperation

Despite the Nordic countries' reputation for having rich health datasets and a history of collaboration, several significant challenges hinder effective cooperation in the secondary use of health data. These challenges can be categorised into governance, legal and ethical, technical, and semantic issues.

4.1 Governance challenges

Cross-border collaboration among Nordic countries, while generally robust, can face challenges due to their governance differences. The varying levels of integration with the EU and EEA can create disparities in policy alignment, particularly in areas of trade, security, and foreign affairs. For instance, non-EU members like Norway and Iceland may have different regulatory frameworks or economic priorities compared to their EU-member counterparts. Despite these challenges, the long-standing tradition of Nordic cooperation, as exemplified by institutions like the Nordic Council, provides a strong foundation for overcoming these hurdles. (87) Additionally, the Nordic countries face similar structural challenges in health data management. Health data is typically decentralised, stored across multiple registries and systems managed by different controllers, and supervised by various authorities. This decentralisation, coupled with a lack of both standardisation and interoperability between systems, makes it difficult to obtain a comprehensive overview and access to all relevant data. (2,10) Consequently, this creates significant challenges for healthcare innovation and research. (2)

The primary challenges of decentralised systems include complex administrative processes, with multiple permissions often required from different authorities, and time-consuming application procedures, e.g. ethical review application or data protection agencies, that frequently necessitate guidance from independent third parties. This complexity increases costs and creates barriers to accessing health data. Furthermore, decentralised systems risk

valuable health data being overlooked or excluded from research and innovation projects, while varying quality and content standards across different sources complicate data utilisation. (2) However, there is a movement towards centralisation, particularly in health data management, where the aim is to combine centralised data management with decentralised local healthcare provision. Centralisation of data management will facilitate research, innovation, and cross-border collaboration in the Nordic region, as well as creating more efficient systems for data access and utilisation. (2)

Currently, researchers frequently face long delays and administrative hurdles when trying to access health data, which can impede research progress and innovation. This challenge is particularly acute when dealing with cross-border projects that must navigate multiple regulatory systems. (1,10,17,19) The extent of these delays varies significantly across Nordic countries, further complicating cross-border collaborations. In Denmark, there is an aim to provide individual-level data within 30 days on average, with initial feedback after three weeks. Finland's system, managed by Findata, appears relatively efficient, having processed over 860 applications since its establishment in 2019. (88) However, Norway faces more extended timelines, with access potentially taking up to a year after permit delivery, depending on requests complexity. (88,89) These disparities in approval times across Nordic countries create additional challenges for researchers planning multinational studies, as they must factor these varying timelines into their project planning. This situation further emphasises the need for harmonised and efficient approval processes across the Nordic region.

4.2 Legal and ethical challenges

Legal and regulatory fragmentation remains a key issue across the Nordic region. All Nordic countries permit the processing of personal health data for research purposes without explicit consent, as long as the research holds significant societal value. (10) However, the countries face complexities of cross-border data-sharing while adhering to strict privacy regulations. While the GDPR has brought some harmonisation, its implementation and interpretation varies within and across Nordic countries, creating complexity for cross-border projects. (2,10) This inconsistency is evident in the varying mandates and roles of ethics committees and data protection authorities between countries, leading to inconsistencies in approval processes for collaborative research projects. (10)

Ethical Review Authorities (ERAs) and Research Ethics Committees (RECs) play a crucial role in ensuring ethical and scientifically responsible research across the Nordic countries. However, their scope and authority differ significantly among nations. For instance, Danish RECs is only involved if research involves human subjects or certain bioinformatics projects, (10,90) while Norwegian RECs have a broader mandate covering research on humans, biological material, and health information. (10,91) Iceland takes an even more comprehensive approach with its National Bioethics Committee overseeing scientific health research in general. (10) Swedish ERAs have a broad mandate, requiring ethical review for studies involving physical interventions on living persons, methods affecting participants physically or mentally, research on traceable biological material, and processing of sensitive personal data or data related to criminal offences. (92) Finland's approach is similarly

comprehensive, mandating ethical review for research that deviates from informed consent principles, intervenes in participants' physical integrity, focuses on minors under 15 without proper consent, exposes participants to exceptionally strong stimuli, risks causing mental harm beyond normal daily life, or could threaten the safety of participants, researchers, or their close associates. (93) These differences in REC scope and authority can lead to inconsistent approval processes for cross-border research projects, adding another layer of complexity of Nordic collaboration efforts. (10)

A key ethical dilemma arises with broad consent forms, where individuals agree to the use of their health data for unspecified future research projects. At the time of consent, participants can only be given general information about data storage, security measures, and typical research scenarios, rather than specifics about individual projects that have not yet been conceived. (94) This lack of specificity raises questions about the validity of such consent. Some ethicists argue that truly informed consent requires knowledge of what one is consenting to, which leads some to question whether broad consent can legitimately be called informed consent at all. This creates tension between researchers' need for flexibility and the ethical principle of informed consent, which ideally requires specific information about data use. (94) Dynamic consent has been proposed as a potential solution to this dilemma. Dynamic consent allows participants to make ongoing, granular decisions about their data use through an interactive digital interface, enabling them to update their preferences over time as new research opportunities arise. (95) This type of consent facilitates study-specific consent through a web-based platform, potentially maintaining informational self-determination while easing the burden on researchers and participants. (94) However, while dynamic consent offers more flexible and ongoing consent processes, it is not definitely declared as a complete resolution to all ethical challenges associated with future data use. It is presented as one of several proposed solutions, with the suggestion that digital tools and platforms might improve patient information and consent management. (94) As data sharing becomes more prevalent, there is an increased risk of privacy breaches and potential misuse of sensitive health information. Balancing the advancement of medical research with the protection of participants' rights and autonomy remains a key challenge in health data research. More research is needed to determine the most effective and ethically sound approaches to consent in this field. (94)

Further complicating the legal landscape are country-specific restrictions and regulatory gaps. Some countries, such as Denmark and Finland, have extensive legal restrictions on transferring data out of the country, which can complicate joint studies. Additionally, most Nordic countries lack innovation-specific regulation, with Finland being a notable exception. (2) This absence of tailored legislation means that innovators often have to rely on consent or attempt to fit their projects under exceptions meant for scientific research. (2)

The combination of varying REC mandates, inconsistent GDPR implementation, country specific data transfer restrictions, and the lack of innovation-specific regulation creates a complex legal environment for cross-border health data research in the Nordic region. This fragmentation poses significant challenges for collaborative projects, potentially hindering the full utilisation of the comprehensive health datasets available across these countries. Addressing these legal challenges will be crucial for enhancing Nordic cooperation in health

data research and unlocking the full potential of the region's valuable health information resources.

4.3 Technical challenges

What is often described as a major challenge when it comes to data exchange is the decentralised governance of digital infrastructure in several of the Nordic countries. The result is a fragmented ecosystem characterised by insufficient interoperability on national level, consequently creating even worse preconditions for cross-border interoperability. This governance-driven fragmentation manifests in the technical realm, where health data is often scattered across different institutions and systems, compounded by a lack of standardisation in data formats and technical systems, which hampers interoperability between countries. (1,19)

To address these challenges, implementing FAIR principles (Findable, Accessible, Interoperable, and Reuseable) has become increasingly important. The status of FAIR implementation varies significantly across the Nordic countries and data domains, with health registers and socioeconomic registers being the most advanced. Key barriers include inconsistent metadata standards, lack of common clinical terminology, and limited use of persistent identifiers for data resources. (1)

Although most Nordic countries have developed their own national data ecosystem, e.g. Helsedata (53) and Forskermaskinen, (10) there is a clear need for a common Nordic foundation for health data-linkage and analysing of health data. Technical standards and operational procedures are crucial for enabling seamless data sharing and analysis across the region. (1,19) Establishing a harmonised Nordic standardised metadata framework and implementing a unified catalogue with integrated search interfaces would enable researchers to efficiently discover and assess available health data across Nordic countries. This standardisation of metadata and development of common clinical language across domains would significantly advance FAIR compliance and facilitate more efficient cross-border research collaboration. (1)

The possibilities and opportunities of utilising existing Nordic infrastructure collaborations with a broad science focus, such as the Nordic e-Infrastructure Collaboration (NEiC), (96) and exploring their experiences of health domain projects (97) is also an area where meaningful synergies could be identified.

4.4 Summary of challenges

Addressing these multifaceted challenges will require continued efforts to align policies, standardised processes, improved infrastructure, and build public trust across the Nordic region. Increased transparency, clearer regulations, and more regional coordination are potential ways forward in enhancing Nordic cooperation on secondary use of health data. By tackling these legal, technical, ethical, and practical obstacles, the Nordic countries can unlock the full potential of their rich health data resources, fostering innovation and improving health outcomes across the region.

5 Value From Nordic Health Data: Future work

The Nordic countries stand in a unique position to lead the way in maximising the value of health data for research, innovation, and improved healthcare outcomes. With a combined population of 27 million people, comprehensive health registries dating back decades, and high levels of public trust, the Nordic region possesses distinct advantages that set it apart in the global health data landscape.

The introduction of the EHDS regulation presents both new responsibilities and opportunities. While the regulation mandates new responsibilities for cross-border health data sharing, it also provides momentum for transformative change in how health data is managed and utilised across borders. The VALO project serves as a crucial stepping stone toward future Nordic collaboration and data exchange, helping prepare the region for EHDS implementation while strengthening existing cooperative frameworks.

The Nordic countries' position at the forefront of digitalisation and innovation capacity provides a strong foundation for this transformation. If health data from across the Nordic countries could be made accessible for secondary use in an efficient yet secure way, it would significantly advance medical research, particularly for rare diseases requiring larger population samples, drive healthcare innovation through public-private partnerships, and enable evidence-based policymaking using comprehensive, high-quality data.

However, realising these opportunities requires addressing several key challenges in harmonising legal frameworks, developing interoperable technical solutions, streamlining governance processes, and establishing sustainable funding models for shared infrastructure.

By continuing to invest in shared solutions and maintaining commitment to cooperation, the Nordic countries are well-positioned to lead the next wave of healthcare advancement through effective utilisation of health data. This leadership role not only benefits the Nordic populations but also sets a valuable example for international collaboration in the evolving landscape of digital health.

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